❖ The Transverse Myelitis Association ❖

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From the Editor
Sandy Siegel

My column in this issue of the newsletter is going to conclude with the following statement: The Transverse Myelitis Association advocates for people who have transverse myelitis; recurrent transverse myelitis; recurrent transverse myelitis and recurrent optic neuritis or Devics Disease; recurrent optic neuritis; and acute disseminating encephalomyelitis or ADEM. We have always had people with these conditions in our membership. The TMA was not focused on their issues, nor were we very clear about our role with regard to their concerns. Our murkiness was a reflection of our ignorance, and perhaps also reflected a lack of clear direction from the medical community.

All of these conditions are neuroimmunologic disorders of the central nervous system. Each of these disorders occurs when a person experiences a demyelinating attack at some location in their central nervous system. Multiple sclerosis is also a neuroimmunologic disorder of the central nervous system. Why did I not identify MS in my list of conditions represented by the TMA? Well, the answer to that question will eventually be addressed in this article.

This article starts with the conclusion because I am going to take you on a circuitous journey; much like the experience the TMA has had since 1994. For those of you who need the classic comic book version that proceeds from point A to point B via the shortest route; you just got it in the first paragraph, and you can get on with life. For those of you who are endowed with great patience and have twenty minutes to devote to reading … this article is really about the manifest purposes for medical concepts or definitions and the latent or less explicit purposes of those definitions. The roadmap I will use on this explanatory journey has been heavily influenced by my experiences teaching physical anthropology and also by my education and experience in cultural anthropology, and particularly linguistics and sociolinguistics. Linguistics is the study of language. Sociolinguistics concerns the way people use language and the meanings of communication in particular social contexts.

Two brilliant linguists came up with this really interesting theory that the words we use in a particular language determine the way we perceive the world around us. What they meant was that the categories we use from our language determine how we see our world, and in fact, limit how we perceive our experiences. For those of you who find this to be a totally fascinating idea and would like to read everything they ever wrote, their names were Edward Sapir and Benjamin Whorf. How this all works is probably a great deal more complicated than has been explained by the Sapir-Whorf hypothesis, but there is no dispute that language strongly influences how we perceive our experience. Each culture has a different language. A feature of those languages is that there are words which serve as categories in classification systems. And for the most part, those categories are arbitrary. For instance, there are some societies and cultures in which the language only has three different color categories. Does this mean that the people who were raised in that society with that particular culture and language only see or perceive three different and distinct colors? No, they see the same things that we see. The categories do not reflect what is possible to see; the categories represent what these people define as meaningful from their perceptions. They group the entire range of all perceivable color into only three different color categories. For instance, what we see and define as yellow, orange, brown and red they group into one category because the distinctions between these gradations of color are not meaningful to their way of life.

Another great example and one which demonstrates the arbitrariness of categories is the system for defining relatives. In American society, all of our first cousins are related to us in the same way regardless of whether they are related through your mother's or father's side of the family. In some societies, there are two very different classes of first cousins. The one type of cousin is called by a term which means brother or sister; they are considered brothers or sisters and are treated as such. The other type of cousin represents the group from whom you are supposed to select your wife or husband. In our culture, it is frowned upon to marry a first cousin, and we do not think of cousins as being the same as our brothers

and sisters. Every society has its own kinship classification system, and there are tremendous differences between these systems. Of course, the American system is the correct system and everyone else in the world is dazed and confused. And of course, they all think the exact same thing about us! Isn't diversity lovely.

How we classify the universe around us with our language does reflect our way of life. Our language and our way of life and the way we think of the world around us are all inextricably bound. To the Inuits who live in the Artic and Subartic snow is central to their world and way of life. There are twenty-two words in their language to describe different kinds of snow. In American English we can describe a type of snow as "the kind that has just the right amount of wetness to make a great snowball." The Inuit language has a single word to describe this kind of snow. Do our words and the way we develop categories influence how we perceive the world? Can you even think of twenty-two different kinds of snow? Snow is not as meaningful to us in our physical and social environment, so we don't need all of those categories. Colors are very meaningful to us, so some paint companies actually sell 140 different shades of white.

A very personal example and one which provides some insight as to how classification or the development of categories works in our language and culture comes from my grandfather. My Zadie was raised in a small village in the Ukraine just outside of Kiev. The people who lived in these villages were peasants. These people were very poor. If you've seen Fiddler on the Roof, it was like that, but without the orchestra and great music. My grandfather knew some Russian because he had been forced to serve in the Czar's army. But his first language, his native language, was Yiddish. At this time, Jews were not permitted to attend the Russian schools and they were isolated from the rest of Russian society. His world was one of horse drawn carts, shacks with no electricity or plumbing and dirt floors. My Zadie came to America during the Pogroms; when they started killing the Jews and burning down their villages, for a change. He came to America as an adult. His native language was not filled with many categories for technology, because his technological world was very simple. He learned English, he learned enough of our culture to be a participant, but he never fully assimilated. He went from dirt shacks in a peasant village to watching a man land on the moon on his television set; yet, he never learned how to drive a car.

In American culture technology is central to our way of life. We have an enormously complicated language to define our technology with literally thousands of concepts to describe it. My Zadie called everything that had an engine a machine. From his world view and his perceptions of the universe, what mattered was that it had an engine and was classified as a machine or it didn't have an engine and was something else. He asked me to cut his lawn with a machine. He asked me to pick him up in the machine to take him to the store. I knew the machine he was talking about from the context of his request. What was meaningful to my Zadie in his classification of technology was the presence or absence of an engine. And, yes, we went to the moon in a machine, a very sophisticated machine.

Where the heck is he going? Hang on, it's going to get worse. Okay, our language and culture provide us with a way to categorize our experience, and these categories influence our perceptions and the way we think about the world around us.

One of the all-time great accomplishments of humankind, after the invention of Chinese food, was Karl von Linne's classification of the plant and animal kingdoms. Linne' was a Swedish botanist who developed a taxonomy that organized all of the known plant and animal types based on a comparison of the similarities and differences of their characteristics. He grouped the categories based on the types of characteristics they shared and based on the characteristics that distinguished them from other groups. Ultimately, he defines a specific plant or animal based on an entirely unique set of characteristics. No other plant or animal possesses the same set of characteristics. Humans share characteristics with all other animals, a fewer number of characteristics with all other vertebrates, a fewer number still with all other mammals, and so forth. But humans have a complete set of characteristics that are unique to only humans, and which distinguish us from all other animals.

Karl was a very cleaver and a very organized person. I would bet that the things in his house were all lined up with the true meridian, as they are in my house.

Okay, I'm getting there; don't hurt the dog.

I was provided with a perspective and a new sense of clarity about TM at the end of March of this year. I had an experience which changed the way I think about TM, because it changed the way I think about the classification of TM. And it, therefore, changed the way I think about the TMA.

Dr. Kerr and I were working on a grant and we were doing lots of writing, talking and emailing. During

Pauline's spring vacation we headed for Baltimore. Dr. Kerr and I had three days to think and talk about TM and the TMA. Dr. Kerr and I communicate often. Ordinarily, we have a long list of items to cover and it is a stream of conscious communication. We summarize our to-do lists before we hang up the phones, but I always feel as though I have spent an hour spinning inside a tornado afterward. Having three uninterrupted days to talk was really wonderful, and the benefits for both of us were significant. There are likely no two people who do more thinking about Transverse Myelitis, who do not have Transverse Myelitis, than Dr. Kerr and I. We also had some time to talk and visit with Chitra and with Dr. Adam Kaplin. It was a remarkable weekend. I believe that we both came away from the discussion with a better understanding of our mission and the nature of relationships between the neuroimmunologic disorders.

The practice of medicine has a classification system. The classification systems in medicine operate in much the same ways as the other classifications that exist in our language and culture and, for that matter, all languages and cultures. The categories serve as a way to classify what is meaningful from the full range of possible experience. And there are direct and explicit purposes and meanings associated with this classification system and there are meanings which are less explicit or obvious.

Now, what is the purpose of the medical classification system? If you asked the medical community why it is that they classify diseases or disorders, they are going to tell you that they have to define the disease because this definition determines how the person is going to be treated. The specific category determines the specific treatment. The definition also allows the medical community to determine prognosis; and we all want to know what's going to happen. These are the explicit purposes of these definitions.

This classification system operates in the same manner as my Zadie's technology classification and Linne's classification of plants and animals. Medicine classifies conditions, disorders, diseases based on a set of characteristics that are unique to that defined category. Each condition is defined as a unique category based on the presence and absence of various characteristics. While there are similarities between certain classes of diseases or disorders, in order to be placed or defined in a specific category, the condition must possess a unique set of characteristics.

At the present state of medical knowledge, there is what I would refer to as a class of neuroimmunologic disorders of the central nervous system. The different diseases or disorders which make up this class of conditions each results from a demyelinating attack at various locations in the central nervous system.

One of the conditions or disorders is Transverse Myelitis. TM is demyelination in the spinal cord only; there is no brain or optic nerve involvement. It is a monophasic condition; the demyelinating attack only occurs once. Most cases of TM are monophasic.

A second condition is Recurrent TM. Recurrent TM is not MS. Recurrent TM involves different and distinct episodes of inflammatory attack in the spinal cord. There is no brain or optic nerve involvement in any of the demyelinating episodes.

MS is a demyelinating attack that can occur in the spinal cord and/or in the optic nerve and does involve demyelination in the brain. The lesions or demyelination that occur in the brain are ordinarily identified in a specific pattern; the lesions tend to be aligned perpendicular to the ventricle (although lesions may be present anywhere in the white matter). MS involves more than one episode and the multiple episodes occur in different locations in the central nervous system.

Devics is another category of these neuroimmunologic conditions. Devics is recurrent spinal cord and optic nerve demyelination. Put another way, Devics is recurrent TM and recurrent Optic Neuritis. It is not TM because there is optic nerve involvement and it is not MS because there is no brain involvement.

ADEM or acute disseminating encephalomyelitis involves demyelination in the spinal cord and in the brain. The demyelination in the brain is different than a demyelinating attack from MS; the lesions are scattered and do not appear in the same pattern as those from an MS attack. It is, like most TM cases, monophasic. It can be characterized by headache or seizures and may involve vision loss. The spinal cord involvement is the same as Transverse Myelitis, as are the associated symptoms.

Finally, Recurrent Optic Neuritis is a category of these neuroimmunologic conditions, which involves multiple episodes of demyelinating attacks of the optic nerve. There is no brain or spinal cord involvement.

I have just described different categories of neuroimmunologic conditions each of which is defined by a unique set of characteristics. While they are all categories of demyelinating attacks of the central nervous system, each can be distinguished and defined based upon the location of the attack and whether the attacks are a monophasic

or recurring event.

In some sense, TM may be conceived of as a subset of the other demyelinating conditions, with the exception of recurrent optic neuritis. All of the symptoms of TM can be found in these other conditions. Spinal cord demyelination does or can take place in TM, Recurrent TM, Devics, ADEM and MS. Spasticity, parasthesias, bowel, bladder and sexual dysfunction, fatigue, muscle weakness or paralysis, or depression from an inflammatory attack in the spinal cord from any of these conditions is going to be pretty much the same, and the treatments for each of these symptoms, regardless of the condition, are going to be the same. From the perspective of symptoms, these conditions share many similar and important characteristics.

As I noted above, it is the disease process which distinguishes the categories; where in the central nervous system the inflammatory attack occurs and whether the attacks are monophasic or multiple. It is suspected that there are some very complicated relationships between these conditions. Besides the fact that they are all demyelinating attacks in the central nervous system, the following are some interesting clues or insights about these relationships.

A person can have a demyelinating attack that occurs only in their spinal cord. There is no brain or optic nerve involvement, so they get a diagnosis of TM. Some time later, they have another episode of demyelination which involves the spinal cord and the brain and may involve optic neuritis. This person will be diagnosed with MS. Their first diagnosis was correct; they had TM. Now they have MS and will be treated as an MS patient.

A person can have an inflammatory attack in the spinal cord and receive a TM diagnosis. A second attack occurs only in the spinal cord again, and the person will receive a Recurrent TM diagnosis. A third demylinating attack can occur in the spinal cord and this time also involve optic neuritis. This person will now be diagnosed as having Devics and will be treated as a Devics patient. The first diagnosis of TM was correct. The second diagnosis of Recurrent TM was correct.

I have come to appreciate and believe that the answers about one of these conditions is going to provide answers to all of these conditions; even if they are different conditions. I also believe that so long as there are distinct characteristics that define each of these categories, they have to be treated as unique and distinct conditions and should be treated that way and studied in that manner. If a person has TM and has not had a second episode in years or if they have ADEM, they are going to be treated differently than a person who has Recurrent TM, MS or Devics. Identifying the differences between these conditions is critical from a medical treatment perspective.

As there is no clear set of causes in all cases for all of these conditions, there is no understanding as to why one person is effected in one place in the central nervous system and not a different place; or why one person has one episode and another person has multiple episodes of demyelination. Why is it that I could have the same flu virus as Pauline and her's could trigger an auto-immune attack of the myelin in her spinal cord, and mine just makes me miserable? How is it possible that I could complain more about my flu symptoms than Pauline complains about her paralysis, bowel and bladder dysfunction and nerve pain? Is there a difference in the immune systems between people who have monophasic versus multiple episodes of demyelinating attacks? If there are differences, could they be genetically based. Could those who experience multiple episodes of these neuroimmunologic disorders have compromised immune systems which are prone to be triggered to attack their own myelin in the spinal cord, optic nerve or brain? Is there some genetic predisposition which might explain weaknesses in the blood brain barrier in different places in the central nervous system which could explain the differences between TM, ADEM, Devics, and Optic Neuritis? These are all questions I would try to answer if I had taken less kinship and linguistics courses and more organic chemistry and microbiology.

When Karl Linne' defined the different categories of animals, he did not know anything about genetics. If he had, he would have had a completely different and really wonderful set of characteristics that he could have used to define groups of animals and to distinguish them from other groups of animals. But he was limited by the then current understandings of biology. He could only use characteristics that he could observe and that he knew. It is not different today. Medical scientists can only use characteristics that they can identify and that they know. If there is no diagnostic test for it, it is not available for this definition. Today, physicians are using MRIs, CAT scans, lumbar punctures and various blood tests to observe the presence or absence of various characteristics. If they observe one set of unique characteristics, you are told you have one condition; if they see something else, you are going to get the diagnosis of a different condition.

One day, they are going to find new characteristics, and then they will better understand how to define these categories, and diagnose these conditions. I have no doubt in my mind but that the paradigm we are thinking

about today will change. And I believe this even more strongly about the neuroimmunologic conditions, because we are thinking about them with such large gaps in our understanding about these conditions.

It is now time for me to shift gears from the explicit medical to the latent purposes of these definitions. When Pauline was first given the diagnosis of Transverse Myelitis, we were told by one of the physicians that TM was really not a disease; it was a description of symptoms. I have thought about that comment a great deal over the years, because as I have described, I think of language and categories in these anthropological terms. I know, I should probably give my brain a rest. Early in my evolution, my reaction to his comment was, "Wow, given all of the stuff this woman has been through, couldn't you at least dignify her experience by giving her a disease? What's with the disorder and condition business?" Early in this process, I felt a reluctance by the medical community to firm up the definition of Pauline's condition. Hey, me and Karl like order.

Okay, maybe I'm being sensitive; I can be overly sensitive. On another occasion, I was listening to physicians talk about the definition of TM. The gist of a remark I heard was, "well, I'm not sure about the specific concept; I know that there is a Transverse Myelitis Association." My translation of this statement was that they were not at all certain that there was a category of unique characteristics that could be defined as TM, but there was an association which was somehow formalizing the definition from outside of the customary practices and rules of medicine.

I thought, "that is really amazing; maybe Deanne Gilmur and Sandy Siegel are responsible for the existence of Transverse Myelitis." That couldn't be; Deanne and I aren't that cleaver or devious. And besides, if I was going to get really creative, I wouldn't invent a disease, I would create a religion. I started thinking; there are physicians all over the world who are looking at a collection of characteristics and they are independently concluding that the person they are evaluating has something that they are going to define as TM. If this isn't something, then all of these different physicians need to stop giving people this diagnosis. So, I concluded, I needn't be paranoid about a conspiracy to concoct TM; Deanne and I didn't do it.

Finally, I was speaking with a physician who had applied for an education grant involving TM. One of the reviewers suggested that funding a TM grant might not be an effective approach because it might result in a balkanization of the neuroimmunologic and spinal cord injury areas. It was at this point that I concluded, that while I am hypersensitive and should probably work on that flaw in my next life, there was something really funky going on with this definition of TM.

If you think only in terms of physiology and biology when trying to make sense of the medical classification system, you are not getting the complete understanding of the system. Language and culture are quite complicated. We have a tendency in our culture to see science as having a set of laws or rules which operate in a very systematic way, and we tend to minimize the impact of social rules on the natural world. But, of course, science does not exist in a vacuum; it exists within a complex culture that strongly influences how science is practiced and also how the laws and rules of science operate.

We can see the interplay of the medical and scientific world and sociocultural world at work all the time. Scientific discoveries would progress at a faster pace if scientists would regularly share the results of their work and would collaborate on a more intimate basis. If all scientists had access to unlimited information, there would be more and more rapid discoveries made across medical disciplines. There are, however, substantial financial rewards and prestige rewards associated with these discoveries, and as a result, most research is done without open and frequent communications between scientists, and the opportunity to build on information during the course of research is sometimes lost. Results are published when the research is completed, and the research results are often proprietary and are patented if there is a financial gain associated with it. An argument could be made that without the underlying competition which is driven by financial rewards and prestige rewards, that research would not progress at all. I am merely pointing out that science and medicine exist in a culture which strongly influences how it is practiced. I am not evaluating the merits of the system or proposing we all move onto the medical research kibbutz.

How we classify and define disease, disorders, conditions has the explicit medical purpose of determining treatment and prognosis. Another aspect of these definitions and classifications has to do with the more latent purposes of these medical classifications. How we classify and define these conditions is also influenced by the broader social and cultural rules in American society. And these less obvious purposes of medical definitions concern funding for research, resources for medical centers, universities and private companies, career opportunities and prestige assignments for scientists, physicians and faculties, and the individual financial rewards which motivate so much of our behavior. A part of the definitional process

concerns a very objective application of rules; another part of this process concerns a very subjective and human application of a totally different set of rules. The medical definitions have a very real set of perhaps unintended social, emotional, psychological, and financial consequences. I do not believe that there is anything unethical or devious or unprofessional about the "other" set of rules operating in this environment. After all it is the same society and culture that establishes both sets of rules and society very certainly defines the goals that are held up as rewards from the application of both sets of rules.

I do believe that over the years, the comments I have heard do reflect a reluctance to define TM as a specific category of disease or disorder. I believe that the reluctance was, in part, accounted for by the lack of understanding about what TM is and how it relates to the other neuroimmunologic conditions. I also believe that this reluctance is partially motivated by the competition for the scarce resources that are available for research and all of the other costs associated with the existence of a particular disorder or disease.

The entire medical community is competing for a finite amount of resources. These resources make research, treatment, education, and quality of life programs possible. These resources are also required for the hiring of faculty, scientists or physicians, the building of facilities, the hiring of staff and the development of the enormous and complex infrastructures that support these people and organizations. The expenses are tremendous.

Who needs another disease with a separate infrastructure and all of the costs associated with it? In this context, I fully appreciate the "balkanized concept." From the perspective of the traumatic spinal cord injury population or the MS population, we might appear as some pesky group trying to siphon off resources from the common good. And we are. Because the common good provides for better treatments and the possibility of restorative therapies for all people in this large community. The common good will not, however, provide our community with the answers to: what is TM, what causes it; what is recurrent TM, what causes it; what is Devics, what causes it; what is ADEM, and what causes it. And I don't think we get to be a disease until we get the answers to those questions.

There was a large and well organized traumatic spinal cord injury community with a very large infrastructure long before there was a TMA, and there was no one who decided to specialize in the treatment of TM or focus on TM research. The same can be said about the MS community. I do not have great faith that the answers about TM are going to emanate from these existing disease communities.

There is no group or individual that is not deserving of a share of these resources. Unfortunately, before there was a TMA or a JHTMC or physicians interested in these conditions, the likelihood that significant resources would be made available to our neighborhood of the neuroimmunologic community just because we were a population in need was not good. So not good, in fact, that even with our organizations, we still aren't getting any of it. But the potential for our ability to compete for resources is growing.

The physician who made the statement about the relationship between the TMA and a definition of TM did, in fact, make a rather insightful comment about the social order and the medical community. The TMA did not invent TM; the medical community discovered TM and this article attempts to make explicit on what basis the discovery was made. The TMA merely gave those with TM a voice and shined a spotlight on their experiences. We helped those with TM find each other and to start to organize an effort to compete for the resources that are available. And we have begun to arm people with information to make them more effective advocates for themselves and their loved ones.

But if the TMA has helped to solidify TM, in my mind, that is a good thing – cause my wife has it; and a bunch of doctors have told her she has it. But what the TMA has accomplished in this regard does not compare with what the Johns Hopkins Transverse Myelitis Center has done. The TMA may have solidified TM into jello; having a premier medical center in the United States establish a center of excellence in TM has transformed it into concrete.

The TMA does not advocate for people with MS. The reasons for this have nothing to do with the medical definitions of the neuroimmunologic disorders. In fact, when it comes to research, we should be advocating for collaborative work. What is learned about TM will benefit the MS community, and the reverse is also true. Unfortunately, for all of the other-than-science reasons, at the present time, there are few benefits to the TM, Devics and ADEM communities as compared to the disadvantages of a union of efforts and organizations.

Before I pull my pants down totally in public, I would like to make myself perfectly clear about what I am contending here. Our medical advisory board is well represented by physicians who specialize in the treatment of people with MS and research on MS. They have been incredibly generous in donating their time, expertise

and resources in providing so many services and assistance to the TMA and the TM community. I have been on many an MS walk-a-thon and have all of the t-shirts to prove it. We have members in our Association who have MS; I love them the same as I love our members with TM, ADEM and Devics. I regularly suggest that our members, regardless of their diagnosis, be treated by a neurologist who specializes in the treatment of MS. I have the utmost respect and appreciation for all of the good that has been done by the MS community! Some of my best friends and favorite relatives have MS.

I have been in contact with various people who work for the MS organizations. Most of them are not aware of TM. I have no idea what their level of awareness or knowledge is of Devics or ADEM, since I can't say I was all that aware of these disorders myself until our members began forcing me to learn about their conditions. I would assume their understanding of all of these conditions are about the same. They are focused on MS, as they should be.

The MS community is not very highly sensitized to the existence of these other conditions or their relationship to the class of neuroimmunologic disorders to which MS also belongs. I have heard from more than a few people with TM that an MS doctor did not want to see them or feel comfortable seeing them because their practice was limited to MS patients and their expertise was MS. If physicians are confused about the relationships between these conditions, I don't expect the lay people who run these organizations to be any more highly evolved. In fairness to the organizations and the physicians who compose this community, if I were in their position, I would likely be doing the same thing. They don't have to pay any attention to us; and they certainly have enough of their own issues to focus on without adding more. And, as I noted, our members have been embraced in far more instances than we have been denied.

A person is one hundred times more likely to get MS than they are to get TM. I am concerned that if we joined forces with the MS community, the answers about TM, ADEM, Devics, and the variants of these conditions would be further buried than they are now. As I have said many times before, we benefit from MS research and from spinal injury research. The central issues for our community, however are not going to be addressed in primarily MS research; we need a focus on our issues by our researchers. And we need to do a better job of competing for our share of these scarce and valuable resources.

I am developing a better awareness of the other-than-scientific implications of these definitions. How we are organized and defined is about more than a disease classification and it has implications for how we are perceived by the medical community, by the government and private institutions that fund research, education and quality of life programs, and the general public. Maybe all of this has been totally obvious to all of you; it wasn't for me. But then let's review the qualifications I bring to this job. I love Pauline very much. When she got TM, it totally broke my heart and I felt helpless to do anything to help her. I ache to see people who are frightened and hurting and I want to do something to make them less frightened and to make their hurts go away. I am willing to work hours and hours for free. And I don't have enough good sense to keep my mouth shut. Let's see, never ran a company, never held a bake sale, and I insisted that my lab partner pith the frog (while I excused myself to go vomit, cry and sit shiva). Do we get the picture?

I left Baltimore thinking, wow, my head hurts and I could sure use an easier hobby. I also felt really blessed to be involved with such amazing people. The physicians on our medical advisory board are such a brilliant and a wonderful group of people.

We have always had members with recurrent TM, Devics, recurrent optic neuritis and ADEM. I am sorry that you have been buried in our ignorance. The TMA is committed to doing more for you. I will work on having more information about these conditions published in our newsletters. We will address more of your unique issues at our symposia. We will work hard to encourage research across the spectrum of neuroimmunologic conditions so that each condition is better understood and so that the relationships between them are better understood. And we will work hard to be sure that there are physicians interested and focused on your treatment, care, and quality of life.

And to conclude with total mayhem in this column, if you have Devics or Recurrent TM or Recurrent Optic Neuritis, I would strongly encourage you to join the MS organizations, to get on their mailing list, to read their publications, to pay close attention to MS research results and to participate in their education opportunities. Due to the element of recurrence in your conditions, you need to be fully educated about the full range of treatment options and any new treatments or medications that are available or are in clinical trials for **multiple** sclerosis. You should probably be discussing these issues with your physicians regularly, and being aware of options is part of what makes you a good advocate for your care. These issues will be thoroughly addressed by the MS organizations. And always re-

main a member of the TMA, because we are committed to making a difference for you and we care about you!

We are going to remain the TMA; it may become a vestigial name reflecting the state of medical understanding in the early 21st century. For now, I'm not paid enough to be motivated to think of a new name and then change it on every publication we currently produce, not to mention the work Jim would have to do on the web site. So, read TM, think neuroimmunologic.

The Transverse Myelitis Association advocates for people who have transverse myelitis, recurrent transverse myelitis, recurrent transverse myelitis and recurrent optic neuritis or Devics Disease; recurrent optic neuritis; and acute disseminating encephalomyelitis or ADEM – and their loved ones and caregivers.

Please take good care of yourselves and each other.

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

The Pathology of Transverse Myelitis

Carlos A. Pardo, MD

Assistant Professor of Neurology and Pathology, Johns Hopkins University School of Medicine
Co-Director, Johns Hopkins Transverse Myelopathy Center

What happened in my spinal cord?
What does myelitis mean?
What is transverse myelitis?
Why did I lose bladder control?
Why do I have pain several months after my attack of TM?

These are just some of the many questions that all patients suffering from transverse myelitis ask after confronting the reality of this problem and its effect on activities of daily living. Often neurologists taking care of TM patients understand the problem, potential causes and consequences. However, for patients and families, much of our explanation is just jargon with no real meaning. Sooner or later, after long hours of reading and web searches, some questions may be answered, but many remain unanswered. What I would like to do in this short introduction to the pathology of transverse myelitis is to explain what we have learned about this condition and how the understanding of the problems that occur during those first few minutes, hours, days or weeks of spinal cord damage may help us establish better treatment approaches and improve quality of life.

Let me start by explaining the meaning of the word *pathology*. My Webster's says that *pathology* is "the study of the essential nature of diseases and specifically of the structural and functional changes produced by them." So, to understand the *pathology* of TM, we need to understand the structure of the spinal cord and how it relates to its function. But what is most important for us to understand is what went wrong and why? In other words, *pathology*, the science of ***Quincy*** (my favorite TV show in the 80's!), is closely related to the science of criminology, as we learned from Sherlock Holmes. *Pathology* is then the science that investigates the scene of the crime, the evidence, the actors and the killers. By studying the pathology of TM, we want to find out what happened and why. Understanding these questions will help us to apprehend the criminals.

Understanding the spinal cord … the scene of the crime!

The spinal cord is an extension of the central nervous system that establishes a structural connection between the brain and the other structures of the body (e.g., arms and legs, bowel, bladder) through nerve fibers. Located inside of the spinal column, the spinal cord is an elongated and cylindrical structure of the central nervous system that is divided into regions that correspond to the bony column in which it is located. So, we have the cervical, thoracic and lumbar-sacral regions of the spinal cord that serve different parts of the periphery. We can say, for example, that the cervical spinal cord serves arm function, the thoracic is mostly for chest and abdominal organs and the lumbar-sacral cord serves the legs and genitalia (Figure 1). Since the spinal cord is really the bridge between the brain and periphery, the information traveling along the cord goes in two directions.

In one direction, the spinal cord carries information from the brain to peripheral areas, particularly motor function that facilitates movement (*descending information*). Nerve fibers called motor nerves originate in the spinal cord as part of the periph-

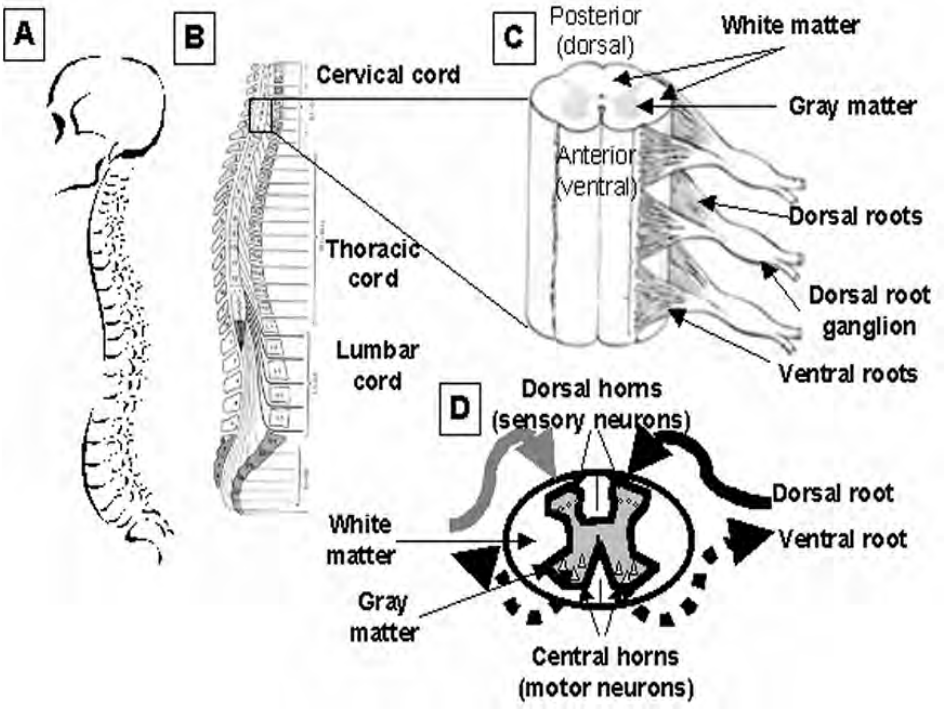


Figure 1

A skull and spine

B The spinal cord is inside of the spinal column. Three major segments of the cord are identified: cervical, thoracic and lumbar.

C Projection of segments of the cervical cord to detail the most important components, the gray and white matter, dorsal and ventral roots and the dorsal root ganglia.

D Diagram with the main component of the spinal cord: dorsal and ventral horns of the gray matter and the dorsal and ventral roots.

These *pathways* are located in the external portion of the spinal cord, in what we call white matter (Figure 2). There are then different pathways specifically located within the white matter of the spinal cord. Each pathway carries specific motor information down to the motor nerves (*descending pathways*) and the periphery or carries specific sensory information from the periphery to the brain (*ascending information*).

The organization of the crime scene!

As with all of the structures in our brain and nervous system, the spinal cord is very well organized. The external portion of the cord is comprised of the white matter that carries the ascending and descending pathways. These pathways are a collection of millions of nerve fibers that carry motor or sensory information. Information exits the spinal cord or comes into the spinal cord through special nerves called *nerve roots* that connect with the nerves of the arms or legs (innervation). Nerve roots that serve the arm originate in the cervical spinal

eral nervous system and travel to different muscle groups in the arms, legs or other structures to facilitate movement. Going in the other direction, the spinal cord collects information from the periphery (e.g., skin, bones, internal organs) by receiving sensory nerve fibers (part of the peripheral nervous system) that connect with nerve cells inside and outside of the spinal cord. These nerve cells branch into nerve fibers that carry sensory information from the spinal cord to centers in the brain in charge of learning about the periphery of our body and are called *ascending information*. Both ascending and descending information travel in specific *ascending pathways* and *descending pathways* that are like highways with millions of nerve fibers going up and down.

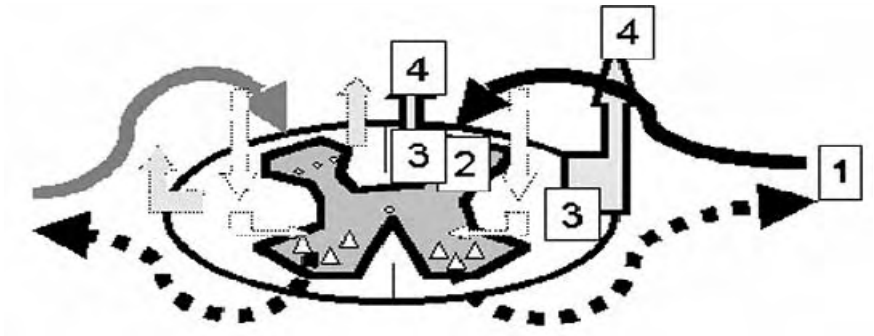


Figure 2 Ascending Pathways (Sensory Function)

1 Information from nerves in the periphery (e.g., skin, muscles) arrives into the dorsal root ganglion and goes to the spinal cord.

2 Nerve fibers connect with neurons in the posterior (dorsal) horn of the spinal cord.

3 Information from neurons in the dorsal horn is distributed to ascending pathways.

4 Ascending pathways in the posterior and lateral region of the spinal cord travel to the brain carrying sensory information.

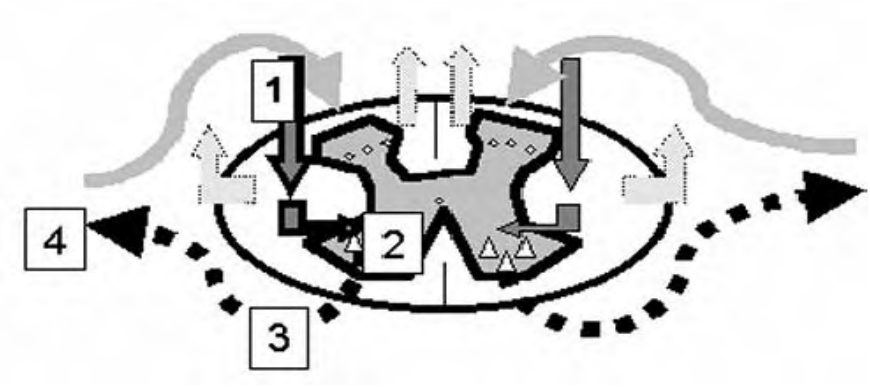


Figure 2 Descending Pathways (Motor Function)

1 Information from neurons in the brain carrying motor information goes down to the spinal cord.

2 Information from descending pathways connects with neurons in the anterior (ventral) horn of the spinal cord.

3 Nerve fibers from motor neurons exit the spinal cord traveling in ventral roots.

4 Nerves (carrying motor information) connect with the periphery (e.g., muscles).

cord and those that innervate the legs and genitalia originate in the lumbosacral region. Centrally located in the spinal cord and surrounded by white matter is the gray matter. This is a butterfly-like structure in which millions of nerve cells, neurons, are located. Neurons play important roles as controllers of motor or sensory function. All information coming down from the brain through the descending tracts (motor function) end in specialized nerve cells called motor neurons. The motor neurons serve as motor engines for the different muscles and structures in the periphery. Motor neuron cells generate motor nerves and are a part of the peripheral nervous system that connects the spinal cord with the periphery. The majority of the motor neurons in the spinal cord are located in the most anterior portion of the cord called the ventral area. These motor neurons are organized along the spinal cord in groups that serve specific regions of the periphery. Information coming from the periphery to the spinal cord is also highly organized. Sensory nerves that carry information from the periphery (i.e., skin, bowel, bladder) to the spinal cord enter the gray matter and are specifically located in the posterior region of the gray matter or dorsal region. From there, these sensory nerve cells give rise to nerve fibers that carry information to the sensory centers of the brain. This information travels to the brain in the white matter in ascending pathways.

So, in summary, two major topographical compartments are found in the spinal cord: the gray matter that contains the nerve cells and the white matter that contains the ascending and descending pathways.

The red matter is … blood!

There is really no red matter, but like all organs in the body, blood is important for the spinal cord. The blood supply for the spinal cord is an important factor for normal function. Blood vessels originating from other brain blood vessels supply the cervical and thoracic cord and a tiny blood vessel originating from an intra-abdominal arterial branch facilitates the blood supply to the lower thoracic and lumbar-sacral cord (Figure 1).

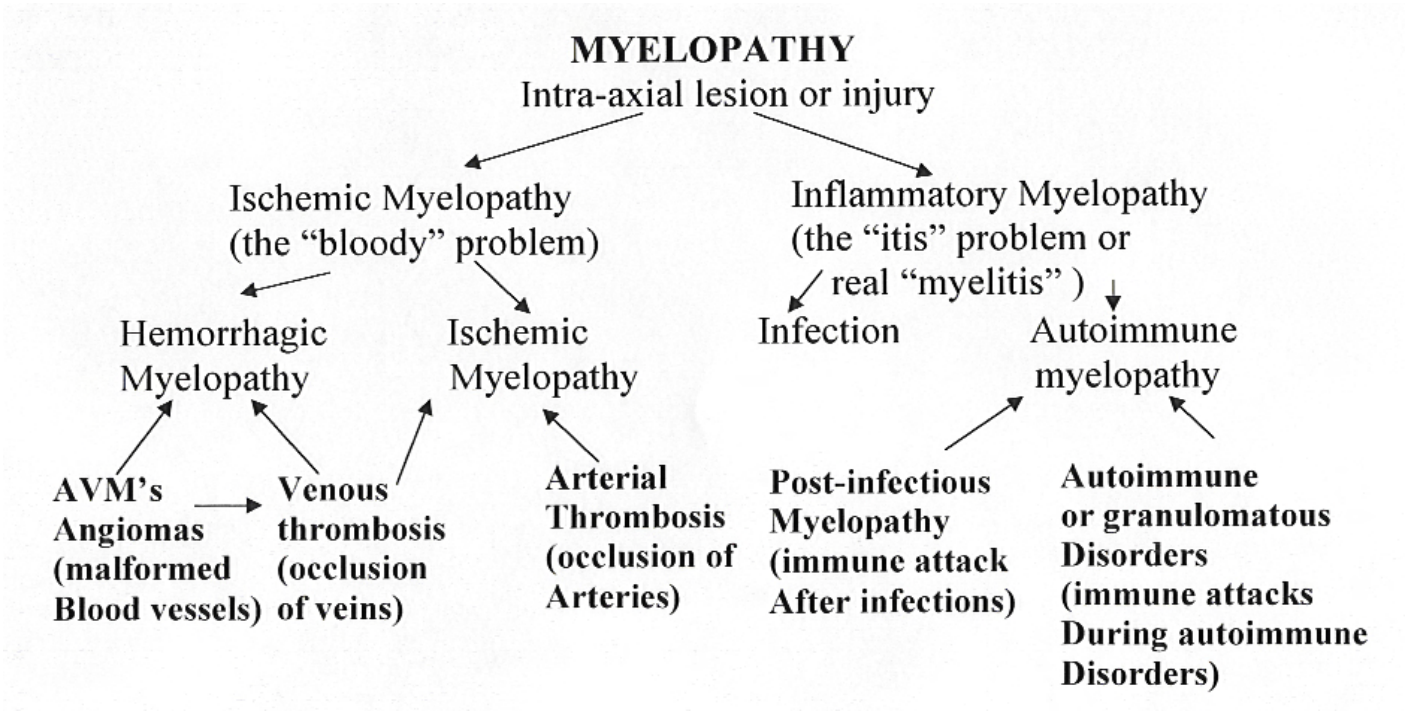
So, what can go wrong in this well organized scenario?

Many factors may disturb the stability in the spinal cord. The extent, magnitude and quality of this instability are variable. These factors may be extrinsic to the cord or may come from structures surrounding the cord, as in spinal trauma when bone fractures or herniated discs damage the cord by compression or disruption of the structure. Other factors may be intrinsic or originate inside the cord. This is what happens in many cases of TM. These intrinsic factors may originate from problems affecting the blood supply or from inflammatory changes resulting from infections, and the reaction generated by the immune system of the body.

The meaning of terms: Myelitis or Myelopathy? … a fire or drowning?

More than a hundred years ago, French and British physicians observed and described TM for the first time … the first Sherlock Holmes involved in the investigation of this problem. When the first pathology studies came out, a common observation in the structure of the spinal cord was a segmental and localized destruction of the tissues. It was often described as “spinal cord softening” or “transverse myelitis,” meaning that a segment of the cord was completely transected. The term “transverse myelitis” survived many years and is still the widely used medical term for this condition. The real situation is that in many cases TM is neither *transverse* nor *myelitis*. As the word defines, *transverse* means “being across or set crosswise.” The reality is that the “crime” does not, in all cases, occur across the entire structure of the spinal cord. In a majority of patients with TM, the injury or lesion occurs only in well delineated areas that may involve part of the cord, either the white matter or gray matter or both. When we

The Spectrum of Pathology in TM … *or much better* … Myelopathies!



observe complete transection of the cord, we then have patients with a fulminate disruption of cord function. This is the reason some patients and also physicians talk about a "partial" transverse myelitis or "incomplete" transverse myelitis to define the extent of the structural damage of the cord.

Now, the other problem in the definition is what *myelitis* means in TM. As a pathology term, everything that ends with ***-itis*** means inflammation. For example, encephal***itis*** means inflammation of the brain. Opthalm***itis*** means inflammation of the eye. Hepa***titis*** means inflammation of the liver. So, myel***itis*** would mean inflammation of the spinal cord. But again, the reality is that **not** all cases of TM are myelitis; not all problems are caused by inflammation of the cord. To explain this situation, I need to name the two major "criminals" involved in the "crime" against the spinal cord in TM. One of them is the ***itis*** or, as I explained, the inflammation of the cord. The other one is a well known criminal … and the name is …. Well, there is no well established name, but we know that this criminal resembles the famous ***stroke*** of the brain or stroke of the heart that attacks many other patients. Yes, in many patients with TM, the criminal is a ***stroke*** of the cord. Since the term *transverse myelitis* has been with us for many years, it is now difficult to modify the term. In many instances, we would prefer to call the problem Myelo***pathy*** instead of Myel***itis*** to mean that there has been a **"…-pathy"** of the spinal cord or, in more accurate terms, a damage or injury to the cord. As I said before, many of these words are just medical terms with no real meaning for patients, where the consequences of "TM" are the same regardless of the cause of the problem. But since we are talking about the pathology of TM, it is much better to set things straight.

Lets learn about the criminals!

There are two major gangs of criminals in TM. One big gang is the ***itis*** gang. The other I will call the ***bloody*** gang. We now know that the ***-itis*** gang produces inflammation of the cord and subsequently damages and destroys focal areas. These are the real myel***itis*** cases. The ***bloody*** gang targets blood supply to the cord either by a stroke of the cord occluding blood vessels or via malformed blood vessels or by attacking blood vessels supplying different areas of the spinal cord. To understand how these gangs operate take a look at Figure 3.

One branch (***itis***) is associated with direct infection of the spinal cord produced by viruses, bacteria, fungi or parasites. This can affect any region of the spinal cord: cervical, thoracic

or lumbo-sacral. The extent of the attack and damage to the cord is variable and depends on the type of organism involved. Some parasites, such as those that cause schistosomiasis and cisticercosis, and viruses, such as herpes, belong to this gang. The main crime occurs when these organisms invade the spinal cord producing focal damage to the cord by triggering inflammation and destruction of the white matter, gray matter or both. The inflammation may spread like wild fire along the cord or may remain localized. The acute clinical presentation depends on the extent and magnitude of the inflammatory reaction mediated by white blood cells and proteins from the bloodstream.

The ***postinfectious*** branch is formed by "friendly fire" from our immune system. The body's defense mechanism, our immune system, is comprised of two lines, proteins called *immunoglobulins* that try to neutralize the infective agent and *white blood cells* that also attack the infective agent or produce substances to neutralize the infection. In the majority of cases, our immune system triumphs, defending our body from diverse types of infections. But in few cases, they mistakenly attack parts of the nervous system. Our immune system ***self*** attacks and damages parts of the spinal cord or brain. Immunoglobulins or white cells, generated against the spinal cord weeks or months after infections, such as gastroenteritis or upper respiratory infections, trigger additional inflammatory chain reactions that damage the structure of the cord. As in the case of direct infection of the cord, the inflammation can spread along the cord or may remain localized.

The third well known branch is comprised of a group of ***systemic autoimmune disorders*** in which the immune system turns against the body it is defending. Some known disorders include Systemic Lupus Erythematosus, a disorder in which autoantibodies are excessively produced. Others, such as multiple sclerosis, a neurological disease associated with autoimmunity, is frequently of concern when patients are diagnosed with transverse myelitis. In many of the autoimmune disorders, damage to the blood vessels and subsequent injury to the white or gray matter structures of the cord are the main cause of the problem.

No blood … no function!

The no-***itis*** "***bloody***" gang is, of course, associated with blood. The blood supply to the spinal cord is fundamental to its function. Any disturbance produced to the blood supply of the cord may have deleterious consequences and is a major concern when evaluating patients with transverse myelopathy (oops, this is ***pathy*** rather than ***itis***!). The "***bloody***" gang may have different faces. One face is ***malformation.*** Abnormal and malformed blood vessels form dysfunctional blood vessels called ***arteriovenous malformations***, which are associated with decreased blood supply to the cord and injury to the white or gray matter structures. Another face is ***clogged pipes***, in which blood vessels supplying the cord get occluded by arteriosclerosis, clots or injury produced by herniated discs or masses external to the cord. In many patients, the attack is quite fast, leaving behind a lot of spinal cord damage. Occasionally, the face of this gang may turn "***bloody***" due to hemorrhages inside the cord.

Why the identification of the criminal's last name is important!

The criminal investigation or the pathological investigation is just the search for the reason **why?** and **how?** Understanding the criminal gang involved, ***itis*** (inflammation) or ***non-it is*** (non-inflammation or ***pathy***), is the first approach for an adequate treatment in TM patients. That is the reason we jump to do more investigation, such as the use of imaging by magnetic resonance or studies of the cerebrospinal fluid. These "searches" help clarify whether the suspect is part of the gang ***itis*** or ***bloody*** and help identify treatment modalities. One example of this concern is when patients are identified as having transverse myel***itis***, it is believed that use of corticosteroids may improve the inflammation. Of course, when the problem is transverse myelopathy, things may turn out to be more difficult and complicated. The reason for the complication, no ***it is***, no inflammation, no response to corticosteroids (or at least, that it is what we believe)!

How to clarify the pathology of TM?

The gang names are important to understanding TM and its consequences. Different approaches of investigation, imaging by MRI, spinal fluid studies or blood testing, facilitate some answers to questions. Occasionally, the use of "biopsies" or tissue sampling for microscopic examination is required. All of these studies are not superfluous, they are necessary to our understanding this condition and how to treat its consequences. After assessment and identification of the sources of the problem, the next step is to evaluate the magnitude of the problem or, in other words, how much damage was done and what we need to do for improvement.

Next: **How the pathology determines the presence or absence of symptoms? Why do I have pain months after my TM?**

Depression in TM
Adam Kaplin, MD, PhD

Dr. Kaplin is an Assistant Professor of the Department of Psychiatry at the Johns Hopkins University School of Medicine and serves as the Chief Psychiatric consultant to the Johns Hopkins Transverse Myelitis and Multiple Sclerosis Centers. Dr. Kaplin also serves on The Transverse Myelitis Association Medical Advisory Board.

Traditionally, Transverse Myelitis (TM) has been thought of as a spinal cord disease, affecting motor, sensory, bowel, bladder and sexual function as a result of a spinal lesion visible by neuroimaging studies. However, TM is an autoimmune neurologic disease of the Central Nervous System (CNS), with activated immune cells seen (by spinal tap) floating in the Cerebro-Spinal Fluid (CSF) that bathes the spinal cord and brain together. TM is probably best thought of as lying on a continuum with recurrent Optic Neuritis (that affects the optic nerves that carries visual signals from the eye to the brain), Neuromyelitis Optica (involving the optic nerves and spinal cord), and Multiple Sclerosis (which can affect anywhere in the CNS). The traditional view of TM as solely a spinal cord disease, which persists today, has eclipsed consideration of the effects of this autoimmune disease on the brain. Multiple Sclerosis (MS), in contrast, has had a fair amount of research into the effect of this autoimmune disease on the brain. A growing body of work has begun to shed light on the impact of this brain involvement in producing depression. In fact, MS has the highest rate of depression thus far described in any major chronic disease, with 20% of patients suffering from depression at any given time and a lifetime prevalence of depression over 50%. Work done at the Johns Hopkins TM Center in collaboration between the Departments of Neurology and Psychiatry has begun to shed light on the prevalence of depression as a reflection of autoimmune disease activity in TM. Before reviewing the findings of this preliminary research, we must first differentiate demoralization, which is a psychological state of overwhelming sadness appearing as a consequence of adverse circumstances, from clinical depression, which we view as a disease of the brain.

Demoralization

There is no despair so absolute as that which comes with the first moments of our first great sorrow, when we have not yet known what it is to have suffered and be healed, to have despaired and have recovered hope.
George Eliot (1819-1880)

Sadness is an understandable and predictable response to suddenly finding oneself thrust against one's will into a life under altered circumstances, in which there is a need to accept losses of desired abilities and confrontation with unwanted struggles. Thus is the case with all chronic diseases. In addition to the potentially dramatic disability that can afflict patients with TM, this disease has certain aspects that make it particularly difficult for many patients to endure. It is more difficult to adapt to acute rather than gradual changes, and TM begins without warning and evolves over hours to days. Moreover, the fact that TM is an uncommon ailment has two troubling consequences for those affected. First, physicians are not often familiar with the diagnosis, prognosis and management of TM, and, as a result, patients commonly go undiagnosed, inadequately educated and under-treated. Second, many patients affected with TM have no contact with anyone else in their area with this disease, and with whom to compare experiences, and so feelings of isolation are all too often the norm.

Sometimes an individual's capacity to adapt is overwhelmed by the stresses with which he is confronted, and he becomes discouraged, bewildered and overwhelmed. This is a state called demoralization. Demoralization has been defined (Frank JD 1991) as a state of helplessness, hopelessness, confusion, subjective incompetence, isolation and diminished self-esteem. The subjective experience of demoralization involves feeling incapable of meeting both internal and external expectations, feelings of being trapped and powerless to change or escape, and feelings of being unique and, therefore, not understood. The combined effect usually leads to frustration, bewilderment and isolation.

To combat the feelings of failure, being overwhelmed and a sense of isolation that collectively represent demoralization, people must be taught how to achieve remoralization. Assistance with developing problem-focused coping skills can instill a new sense of progressive mastery. For example, building rest periods into an afternoon schedule can combat fatigue. Shopping at off-peak times can avoid feelings of being rushed and embarrassed publicly because of a disability. Individual and group support and education can help combat hopelessness and isolation. Cognitive reframing can be employed to help examine unfair assumptions. For example, reexamining the beliefs that all of the gains achieved through rehabilitation are insignificant, because they did not result in complete recovery helps dispel unrealistic short-term expectations. Sometimes gaining an appreciation for one's own accomplishments by viewing them through someone else's perspective can be very comforting and inspiring.

Psychosocial Impact and Long Term Adaptation

MS, being more common, has been investigated more extensively than TM. A study of MS patients whose average time since diagnosis was nine years, examined their subjective experiences and the psychosocial consequences of their disease (Mohr, Dick et al. 1999). The results of this study are very instructive, in that they demonstrate that even though autoimmune neurologic diseases can be difficult to adapt to acutely, most patients appreciate, over time, the beneficial as well as detrimental effects of their illness on their lives. In this study, the minority of patients (20%) reported that MS had led to a deterioration in their relationships, most often characterized as concerns that they were not as good a mate or that their partners were angry or irritated more often. There were 30% who reported feeling demoralized, with feelings of sadness, loss of independence, or uncertainty about the future. The majority of patients (60%) endorsed finding benefit as a result of contracting their disease: their relationships seemed closer, they felt they were more compassionate and communicative, and they gained a better appreciation of, and perspective on, life. Thus, over time, as the body and mind adapt to life under altered circumstances, unrelenting sadness is usually tempered by adaptation, appreciation and growth. Depression is among the reasons that individuals find themselves incapable of coping with their disease and moving on with their lives, even after many months or years.

What is Depression?

The sadness that accompanies demoralization is not equivalent to clinical depression (which will subsequently be referred to as Depression). Sadness is a symptom whereas Depression is a clinical syndrome; a constellation of several symptoms that cluster together in affected individuals. Sadness is to Depression what cough is to pneumonia; cough can be an indicator of pneumonia, but not every cough is the result of pneumonia and sometimes pneumonia can present without a cough. If the cough is productive of green mucous and accompanied by fever, rapid breathing and evidence of infection in a lung by examination or x-ray, we call this the syndrome pneumonia. What then is the syndrome of Major Depressive Disorder (as Depression is referred to in the medical literature)? The cardinal features are a fixed and unresponsive low mood, poor self-attitude or self-esteem and decreased vitality. How can these features be translated into straightforward diagnostic criteria?

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) is the main diagnostic reference of Mental Health professionals in the United States. The DSM-IV criteria for Major Depression require the presence of at least five of the nine following symptoms: 1) decreased interest (or pleasure) and/or; 2) low mood; 3) increased or decreased sleep; 4) increased or decreased appetite; 5) feelings of guilt or worthlessness; 6) subjective sense of fatigue or low energy; 7) poor concentration; 8) feeling/appearing as though one's thoughts and actions are either slowed down (e.g., *dragging*) or sped up (e.g., *agitated*); and 9) thoughts of death or suicide.

Because the minority of individuals suffering from depression seek treatment, and those that do often conceal their diagnosis from friends because of the stigma that surrounds mental illness, the prevalence of Depression is often unappreciated. In the general population, Depression affects 5% of individuals at any given time, and 17% of individuals will suffer from Depression during the course of their lifetime. Depression is a very debilitating disease. Compared to the leading medical causes of chronic disability, Depression is second only to heart disease in terms of its impact on daily functioning. Depression is also a lethal disease, resulting in suicide in up to 15% of those severely affected. In the United States, suicide is the third leading cause of death in those 1-24 years of age, and the fourth leading cause for young adults aged 24-44. In MS, suicide is the third leading cause of death overall, after pneumonia and cancer, and occurs at a rate 7.5 times that of the general population. Compared to other common causes of death in MS, suicide tends to occur in relatively younger individuals who have milder disability, making the years of life lost particularly tragic.

We are no more accustomed to thinking about how our brains regulate our moods, much as thermostats regulate the temperature within our homes, than we are to considering how our brains facilitate our use of language to communicate. Although it can result from a combination of genetic predispositions and environmental stressors, a number of medical diseases are known to predispose to Depression. Neuropsychiatric diseases that cause insults to the brain are known to be associated with extremely high rates of Depression. Diseases such as strokes, brain tumors, Alzheimers and Parkinsons disease are associated with rates of Depression between 30-50%. Importantly, studies have shown that Depression in such diseases is not simply an inevitable reaction to severe adversity. For example, Amyotrophic Lateral Sclerosis (also known as ALS or Lou Gehrig's Disease) is a selective motor neuron disease resulting in the paralysis of all skeletal muscles, which follows a relentless course and usually results in death from respiratory failure or aspiration in three to five years. There is no general insult

to the brain and there is no increase in the rate of Depression seen in patients afflicted with this devastating illness. Thus, Depression should not be assumed to be an inevitable or even common outcome of misfortune alone.

Of all the medical conditions reported to date, MS is believed to have the highest rate of associated Depression, with a lifetime prevalence following diagnosis of 50-60% (Patten and Metz 1997). Evidence for a role of the immune system's effects on the brain as a contributor to Depression in MS includes the following three findings: 1) patients with MS who become depressed do not have a greater likelihood of having depressed relatives than non-depressed MS patients, suggesting an insult, and not a genetic predisposition, plays the key role, 2) Depression increases during periods of immune-system activation resulting in disease exacerbation, and 3) there is no correlation between the degree of disability and occurrence of Depression in MS patients.

TM and Depression

Work done in the Johns Hopkins TM Center in collaboration between the Departments of Neurology and Psychiatry has begun to examine the rates of Depression in patients with TM. Only a summary of the initial findings will be presented here. Evidence was obtained for rates of Depression in TM patients exceeding those seen in comparably disabled MS patients. As in previous studies of MS patients, there was no correlation between severity of Depression in TM patients and motor, bladder or sexual dysfunction. There was a modest correlation between Depression and sensory disability (predominantly symptoms associated with prickling, tingling or numbness). Whether this represents a lowered tolerance for these symptoms in patients with Depression or, alternatively, an effect of sensory symptoms on patient's mood cannot be determined from these findings. It may be fair to suggest that of the known ongoing chronic symptoms of TM, sensory symptoms (including chronic pain) may be among the most distressing and difficult to accommodate. An additional association was found between rates of Depression and history of IV steroid treatment. Patients who received IV steroids did not appear to differ with respect to the severity of symptoms at presentation or level of ongoing disability following recovery. The possibility cannot yet be excluded that those patients who appeared most distressed because of Depression at the time of presentation were more likely to be treated with IV steroids. Because steroids are known to cause Depression in numerous other patient populations, the finding of higher rates of Depression in TM patients who received steroid treatment suggests that it would be prudent to closely monitor the patient's mood, if they receive such treatments.

We found high rates of Depression in TM reminiscent of what had been described previously in MS. We wondered whether this Depression was a marker for brain involvement due to immune-activation in the CNS. In addition to high rates of Depression, patients with MS also suffer from elevated rates of cognitive impairment manifesting as difficulties with certain tasks of concentration, short-term recall of details and processing speed. When we examined mental processing in TM patients, we found preliminary evidence that they excelled at many cognitive tasks. There were subtle paper-and-pencil tests, however, on which some TM patients performed worse than expected, and these were the same tests that often were difficult for MS patients. Clinically, we have noted that a minority of TM patients, even those without depression and on no medications, report that following the onset of their neurologic disease, they could no longer remember as many details without writing them down, and required additional time to complete complex mental tasks.

Special Considerations in TM Depression

The importance of making the diagnosis of Depression in TM cannot be overestimated. Often what is most debilitating is not the requirement for assistance with walking or the chronic pain that must be endured, but the Depression that leads to difficulty getting out of bed, social isolation and lowered pain tolerance. Routinely for patients with TM and Depression, the majority of their disability is due to the Depression and treatment leads to a dramatic increase in their function. Depression, despite its often devastating impact on patients, is a treatable disease with the majority of patients who receive adequate treatment able to make a complete symptomatic recovery. What is required to achieve this result is often the same level of aggressive management that TM patients routinely invest in managing other aspects of the effects of their disease, such as physical therapy and rehabilitation to enhance ambulation, or urologic consultation for bladder management. Before Depression can be managed, however, it must be properly diagnosed.

As in the case of many medical or neurologic diseases, recognizing Depression in TM patients can be challenging because of the overlap of symptoms between these psychiatric and neurologic diseases. Fatigue and poor concentration, for example, occur in many patients with TM making reliance on these symptoms difficult in making a diagnosis of Depression.

Certain clues that can help differentiate symptoms of TM from those of Depression can be recommended. Feelings of self-blame, guilt and self-recrimination are not common reactions to a medical illness, but are almost always found to some degree in Depression. The pervasiveness of symptoms can also suggest Depression. Low mood most of the time or loss of pleasure in activities that require skills that are made more difficult because of neurologic deficits can occur commonly in TM, particularly during the first few weeks of adjustment to this disease. But low mood all of the time, and lack of pleasure in all activities should raise suspicion for Depression. Similarly, a failure to progress beyond the acute shock of being afflicted with TM after many months or years should raise questions about a supervening Depression. The statement "He/She is not the same person since the disease hit," many months after the disease onset, should also raise suspicion for a Depression. If an individual was progressing well, initially, in terms of their recovery from their neurologic deficits, but suddenly stopped progressing and, in fact, began to lose ground, the possibility of Depression should be entertained as a possible cause. Finally, suicidal thoughts are the result of Depression until proven otherwise, and should prompt an urgent assessment by a trained physician or Mental Health professional. This is because the rate of suicide in TM Depression appears at least as great, if not greater, as that found in other medical conditions.

Ultimately, the diagnosis of Depression can best be made by an individual, usually a physician, with extensive training and expertise in mood disorders, such as a psychiatrist. Just as individuals afflicted with TM could not rely on their own knowledge or that of their loved ones to make the neurologic diagnosis, only a trained professional can confirm and assist with the treatment of Depression. If there is any question about whether a person is afflicted with Depression, an evaluation should certainly be requested.

Barriers to Seeking and Accepting Treatment for TM Depression

Rehabilitation and recovery from TM is often a painstaking and laborious journey. Adjusting to life under altered circumstances when neurologic deficits become long-term can be dramatically taxing. Unfortunately, symptoms of Depression, such as hopelessness and loss of interest, are often first interpreted as "giving up" and equated with being "weak" or "lazy." Moreover, many people equate Depression with being "crazy" and so avoid seeking treatment for this reason. Recognizing that Depression is a chemical imbalance in the brain that is treated with a class of chemicals called antidepressants, rather than a character flaw or personal failure, can sometimes prove helpful in combating this stigma.

Preconceptions and myths about antidepressants also represent common barriers to accepting treatment for Depression. Antidepressants specifically target and treat changes in the brains of patients who are suffering from Depression, but they have no mood elevating effects on individuals who are not depressed. As a result, antidepressants are not addicting, like drugs that induce euphoria, and they have no street value. And antidepressants do not give people "fake" feelings or make them feel things they would not normally feel. Instead, antidepressants restore the normal cycle of ups and downs, in response to life's rewards and stresses, that is lost in individuals suffering from Depression. Finally, individuals occasionally refrain from using antidepressants based on a perception that they do not want to "end up like a zombie" based on knowing or having heard of someone who was not the same once they started taking medication. The fallacy in this argument is that Depression is far more likely to make someone appear impaired then is the medication that is started to treat his mood disorder. While it is true that medications that are used to treat other mental disorders, such as schizophrenia, can produce noticeable side effects such as over-sedation and stiffness, the judicious use of antidepressants by trained psychiatrists results in a return to previous functioning in patients in whom Depression has made their behavior different. The goal with antidepressant therapy is to return an effected individual to the helm of their own ship, and allow them better to chart the course of their thoughts, emotions and behaviors as they regain control of the direction their life is taking. Rather than develop noticeable side effects that suggest a person is being treated for depression with medication, the only thing that other people notice is that the person being treated seems "more like their old self."

The biggest barrier to seeking and accepting treatment for depression, bar none, is the effects of depression itself, which makes people hopeless, unmotivated and unable to imagine that things could get better. Ironically, it is these same symptoms of Depression that are among the important reasons an individual requires treatment, yet they interfere with his ability to get the help he needs. The following three points can help overcome the inertia of such situations. First, successful treatment of Depression requires an individual be compliant with his treatment, not that he believe he will return to being well. Second, in light of the fact that what has been tried has clearly not succeeded in changing the situation, accepting treatment for De-

pression is often the only reasonable course of action. Even if treatment were to fail, the person will certainly be no worse off for having tried something new. And third, sometimes we must all accept the advice of our loved ones, knowing that it is offered in good faith and with an objectivity that may elude us for the moment, especially in situations where our own judgment may be compromised by an illness. To this end, caregivers often play a critical role in persuading patients to seek and accept treatment for their Depression.

Who Cares for the Caregivers?

There are both positive and negative aspects of being a caregiver; in reality, being able to care for the people whom we love, in their time of need, is both a privilege and a burden. A full consideration of the impact of TM on caregivers goes beyond the scope of this article. It is necessary to point out, however, that caregivers are dramatically impacted by both TM and Depression in the people whom they love. Despite this fact, caregivers, care recipients and health care providers usually focus virtually all of their attention on the well being of the patient with TM and Depression, often to the neglect of concerns for the caregiver. In general, the caregiver's health status is often compromised because of neglect of their own health. This occurs despite the fact that the wellbeing of the care recipient is often vitally dependent on the continued efforts and support from the caregiver, which can best be furnished by a healthy individual. Studies have shown that the care recipient variables associated with increased caregiver burden include an unstable course, increased physical disability, pain and depression. Since Depression exacerbates all of these variables, caregivers often have a very real personal stake in whether a care recipient receives adequate treatment for their mood disorder.

Four issues can be recommended for caregivers to keep in mind in caring for their loved ones without neglecting themselves. First, caregivers should enhance their problem-focused coping skills. This usually involves recognizing what can and cannot be changed, and trying different solutions to the problems that arise until the right one is found. Both caregivers and care recipients must avoid entrenchment in failed solutions that only serve to increase distress. Second, information is crucial because what caregivers don't know about TM and Depression will increase their anxiety and prevent them from being able to efficiently problem solve. Peer education opportunities are often invaluable for both information and support. Third, caregivers must remember to periodically ask themselves "how am I doing?" Taking care of their own needs should not be viewed as being in conflict with the care recipient's needs. Caregivers are no good to their care recipients if they are burnt out, and knowing how to get additional help is often critical to the wellbeing of both parties. And fourth, caregivers and care recipients must not lose sight of the obvious fact that they are in this together. Coping strategies must therefore be complimentary. There are often multiple solutions to the same problems, so a premium should often be placed on maintaining enough flexibility to maximize the benefits for both care recipients and caregivers.

Conclusion

Sadness and demoralization are commonly the result of the acute hardships that people afflicted with TM are made to undergo. Time to adjust and strategies to achieve remoralization are the keys to recovery from these acute situations. Depression, on the other hand, is a disease that appears to be at least, in part, a direct result of the effects of the activated immune system in TM patients on their brain. Depression is not a character flaw or sign of personal weakness, anymore than is diabetes or hypertension. Like other medical illnesses, Depression is a disease that is associated with considerable morbidity and mortality, and, therefore, must be aggressively identified and treated. Fortunately, Depression is also one of the most treatable consequences of TM, with the expectation that individuals will make a complete recovery with proper management. Finally, it is imperative to consider the impact that TM and Depression have on both patients and their loved ones, because success will ultimately be measured in how well individuals are functioning in the context of their families.

It has been argued in this article that Depression in TM, as has been suggested in MS, can be the result of the immune system's influence on the brain. We are actively pursuing the mechanisms underlying this influence. Recent studies have reported on the effect that treating Depression has on immune system functioning. Preliminary studies have suggested that Depressed MS patients have even more aggressive immune systems, capable of wreaking greater neurologic damage, than their non-depressed counterparts (Mohr, Goodkin et al. 2001). Treatment of Depression in these MS patients led to an amelioration of their immune system, suggesting that treating Depression could be of important benefit to patient's neurologic as well as psychiatric wellbeing.

Many patients with TM suffer greatly, often without timely diagnosis or treatment of their neurologic disease. Importantly, the Depression that can accompany this disease should not similarly be overlooked or inade-

quately treated, because of the tremendous benefits patients and their loved ones can obtain from proper management.

The one law that does not change is that everything changes, and the hardship I was bearing today was only a breath away from the pleasures I would have tomorrow, and those pleasures would be all the richer because of the memories of this I was enduring. Louis L'Amour (1908-1988)

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The Spiritual Life of Transverse Myelitis

Rabbi Gary A. Huber

Congregation Beth Tikvah

Several months ago I asked my friend Sandy Siegel if I could write an article for the Newsletter regarding spiritual approaches in coping with all of the difficult physical, social and emotional issues surrounding TM. My inspiration for this goes back to the wonderfully happy event of Sandy and Pauline's wedding, at which I had the great joy and honor of officiating. I officiate at many weddings but I cannot recall in my 25 years as a rabbi a more joyous event. The sanctuary seemed to glow from the happiness of the gathered guests who came to share their love with two very special people. But this event was unique in another regard: many of the guests present had lived many years with TM or were related to someone with TM.

Reflecting back on this, I wondered if there were special issues relating to the spiritual life affecting folks with TM and their families. At Sandy's encouragement, I interviewed about 15 individuals and families, as well as several medical specialists, as to the role of spirituality and religious faith in their life. And what I discovered is that they have a very special insight into the life of the spirit that is both deeply inspirational as well as profoundly insightful. People with TM and their families have much to teach the world about the role of faith and the meaning of human suffering.

No doubt, the central emotional challenge relating to TM is clinical depression. And the sense of despair often takes on a religious dimension. Dr. Adam Kaplin, professor of psychiatry at Johns Hopkins School of Medicine, told me that "many if not all of the TM patients I see report struggles with questions such as 'why did this happen to me?' A history of past or current religious conviction can be one of my greatest allies as a psychiatrist in attempting to assist my patients with turning away from suicide as an option and finding structure and support for themselves especially during grim times." Actually, at first I fully expected to hear many tales of how the disease had utterly destroyed any sense of faith in God or even faith in the goodness of life. I was wrong. If anything, my conversations with several individuals point in the opposite direction: a growth in faith and a deepening of faith. But the faith of people with TM is not the same as before their diagnosis. It is a more thoughtful, more profound and a more mature faith. By that I mean a faith that comes after many a "dark night of the soul" and after periods of anger at God.

This bears some comment. As a clergyman, I am never worried about someone being angry at God. Anger at God following a diagnosis of TM is a natural and expected reaction to a life-transforming event. And, in a very real sense, it is a statement of intimacy with God. After all, you can only be angry at someone you believe exists and has an important role in your life. I recall the words of the Nobel laureate Elie Weisel, who alone of his entire family survived the hell of Auschwitz: "I can sometimes be very angry at God and sometimes I can be very much in love with God, but I can never be without God." I know that many people with TM have felt the same. Anger at God is an expected emotion for folks who suffer from such a difficult illness. The question is: does one get stuck at anger or does one move on in the life of faith? The testament of the people I interviewed is one of very impressive spiritual growth.

In what ways? Though the respondents (and their families) were from a large variety of religious traditions and practices, *all of them to a person* expressed three fundamental gifts that their religious faith bestowed on their lives: a feeling of gratitude, a sense of perspective and a renewed experience of self-esteem. From a psychological standpoint, these three comprise the fundamental armor, a kind of immune system, in the daily battle against depression. From a theological standpoint, they point to the life God wants, I believe, for each of His children: one of spiritual fulfillment, empathetic compassion for others and a fundamental regard for one's self.

Gratitude. One definition of gratitude is the ability to be mindful and appreciative of the blessings that are in one's life, regardless of your difficulties and struggles. Put differently, it is very difficult to be depressed and profoundly filled with gratitude, at the same time. The opposite of being grateful is taking these blessings in your life for granted, which we of course do all the time. Many people focused on this as the greatest benefit of their prayer life. While some people feel very comfortable in structured ritual traditions and others emphasize more spontaneous private prayer, what is fascinating is that no one said that their primary or first prayer is to be healed. That is always prayer #2. Prayer #1 is to simply thank God for the blessings that are in one's life: your spouse, your children, life, nature, freedom, your mind, etc. As one person put it: "At first, all I wanted was for this miracle working Jesus to heal my body. That's all I thought I needed. But I needed lots more. Having been hit with TM at 15 forced me to seek God for answers and comfort and the ability to handle it all. Even more than healing, I pray daily for strength to cope. And that starts with counting my blessings." Many people commented that "my hope and strength to deal with TM on a daily basis comes mostly through knowing God's character and His promises" and that "my disease makes me look upon others with great compassion, because I know all about suffering. This, too, is part of God's plan for me."

Perspective. Another theme that emerged in my conversations is that one's religious faith literally gives one the largest perspective one could hope for: the perspective of God. It is to see one's pain from the larger and grand perspective of eternity or God's purpose and thus to achieve a degree of separation between one's self and one's body. As one person put it: "My body is the temporary tent of my soul." This is a crucial way to think. It is to remember that we are not bodies inhabited by a soul, but rather souls who for a time occupy a body. This shift in focus reminds us that we are created in the Divine image, and even though the body is corruptible and suffers pain, my true and essential self is imperishable and indestructible. This thought gives one great strength and courage in the battle against despair and depression.

Self-Esteem. One of the tasks of any theology is to attempt to answer the age old question as to the suffering of the innocent. The classic cry of the Biblical Job is to ask why the righteous suffer and there are as many answers to this as there are religions. But one of the standard "answers" one sometimes hears, and that is proposed in the Book of Job, is that suffering is always due to some bad thing, some sin that the person committed. In fact, the author of Job puts this view into the mouth of Job's so-called friends, who are not very friendly and whom the book treats with disdain. (God appears at the end of the Book and dismisses this view). Still, it is a simple and often heard view. What was very interesting is that not one of my respondents said that they felt they were being punished with TM for being a bad, sinful person. They are not only wise in this response, but they said the very opposite. Each of them expressed how deeply loved they felt by God and how worthy of that love they felt. Said one person: "I feel comfortable and confident with the relationship I have with God and I know that I am very blessed. I believe God loves me and accepts me just the way I am. I am in control of my life and take responsibility for my actions. Bad things do happen to people, and life is very difficult at times. Still, I think God does have a plan for my life, and occasionally he needs to guide me in a different direction from what I had planned for myself. When this happens, I rely on my faith in God, and trust he knows what is best for me at that time. My faith gives me confidence and assurance. The stories I've heard growing up about the wonder of God are very real for me. I know what that kind of love and acceptance feels like. I believe God loves me in this wonderful way. How blessed am I to have such love in my life."

While each of my respondents shared their faith and its role in coping with TM, there was one additional insight many of them shared. Each one in some way made helping other people a key element in their lives. One is a spokesperson for TM research, another a teacher, another volunteers in her church to feed the hungry. All of these serve to take themselves out of themselves for a few moments by focusing on the needs of others. They feel they have something essential to contribute to society, and they are right. It is often said that volunteering to help others is good for them. What needs to be stressed as well is that it is good for you, too! In all these ways, pursuing the life of the spirit is a key element in coping with TM.

Translational Pain Research at the Brigham and Women's Hospital: Help for People with TM who Suffer from Pain

Christine Sang, MD, MPH is an Assistant Professor at the Harvard Medical School and the Director of Translational Pain Research at the Brigham and Women's Hospital in Boston, Massachusetts. She serves on the Board of Directors to the American Pain Society, and is a Founder and serves on the Steering Committee of the Neuropathic Pain Institute. She also serves on the advisory board committees of several companies that develop new drugs for pain, and is a consultant for the FDA on the treatment of pain syndromes.

Dr. Sang and our research team work together to bring laboratory research into a safe and effective clinical research setting. The primary aim of our ongoing research is to systematically evaluate new drugs for pain and to determine the cause of different types of pain to improve therapy. Our overall goal is to relieve each person's pain experience, which we hope will ultimately improve quality of life. The focus of our research group is spinal cord pain following injury, infection, or inflammation, including transverse myelitis. We realize that people suffer from severe pain which can prohibit them from everyday activities. With each person, pain varies in its intensity, frequency, and duration of episodes, as well as in overall sensations. This pain can be at its best annoying, and at its worst, nearly unbearable.

Although there are many types of pain, there are two broad categories that distinguish the mechanisms of pain: mechanical pain and neuropathic pain. Mechanical pain is caused by overuse and subsequent damage to normal tissues; such as bones, joints, and muscles. It often becomes worse with movement, and eases with rest. This pain usually responds well to existing pain treatments, such as narcotics and NSAIDS (i.e., ibuprofen), and will often go away when the body heals or when the problem is removed. There are numerous medical and surgical conditions that may cause neuropathic pain. Damage to peripheral nerves can also lead to neuropathic pain, but is often easier to treat. The conditions that may cause neuropathic pain include:

- Spinal cord (central) pain
- Painful peripheral neuropathy (due to diabetes, AIDS, chemotherapy, etc.)
- Radiculopathy (damage to nerve roots)
- Trigeminal neuralgia
- Complex regional pain syndromes (formerly reflex sympathetic dystrophy)
- Phantom limb pain
- Pain following mastectomy, thoracotomy, or other surgeries
- Pain following shingles (postherpetic neuralgia)
- Cancer infiltrating the nerve, plexus, or root.

Central pain can be caused by damage to the spinal cord. In essence, the spinal cord and the brain interpret otherwise normal sensations as pain. Central pain can be described in many ways -- burning, electric, tingling, shooting, stabbing, numbness, aching, throbbing, or squeezing. It can be very difficult to relieve. The responses to currently available pain treatments are often limited by side effects – such as drowsiness, dry mouth, and dizziness. The side effects and lack of adequate analgesia are frustrating for both the patient and physician. Central pain may occur at the level of injury due to damage to the nerve roots, as well as to the spinal cord itself. Doctors and other health care professionals may refer to this as "girdle zone pain." This pain follows a band-like pattern, such as circumferentially from the stomach around to the back. Central spinal cord pain may also occur everywhere below the level of injury, even if the entire cross-section of the cord is not damaged. This pain is often made worse with light touch or cold.

Central pain, like chronic pain in general, may begin at the time of injury or develop slowly over months or years. It can persist for long periods of time, and interfere with one's quality of life. According to some reports, as many as 90% of people with SCI have had chronic pain.

Unfortunately, central pain does not usually respond well to narcotics (e.g., morphine). On the other hand, the pain can respond to neuropathic pain medications (e.g., certain anticonvulsants or antidepressants). Some physicians recommend nerve root blocks that will numb the painful areas. This numb effect only lasts a short time and returns to baseline. Sometimes, a surgical procedure such as DREZ (dorsal root entry zone), rhizotomy, or cordotomy is recommended, although these procedures may result in yet another (secondary) spinal cord pain syndrome.

As neuropathic pain can be intermittent or constant, localized in one specific region or affecting the entire body below the level of injury, our research aims to treat the specific mechanisms believed to cause central pain, rather than merely masking the pain. Our study evaluates new drugs, as well as new methods of delivering conventional drugs, that can hopefully reduce chronic central spinal cord pain with fewer side effects than currently available medications. We usu-

ally have multiple studies going on simultaneously and we are always looking at new therapies and different ways to relieve neuropathic pain.

The Translational Pain Research Program at the Brigham and Women's Hospital in Boston is committed to working with people with TM and the other neuroimmunologic disorders to find an effective approach to treating pain. Our funding sources have included the Paralyzed Veterans of America, The Christopher Reeve Paralysis Foundation, and the National Institute of Neurological Disorders and Stroke (National Institutes of Health). Our program will work with patients and will also consult with and work with your physicians.

We will continue working with you until the goal of relieving your pain is achieved.

For more information, please contact us:

Kate Jenkins, B.A., Program Coordinator

Leah McInerney-Killion, R.N., B.S.N., Lead Study Nurse

Kristie Chin, B.S. Study Coordinator

Aparna Sarin, M.D., M.P.H. Research Fellow

Karen Wang, B.A, B.S, Research Assistant

Christine Sang, MD, MPH, Principal Investigator

Translational Pain Research
Department of Anesthesiology, Perioperative and Pain Medicine
Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115

Office (617) 525-7246,
Page (617) 726-2066
Fax (425) 675-5556

http://www.mgh.harvard.edu/paintrials

Considerations in Achieving Bowel Continence

Katharine Finney Kinsman, CRNP

Kathy is a nurse practitioner at the Center for Spina Bifida and Related Conditions, Kennedy Krieger Institute, Baltimore MD. Kathy conducts a Continence Clinic and has developed an expertise in managing incontinence due to a wide variety of conditions. The Clinic conducts evaluations and focuses on the management of urinary and bowel incontinence through an interdisciplinary approach that includes Nursing, Behavioral Psychology, and Occupational Therapy.

Introduction

Transverse myelitis (TM) is a rare disorder that results in spinal cord inflammation which causes secondary conditions such as immobility, risk of skin breakdown, and bowel and bladder dysfunction. Researchers have found that generally, about two-thirds of those affected by this disorder are left with a moderate to severe degree of permanent impairments. Even in those that recover, there is nearly always a temporary time during which organ systems such as the bowel and bladder are affected.

This article will focus on how an individual with a neurogenic bowel can achieve continence. This author shares the belief of a growing number of health care practitioners that every individual *deserves to* and has *the right to expect* to be continent. If help is not available at your particular location, keep looking, because there are many different types of health care providers who may have expertise in this area.

Terminology

There are many strategies to approaching continence, but unfortunately there is no one way that will absolutely work for every person. That is part of the challenge facing both the provider and the patient. Before it is possible to discuss specific strategies, one must understand some commonly used terms.

Neurogenic bowel is a very broad term that can apply to anyone who has nerve injury (temporary or permanent) to the part of the spinal cord that controls bowel function. The bowel and bladder are controlled both centrally, with messages traveling from the brain to the bladder or bowel, as well as peripherally, by nerves that branch off from the spinal cord. The lowest portion of the spinal cord, located in the sacral area, houses the nerves that impact bowel and bladder continence. Damage or inflammation to either the spinal cord or the pathway through which messages travel from brain to lower spinal cord may result in an inability to sense or feel the need to have a bowel movement. Additionally, there is often lack of voluntary control over the rectal muscles. An individual with intact neural pathways can consciously initiate defecation by relaxing the anal sphincter to allow the passage of stool or conversely, squeeze the anal sphincter to hold back stool which has already passed into the rectal vault. Without the ability to control the anal sphincter, when stool enters the rectum, there is the risk of an unplanned spontaneous bowel movement.

A person is considered continent if they are able to be free from unexpected accidents. For example, an individual without neurological problems, who is toilet trained, anticipates the need to go and can make it to the toilet in time to have a bowel movement. Conversely, an individual with

TM affecting the lower spinal cord would require a bowel regime whereby bowel movements occur on the toilet, but as a result of timed toileting with or without an enema, suppository, or other measures. Both individuals would then be free of accidents (continent) and able to wear regular underwear. There are several other factors that must be contemplated to really understand how to achieve bowel continence.

Developmental Considerations

An individual's developmental age must be considered to know when it is appropriate to start a toileting program. In fact, it is really more important to understand one's developmental age than the actual chronological age. A child is considered developmentally ready for toileting when he or she is able to participate in his or her program. Success can only be achieved if the child (or any individual) is an active participant and believes there are benefits to obtaining continence. This usually occurs around the age of three. If, however, a procedure such as regular enemas must be performed, the child may need to be older. I always encourage my families not to send an otherwise developmentally normal child to school in diapers, if at all possible.

Children like to copy one another, so if a sibling or a parent models a behavior such as going to the bathroom, a child is likely to want to do it too. There are books and videos available that expose the child to going to the bathroom on the toilet. In addition, medical supply companies have coloring books and video's available for children who are learning to catheterize as a part of their continence program.

Behavioral Considerations

Often, incontinent individuals have encountered teasing or ridicule from peers, family members, or other insensitive people who do not understand the situation. The whole subject may be fraught with negative emotion for the incontinent individual. Social punishment is not an effective treatment for incontinence, and is frequently observed to exact a heavy toll on one's self esteem and self efficacy.

Becoming continent takes a lot of work for both the patient and their family or significant others. Comprehensive bathroom habit diaries need to be kept, food and fluid intake must be considered, and ultimately, behavioral changes incorporated with specific regular routines must be followed. This takes sustained motivation, dedication and above all, patience. Children often require tangible rewards and varied approaches to keep them interested. At times, formal behavioral therapy is required to establish lifestyle changes. Often, the difference between continence and incontinence lies in minute details that ultimately, when put together like pieces of a puzzle, yield a solution.

Emotional Impact

Our society expects all individuals to be continent after about the age of three. The inability to control one's bowel and bladder carries an enormous social and emotional stigma. The impact that having accidents or wearing diapers has on a child or an adult cannot be over emphasized. Recent research with children who have spina bifida revealed that chronic incontinence caused greater distress than any other associated problem, including paralysis of the legs and the inability to walk. These results are very likely similar for individuals with other neurological disabilities.

Becoming continent is a journey that is unique to each individual. There are no "cook book" answers, but at the same time, there are almost an endless number of strategies or combination of strategies to try. Developing trust and confidence in one's medical team is essential to be able to tackle continence both emotionally and physically. After considering the above factors, the basic question is still "but how does one go about this?"

Getting Started

Treatment regimes usually involve a combination of dietary manipulation, behavior modification, medication, and positive reinforcement initiated in a stepwise approach. Laxatives by mouth should be used with caution, because of the difficulty in predicting when they may work.

Taking advantage of the body's natural reflexes and biomechanics should always be used if possible. One example is that of the gastrocolic reflex. This is the body's natural response to a full stomach. After a meal, the stomach becomes stretched and messages are sent telling this to the brain. Involuntary squeezing of the smooth muscles of the gut occurs in waves, known as peristalsis. The food is digested as it moves through the small bowel and then into the large bowel. It becomes more formed as it moves closer to the rectum. As the waves of peristalsis occur, the bowel contents are moved along. What we perceive is sometimes cramping or gas or "the feeling that it is time to go." This reflex occurs even if one can not feel it or perceive it. Some people have a very strong reaction after meals and some do not. Those that say, "I am like clockwork; I go to the bathroom every morning after breakfast no matter what" are usually ones with a

strong gastrocolic reflex. One way to tell if you have a strong gastrocolic reflex and to identify other toileting patterns is to keep a diary of toileting habits for one to two weeks. Variables to track include bowel movement timing and if there is an association with incontinence or not. Every two hour undergarment checks may be necessary for those that have no awareness of when they go. Bathroom habit trackers should also provide information such as size and consistency of the stools.

An example of the use of body biomechanics is one's position on the toilet. Sit comfortably on the toilet. Make sure there is no danger of falling in or off on the floor. A well-fitting seat and something to hold on to for balance goes a long way in assisting with relaxation. Remember, stool is passed when lower pelvic muscles are relaxed. The body is in the best anatomic position for defecation when the pelvic muscles are allowed to relax and descend. Legs should be spread apart and knees should be higher than the pelvis such as when one's feet are up on a stool or telephone books placed on either side of the toilet. When trying to evacuate the stool, push by tightening the stomach muscles. Coughing or laughing help facilitate pushing. When teaching a child to push, I pretend I am holding a birthday cake and tell the child to blow out the candles, or tell the child to imagine he is the wolf in *The Three Little Pigs* and try to "huff and puff and blow the house down."

Finally, one must consider that achieving continence is bit like riding a bike on a tight rope. Stool must pass through the bowel at a rate sufficient to produce soft but formed stool. If the passage is too swift, too much water will remain in the stool and it will be too loose. Conversely, if the passage is too slow, the stool may become hard and "back-up" in the system. How often one has a bowel movement is usually not as important as the consistency and quantity of the stool.

Developing a Plan

Bowel programs start with the practitioner completing a problem history and physical examination. Questions to be answered by the examination include: Is the abdomen soft or firm, which could indicate large amounts of retained stool. Is there stool in the rectal vault? Can the individual voluntarily squeeze the anal sphincter muscle? Is there a perianal wink reflex? Finally, what is the current neurological sensory and motor level of the individual?

In this author's experience, bowel programs are more successful if routine interventions are begun after the colon is cleaned out. Accidents can not occur if there is no stool in the lower colon and rectum. Though an initial cleanout is the first step, the real success lies in making sure the colon stays clean till the next time the person is in a controlled setting (such as in the bathroom) and on the toilet!

Colonic cleanouts can be accomplished in a myriad of ways such as with oral laxatives, enemas, suppositories, or a combination thereof. Colonic cleanouts are not fun, but if orchestrated correctly, take a single day to complete. To most, this is a small price to pay for continence.

The maintenance part of the bowel program should begin immediately after the cleanout to keep stool from backing up in the system again. Beginning with non-invasive measures such as behavioral and dietary changes may be all that is needed, particularly if there is even partial bowel control. If oral laxatives are used, the doses may need to be **very small**; remember that the ability to predict when a laxative is going to work is very difficult. Laxatives are often better used just to move the stool along at a better pace rather than to actually cause a bowel movement. Interventions such as digital stimulation, suppositories or enemas are generally far more predictable. Add or change one measure at a time so that it is clear what has helped and what has not.

When conservative medical management is inadequate, there are multiple surgical or procedural options including surgical continent stomas, cecostomy buttons, and incontinent ostomies. An option that works for one may not be right for another. Important factors that may influence one's choice include patient age, complication rates of the procedure, knowledge of long-term outcomes, and ability to be independent with the overall bowel program. There is an increased prevalence of pediatric surgeons and interventional radiologists who are committed to working on interdisciplinary teams with the goal of achieving social continence.

Bowel continence in an individual with neurologic injuries such as transverse myelitis is achievable with a multilayered approach, patience and perseverance. It is important to realize that advances are occurring on a regular basis and that there are a variety of professionals that can direct patients and families through the myriad of options available.

Update on Research at the Johns Hopkins Transverse Myelopathy Center
Chitra Krishnan

There is always a great deal of activity going on at the JHTMC. The most significant changes have been the addition of four new people to our staff. **Peter Calabresi, MD** is a close colleague of Dr. Kerr, is a neurologist, and recently joined the Hopkins faculty. He is the director of the Johns Hopkins MS Center (JHMSC). Dr. Calabresi is a well-known immunologist and is applying this training to the development of new treatments for MS. Dr. Calabresi is also an expert in running clinical trials. He and Dr. Kerr are already working on developing new treatments for acute TM and are working towards a clinical trial within the next 12-18 months**.**

Sanjay Keswani (MBBS) is also a new neurologist recruit onto the Hopkins faculty. Dr. Keswani's research and clinical interests have previously been HIV-related neurology and mechanisms of peripheral nerve degeneration. But we have convinced him that the study of TM is really where it's at! He is now beginning to investigate how axons get damaged in the spinal cord and will run the first human study in protecting those axons during the acute phase of TM.

Edie Goldberg (RN) is a nurse who has just joined the JHTMC. Edie was first a nurse and most recently came from Pfizer where she was one of the best hospital representatives in the entire country (this is important because it is always good to have an "in" with a big pharmaceutical company). Edie will run the clinical trials at the JHTMC and the JHMSC. She will also serve to assist with clinical matters of patients that Dr. Kerr has seen, i.e., medication refills, change in status, new symptoms, etc. Since it is sometimes difficult to reach Dr. Kerr, Edie (and I) can handle many of the patient's questions. Edie's addition to our staff will allow us to provide even better service to our patients.

Finally, **Deepa Desphande** (Masters degree in biology **and** biotechnology) has joined the JHTMC research team. She has joined us from Texas A and M University and will run the immunology projects in the lab. These studies have already begun to reveal fascinating insights into the acute inflammatory process in TM patients, giving us potential new therapeutic strategies to pursue.

We will provide a brief overview of our ongoing projects, using this as an update to the previous newsletter.

Continued Development of the Clinical Database of TM
- Includes over 400 patients with transverse myelitis
- Cross-sectional and longitudinal
- CSF, serological, radiological, clinical components

Clinical Classification Project of Monophasic TM
- Clinical Features
- Risk Factors
- Prognostic Factors
- Outcomes
- Scientific manuscript to be submitted this year

Recurrent TM
- 20% of all TM patients seen at the JHTMC are recurrent cases
- A particular antibody in the blood of some patients predicts a possible recurrent course
- Scientific manuscript accepted and will be published this year (Hummers, Krishnan et al., 2003)
- Clinical course and immunologic abnormalities in patients with recurrent TM
- Treatment Strategies

Pediatric TM
- Studying a possible correlation with immunization
- Clinical features
- Outcomes
- Scientific manuscript to be submitted this year

Risk Factors in the Development of TM
- Federally funded grant to study the frequency of particular events that occur prior to the development of TM
- We will compare the frequency of these events in TM and in other neurologic disorders to see if they are more common in TM patients
- If so, it provides us a lead in defining **how** these events may trigger TM

Spasticity Treatment Trial
- We want to develop better treatment strategies for spasticity in patients with TM since the regular treatment options (tizanidine, baclofen, diazepam) have problems, e.g., fatigue and sleepiness
- Tiagabine (Gabitril) vs. placebo
- Crossover design
- Potentially less sedating than baclofen, tizanidine, diazepam

Depression and Cognitive Impairment with TM
- We want to investigate the frequency and mechanisms of depression and subtle cognitive changes that occur in some people after TM
- Funded clinical trial (run by Dr. Adam Kaplin) that is now enrolling patients in the acute phase of TM
- Novel neuroimaging-magnetic resonance spectroscopy-and cytokine profiles to assess pathophysiology

Novel Imaging of The Spinal Cord

- We want to investigate a better strategy to image the spinal cord
- We are developing a new MRI protocol (magnetization transfer) that may help to define the extent of inflammation in the spinal cord and how much damage is occurring
- If this technique does give us a better understanding of the spinal cord process, it may allow us to identify patients who need more aggressive treatment

Animal Model of TM

- We are trying to develop an animal model of TM
- Some early studies suggest that if we give a rat the same inflammatory proteins that are present in the spinal fluid of TM patients, they get weak
- This now gives us a way to test **how** the spinal cord gets weak

Stem Cells In TM

- Not near clinical trials
- **But…**
- In animals, we can protect from ongoing neural injury using stem cells
- We can now generate new motor neurons and coax axons to grow out of the spinal cord
- We are getting closer, but these studies are so expensive and we have not yet convinced the federal government to fund such studies.
- **We will succeed**, but not yet

Announcing the 2004 Symposium in Baltimore

Sandy Siegel

The Transverse Myelitis Association and the Johns Hopkins Transverse Myelitis Center are co-sponsoring the 2004 Symposium on the Neuroimmunologic Diseases of the Central Nervous System. The symposium will focus on TM, Devics and ADEM, and will include both pediatric and adult cases of these neuroimmunologic conditions.

The symposium will be held at the Hyatt Regency at the Inner Harbor in Baltimore from Wednesday, August 18 through Sunday, August 22. Members of the TMA are going to get a rate of $115 plus tax per night for a single or double occupancy room at the Hyatt. For planning purposes and also to accommodate the Hyatt, we are asking our members to make their reservations as quickly as possible. The Association, the JHTMC and the Hyatt are going to require some sense of the size of our attendance to plan for meeting space. While we are hoping that they will have sufficient space for us, it is possible that we would have to limit the numbers of people who can attend the symposium. The one certain way for us to avoid any limitations is to have people make reservations at the hotel by January 2004.

To make a reservation at the Hyatt, please call (800) 233-1234. To get the TMA membership rate, please identify yourself as a member and let the customer service person know that you are attending the TMA/JHTMC Symposium. By making your reservation, your credit card will not be charged in advance of your stay. The Hyatt does, however, have a cancellation policy and you would have at least a week to cancel this reservation before the symposium.

The Hyatt has thirteen accessible rooms and only three of the 13 rooms have roll-in showers. Please do not ask for an accessible room unless it is absolutely necessary that you have one. If you need an accessible room, please indicate that need when you make your reservation. At the time you make your reservation, you are going to be given a room that is not accessible, to be certain that you obtain a reservation, and then you will be placed on a list that will ultimately be given to the JHTMC and the rooms are going to be assigned on the basis of the greatest need. If you can travel with a companion who is able to assist you with transfers, please consider doing so. We are sorry for the inconvenience this may cause any of you. We are trying to find an equitable solution to a difficult problem. **If you are going to request an accessible room, you need to make your reservation before April 1, 2004; the list of requests will be given to the JHTMC on April 1st.** The accessible rooms at the Hyatt will not be available after April 1st. Please be certain to communicate any other needs you may have, such as for a shower bench, at the time you make your reservation.

It is important to bear in mind that making your reservation at the Hyatt is a different process and fee from the symposium registration. The registration process will begin in the winter or early spring; you will receive the registration materials by mail in the next newsletter or in a separate mailing from the Johns Hopkins Continuing Medical Education (CME) Office. The registration fee will be set based on the costs of conducting the symposium.

We wanted to provide you with some idea of a possible registration fee so that you were able to decide whether you should make the hotel reservations. Based on a guess of 200 TMA members attending the symposium, the registration fee would be approximately $300 per person. If our fundraising efforts do not succeed in raising anything, the registration fee could be more or less than this amount depending on the numbers of people who register to attend. If we are able to raise a lot of money, the registration fee could be a great deal less.

The symposium is an educational and networking opportunity for people who have the neuroimmunologic conditions and their caregivers, for the medical professionals who provide treatment to this rare disease population, as well as scientists and physicians who are performing research in rehabilitative and restorative therapies. Presentations will be made by a group of physician specialists focused on the full range of symptom management issues of concern to the TM, Devics and ADEM community. The goal of this section of the program is to assist the person to become an informed and effective advocate for their treatment and medical care. In addition to the many physical symptoms people need to address, they are also faced with significant social and emotional issues, which surround having a devastating illness. The symposium will also attend to these important issues through presentations by experts from a variety of medical and other disciplines.

In addition to the formal presentations, there will be extensive opportunity for TMA members to ask questions of the specialists. An entire session will involve a discussion and question and answer program which will include the patient and caregiver community and the medical specialist community.

The symptom management section of the symposium will be the focus of approximately half of the program. The other half of the program will be devoted to the science and research on the neuroimmunologic disorders and restorative therapies. While the science and research portion of the program is of primary interest to the physician/scientist participants, it is equally beneficial for the TMA membership. It has been our experience that knowledge of the research is an important component of how we all think about the potential for improved quality of life for ourselves and our loved ones. A major portion of the program is devoted to rehabilitative and management strategies, as the TMA is committed to the highest quality of life for people who suffer from these neuroimmunologic conditions today. The current state of research, however, represents the future potential for a better and significantly improved quality of life.

As these are rare conditions and there is no concentration of people in any community around the country or around the world, most of those with these neuroimmunologic conditions have never met another person who shares their disorder. We are sensitive to the needs of bringing together people with the rare neuroimmunologic conditions and their caregivers to offer them the opportunity to share in their experiences, to help people feel less isolated, to foster social support and networks, and to provide critical information to help people better understand their conditions. We know from the previous meetings that most people create lifelong friendships at these gatherings. There will be numerous opportunities for people to meet and socialize.

The symposium program has also been designed to encourage and maximize the interactions between the medical community and the patient and caregiver communities. This interaction will be promoted both in a formal setting with discussions and question and answer sessions, as well as in more informal settings during social activities and meals. Physicians learn a great deal about the personal experiences of the people who have these conditions through these informal connections.

The TMA/JHTMC Symposium will be offering CME credits through the Johns Hopkins Continuing Education Program. From the patient and advocacy perspective, this represents a tremendous opportunity to attract interested medical professionals and scientists into an important area of treatment and research. This educational opportunity will result in the sharing of best practices in treatment, as well as provide the synergies that result from the scientists sharing new information, techniques and research results.

The TMA and JHTMC are also strongly committed to better educating the first line of defense in the diagnosis and treatment of these neuroimmunologic disorders. Emergency physicians, general practitioners, and pediatricians are the physicians who first see a patient who is presenting with the symptoms of TM, ADEM, and Devics. A rapid diagnosis and treatment is critical for the patient. The TMA and JHTMC will promote the educational program to these medical specializations in an attempt to increase awareness and to better educate these disciplines about diagnostic techniques.

If you have not attended a previous TMA/JHTMC Symposium, we strongly urge you to participate in this important event. If you have attended

other workshops and symposia, the 2004 meeting will offer you the opportunity to learn about the most up-to-date symptom management strategies and research and to renew your friendships from the TMA membership. This is also an important opportunity to meet the physicians and scientists who are focused on the neuroimmunologic conditions.

The TMA and the JHTMC have already begun the fundraising efforts for the 2004 symposium. We need for you to get involved! There are three levels of fundraising in which I am going to encourage you to participate. The first level is the formal fundraising program that is being directed by the TMA and the JHTMC. This effort is being coordinated by Chitra Krishnan from the JHTMC and by Stephen Miller and myself from the TMA. If you would like to assist in these efforts, please contact Stephen. You can reach Stephen by email at: smiller@myelitis.org or call (937)453-9832.

The second level of fundraising involves the activities that our membership regularly engages in to raise money for the TMA operating expenses and for TM research. There are hop-a-thons, hoop-a-thons, roll-a-thons, read-a-thons, dinner parties, auctions, raffles, golf outings and many other programs going on all the time around the country and around the world. Amazing, kind, and generous people take the personal responsibility to perform these wonderful deeds. Often, we don't even hear about these events until after they have been completed. To say that we are grateful for these efforts is the greatest of understatements. We need for more people to get involved in more of these efforts and please direct the funds to the 2004 symposium. This can be easily accomplished by writing "2004 symposium" on the checks or in a letter accompanying the checks that are sent to the TMA. Paula will be sure to designate these funds for the 2004 symposium. All funds that are raised above the costs of the symposium will be designated to the TMA research fund. The TMA and the JHTMC are fully committed to encouraging research on the neuroimmunologic conditions and to attracting the best physicians and scientists into this area of research.

The TMA and JHTMC will determine the registration fee in January 2004 and the fee will be set to cover the total cost of the symposium. Our fundraising goal is to raise enough money so that there is no registration fee and so that there is a substantial amount of money designated for the research fund. We would love to have the only cost for our membership be their travel and hotel and a few dinners during the symposium weekend. Whether we can realize that goal is going to depend on you. We are going to commit hundreds of hours to raising money and to applying for foundation grants. There are no guarantees that these efforts will result in raising anything. Our most effective fundraising efforts are those that are conducted by our members who do their fundraising in their local communities and with their family and friends. These are the people who care most about TM; these are the only people who know anything about these neuroimmunologic conditions and how they have impacted our lives.

There was no registration fee for the TMA Childrens and Family Workshop that was held in Columbus, Ohio in the summer of 2002. All of the costs of the workshop were covered from fundraising. The vast majority of money was raised by the parents in their fundraising efforts with their family and friends. I accomplished the same goals by fundraising with Pauline's and my family and friends.

Please get involved in fundraising efforts. Help us provide this important opportunity to the many deserving people in our community who need this education and support. By reducing or eliminating a registration fee for the symposium, we will widen the numbers of people who are able to attend.

The final level of fundraising I would like for you to consider is fundraising with your family and friends to help you cover your personal costs for travel and the hotel. We have members from across the United States and from around the world. Whether you live in India or Brazil or Australia or Alaska or San Francisco or Chicago, you should be able to attend this symposium. You need to begin today to fundraise with your family and friends. If they know how important it is for you to come to this symposium, they will want to help you. If you are not comfortable asking for financial help, hold a personal fundraiser to cover your travel and hotel costs. You can hold a bake sale in your church or find some other creative ways to raise the money to make this happen for you. We have such a difficult time asking for help in America. Please don't let your pride interfere with the opportunity to have this life changing experience for yourself. If you have never met another person who has your condition, you owe it to yourself to find the support, compassion and understanding that you will only find from others who have been through this same experience.

If you are looking for information about how to get involved in fundraising or what sorts of things you can be doing, please go to the donations page on the TMA web site. There is a great deal of information about the TMA and about fundraising on this site.

Also, you can get some great ideas for fundraising activities from the newsletters, all of which are posted on the web site.

Please get yourself motivated to make this enormous difference for yourself and for others who share in your experiences. Please help me make this opportunity available to as many people as possible by keeping the registration fee as low as possible. Please, let's make this an opportunity to get seriously energized to raise money for TM research.

Inviting Your Physicians and Therapists to the 2004 TMA/ JHTMC Symposium

We all want the best care and treatment for TM, recurrent TM, ADEM, and Devics; we want this for ourselves and our loved ones. Most of the people in the TM community have a number of medical professionals involved in the treatment of their symptoms, i.e., neurologists, physiatrists, urologists, physical therapists and occupational therapists. How important is it to you that these physicians and therapists have the most comprehensive understanding of your condition and also know the most recent developments in the techniques and therapies for managing your symptoms? We are excited to offer you and your medical professionals this educational opportunity.

We would like to invite your physicians and therapists to attend the 2004 TMA/JHTMC Symposium in Baltimore. And we would encourage you to advocate for them to accept this invitation; be nice, be gentle, be diplomatic, but do strongly encourage them to attend. It is in your greatest interest that they come to this educational symposium. They will receive CME credits from Johns Hopkins. Not only will they be able to attend the presentations about the neuroimmunologic conditions and learn about the most up-to-date treatment practices for symptoms, they will also be able to talk to other physicians who are caring for TM patients and they will be able to meet many other people with TM and their caregivers. Now, how great would that be?

Here is how you can help to make this happen. Please send us the names and postal addresses of all of your physicians and therapists. Be sure to identify their specialization (i.e., neurologist, physiatrist, urologist, PT or OT) along with their full name and complete postal address.

We would prefer to receive this information electronically in an email message. If you do not have a computer or internet access, you may send this information in a letter. You should send this information as quickly as possible, as we will need time to compile the mailing lists. You have until the end of November to send us your physicians' and therapists' names and contact information. The JHTMC and Dr. Kerr will send them a personal letter of invitation to the symposium, along with the registration packet and program agenda.

Please send your information via email to:

dcapen@myelitis.org

If you send the information via the postal service, please mail it to:

Debbie Capen
Secretary
The Transverse Myelitis Association
PO Box 2084
Hemet CA 92546

Please remember to include your physician's and therapist's complete names and postal addresses. And please remember to include their medical specializations.

This is a wonderful opportunity for us to increase the quality of care our members are receiving from the medical community. Please help us to take advantage of this great opportunity!

TMA Members: Portions of Your 2004 Baltimore Symposium Trip May be Tax Deductible

Paula Lazzeri

You can include in medical expenses amounts paid for admission and transportation to a medical conference if the medical conference concerns the chronic illness of yourself, your spouse, or your dependent. You are only going to be able to take this deduction if you itemize on 1040 Schedule A. The costs of the medical conference must be primarily for and necessary to the medical care of you, your spouse, or your dependent. You must spend the majority of your time at the conference attending sessions on medical information. The cost of meals and lodging while attending the conference is not deductible as a medical expense.

You should, of course, know the tax law or consult with your tax advisor before taking any deductions. For more information on this deduction see IRS Publication 502, Medical and Dental Expenses.

Additional information may also be found at:

http://www.irs.gov/individuals/index.html.

The Board of Directors elected Stephen J. Miller to serve as the next Vice President of The Transverse Myelitis Association.

One crisp November morning somewhere around 3:30, I stirred, awoke, got up and went to use the bathroom and then went back to bed. At 7:00 that same Friday morning, as was the Miller home's daily routine, my mother came into my room to wake me for school. I can remember her words very clearly still, "Stephen, its 7:00 and time to get up and get moving." I looked to her and said, "Ma… I can't. I can't get up." Now, being a typical 13-year-old boy and having a well-earned reputation for pranks, my mother didn't give it a second thought. She smiled, went downstairs and began putting breakfast together.

Around 7:10, she called up the stairs for me to be getting ready for school. Again, I said, "Ma, I can't get up. I can't move – really;" only this time she didn't hear me, because my voice was so weakened that even talking loudly came out only as a whisper. She came up to my room again thinking I had fallen back to sleep and was surprised to see me wide-awake. She (again) reminded me of the time and my dwindling opportunity to get any breakfast before the school bus came. I told her, "I can't move, Ma. I can't move anything. It's like my whole body fell asleep and it won't wake up."

That moment in time is very significant because it was the pre-cursor to the next moment. The next moment in time is burned into my memory. It was the realization that sometime in the past 3 ½ hours, *something* had gone terribly wrong. Something very real, something very unknown and something very frightening.

That day, Friday, November 18, 1983, not only kicked off the worst weekend I've ever known, but it also marked the first day of the rest of my life.

My mother is an R.N. and so is the neighbor lady from across the street, so the two of them put their heads together and did a quick evaluation before the doctor was called. After talking to the doctor, I was taken to the E.R. at Mercy Hospital in Portsmouth, Ohio (the closest town to us and about 30 minutes away) where our family doctor met us. He was just as baffled as the next guy and began searching for clues.

By 2:30 that afternoon they had run out of ideas and options and had began calling pediatric specialists around the state hunting for ideas. The decision was made to take me to Children's Hospital in Columbus, Ohio via ambulance and we left for the two-hour trip by 3:00. My condition had worsened to the point where I had a fever, was beginning to vomit and still had difficulty breathing.

We arrived at Children's Hospital, were met at the door and taken straight to room 505, bed A just about 5:15. It was then the "real" work began in the search to understand why a normal, healthy, active, 13-year-old boy with no history of illness and having not so much as a drippy nose went from perfectly normal to completely paralyzed in just over three hours.

The tests began that night at 9:00 with the first of three mylograms. Testing took a break Saturday morning around dawn and continued off and on all weekend. Monday morning brought the first session of physical therapy. There would be four years more of them to follow.

They still did not know what had caused my paralysis or what the prognosis would be, or for that matter, what it could be. I was finally diagnosed several weeks later by a pediatric neurologist as having Transverse Myelitis.

I left the hospital a week before Christmas and was back in on New Years day with a bladder infection. I was sent home again two weeks later and was in and out of the hospital several times again over the next few months as my body adjusted to it's new state of "normal."

In the spring of 1984, I entered Ohio State University's Physical Rehabilitation Unit, Dodd Hall. I thought I had adjusted to life just fine up to that point, but then came the Sunday afternoon when I moved in to Dodd. It seemed pretty uneventful until Monday morning when I met my new P.T. Her name was Laura and she explained the rules and how things worked with P.T. and O.T. and scheduling, etc.

During my time at Dodd Hall, I celebrated my 14th birthday; witnessed two deaths (one of which was my roommate) and saw several people quit the rehabilitation game. But I also saw other things…some very important things. Things like seeing someone learn to sit up again, and learn to stand again, and learn to use crutches and take a step or two again. I saw people with severe disabilities much, much worse than mine; laugh at themselves and their situation. I saw a quadriplegic dance and I saw a man with a wheelchair ride a wheelie down a flight of steps (on purpose) and revel in our cheers and applause at such a task. I saw humor and per-

sonalities reborn and people learn to adjust and compensate and to "try, try again" and smile all the way back to their room for what they had accomplished. I saw several people, who had arrived in a wheelchair, walk out the front door to the waiting car on there own power the day they left the hospital. I was one of those.

I went home from Dodd Hall ready to take on life, as I now knew it – as a boy with Transverse Myelitis. A condition that nobody understood and a term I still had difficulty pronouncing.

And so it was for Stephen, and as it has been for so many of you. Stephen lived his life. He went to college to become an architect. He met his beautiful wife, Michelle, who has a degree in biology and library science. Michelle and Stephen got married and started their wonderful family. They have two daughters, Katherine and Elizabeth. The Miller family lives in Jamestown, Ohio, a small farming community near Dayton. After the onset of TM, Stephen lived the next 18 years of life and never met another person who had TM. Also, like so many of you, Stephen, on a whim, typed Transverse Myelitis into his web browser and found the TMA. This was a Wednesday. That night I received a phone call from Stephen and we talked for a while and arranged to meet for lunch the following Saturday.

When Pauline walked in the door of the restaurant, she was the first person that Stephen had ever met with TM. After 18 long years, Stephen was introduced to the TM community. We sat in the restaurant and talked for the next six hours! Stephen and Pauline had so much in common and shared so many similar experiences; similar onset symptoms, both going through rehabilitation at Dodd Hall, both walking with canes, both having left foot pedals installed in their cars.

In a very short time, Pauline and I got to know Stephen really well. We asked him to get involved in the Children's and Family Workshop. Stephen gave one of the speeches to the families to open the workshop and he participated throughout the weekend as a companion to the children with TM and their siblings. He has taken a leadership role in developing the Ohio Support Group. And he has provided tremendous support to Pauline and I in assisting with the TMA mailings and also getting actively involved in fundraising efforts.

Stephen brings so much experience and talent to the TMA. He is extremely bright and creative. He is also a wonderful communicator. Perhaps most importantly, Stephen has a very large heart; he is filled with compassion, kindness and sensitivity. We are very excited to have Stephen involved in the TMA and we know that Stephen is really honored to serve this wonderful community of people with TM, recurrent TM, ADEM, and Devics and their caregivers. We know that Stephen will serve you with honor, with enthusiasm and with humility. Thank you, Stephen for taking on this awesome responsibility. We are so pleased that you finally found the TMA and we are so grateful for your willingness to serve in this important role.

Suspended Weight Treadmill Training: A Patient's Perspective

Paula Lazzeri

Since I read Dr. Levy and Dr. Behrman's article about suspended weight treadmill walking training in the October 2001 TMA Newsletter, I wondered if I might derive some benefit from this program. I am a C6-7 incomplete paraplegic from getting TM when I was only 12 years old. After consulting my rehabilitation physician, she recommended the program so long as my back passed a full spinal exam by an orthopedic physician. I have a full spinal fusion due to scoliosis and we wanted to be sure it would not harm my back. Thankfully, I passed with flying colors and began the suspended weight treadmill walking program at the University of Washington Hospital in November 2002.

The first appointment was great. It took time to do some range of motion exercises and to put on the harness, but I was up on my feet after that. My PT was right there at my side helping and encouraging me with every step. My right leg is stronger than my left, so my PT stood to the left of me and moved that leg each time. I was able to move my right leg, but only for a short period of time. During that first appointment, I managed to stay walking for ten minutes with one rest break. It was an exhausting experience. It was also an exhilarating experience. I was able to look directly into my therapist's eyes and to talk to her while I was standing, instead of looking up at her while sitting. I was able to look out across Lake Washington (the treadmill sits in front of a big window), instead of not being able to see out of the window at all from my chair. I was able to give my backside a long pressure relief. And I was able to achieve the closest feeling to walking I had experienced in 24 years. The exhaustion was well worth it!

In total, I have had eight treadmill walking experiences, all within a two-month period. With each appointment, I got a little stronger, walked a little longer, and noticed much less spasticity. I have not been able to schedule another appointment for the past seven months. I hope to resume the program soon. I would like to con-

tinue with at least three appointments a month.

During a few of my appointments, I invited my parents and a friend, Heather O'Dell, to observe my program. Heather's mom, Drema, also has TM. I thought it might be interesting for you to read their perceptions of my training program.

My parents, Norm and Gayle Peltier: We were very impressed with the treadmill therapy. We could see the value of this kind of workout. The professional who worked with you was very thorough and completely tuned in to your responses. She was always one step ahead of you in anticipating your needs. That is half of the reason for success. The other is your willingness to do this type of therapy. You put all you were capable of into it and, as far as we could see, it was good for you both physically and emotionally. We really hope you continue to do it. It can only help you. And, of course, because we love you so much, anything that can benefit you, we are completely in favor of. We got a kick out of Myk and Jesse's response to it, also. They were very caught up in the technical end of it. It didn't surprise us with Myk, though. He is always very involved with your welfare and devoted to you. We love that boy!

Heather O'Dell: I had the wonderful opportunity to attend a physical therapy appointment with Paula while I was visiting her in Seattle in November. This wasn't a typical appointment. At this appointment, Paula would actually get to walk on a treadmill. When we got there, the physical therapist, Emily, warmed up Paula's legs. Once Paula had been pulled and stretched like Gumby, Emily moved her over to the treadmill. She first hooked Paula up into a harness-like contraption. Once she got her all strapped up, she turned on the machine that actually lifted Paula up out of her chair. Paula's feet were on the treadmill, and it just lifted her upper body up out of the chair. Once she had her lifted, she then moved the chair out of the way. So, basically, Paula was somewhat suspended; only her feet were on the treadmill.

There was another contraption that had handles on it so that Paula could hold on while she was walking. At this point, I was just amazed seeing Paula standing upright for this length of time. Next, Emily turned the treadmill on. Paula then took her first step on the treadmill. Wow, now that was amazing. Emily got down and helped Paula move her one foot, the foot that isn't as strong as the other one. Paula did such a great job. It was a bit overwhelming to see someone who can't walk actually get to kind of walk. I just sat back in utter amazement and watched. As Paula would get tired, Emily would turn the treadmill off so that she could have a break.

I must admit, I couldn't help but chuckle a bit at the sight of Paula hooked up with straps hanging from above. She kind of reminded me of a puppet on a string. I could have had some real fun controlling those straps and making her dance and sway to and fro. As I was saying, Paula would rest and then go at it again. This was one of the coolest things I have ever had the pleasure of seeing. To see someone who spends her life in a chair, unable to walk, actually get to stand up and have the freedom of moving her legs; that was just amazing. I can't begin to understand how that must feel.

I would like to thank Paula for allowing me to share this experience with her. I was very honored. What an emotional experience it was, to see my friend walk. It meant a lot to me watching her do it. I know it meant so much more to Paula actually getting to walk.

I would like to thank Myk, Jesse, my parents, my therapists, and my friends, like Heather, for all of the encouragement and love they give to me daily. If you are given an opportunity to try the treadmill program, I would recommend it. It is certainly worth a try!

Swimming: You Might Want to Give it a Try

John Craven

The most satisfying thing I've done since my TM attack is swimming. It felt good. It gave me exercise. It got me out of the house. It made me feel whole like nothing else I've done. While I'm swimming, I feel normal. I'm proud of myself.

If you have the use of your arms, you can swim. It doesn't matter whether you "know how to swim." You can learn. I was amazed the first time I tried swimming a lap again; I didn't get exhausted! Normally, the smallest physical activity causes complete fatigue. My guess is that I overheat quickly, and tire from the pain. In the water, that doesn't happen.

I was a swimmer before my life changed. I had to learn to swim so that I could compete in triathlons. I was an average runner. I was above average on a bicycle, but I tended toward the bottom when swimming. I mean the bottom of the pool. That wouldn't do. The swimming part comes first, so I wouldn't even get to ***start*** with the others!

So I learned to swim, and discovered something surprising. Once I could swim horizontally, I could get this wonderful relaxation. No impact, no noise. It is extremely peaceful. I joined "Masters Swimming" which is

all over the world. The "Masters" part means you're old. I was old, so I qualified.

I actually competed in Masters swim meets. I would come in last, but I competed. Actually, I won once. There were only two of us in the event, and the other guy got disqualified. I won! I kept the blue ribbon. I just never told people the details.

So in a triathlon, if you can actually ***do*** all three, you are above average. My first was called the SpudMan. I live in Idaho. The Ironman is in Hawaii. That's a long way from Idaho.

My problem now is pain from my chest down. If I can relax, the pain decreases. Meditation works to get relaxed, but doesn't let me ***do*** anything.

Then I tried swimming. My sister-in-law, Carol, suggested it while we were visiting them. I was still coordinated. I still had the muscle memory; like riding a bike! I just let my legs drag.

That's the point: you can let your legs drag in the water, and swim just fine! In fact, in my life "before," I was such a lousy kicker that if I just kicked while holding a kick-board, I would go backwards!

Lesson 1: Breathing

This is the one thing that bothers most people. It's best if you inhale when your mouth is ***up***. Look at a picture of a real swimmer swimming. You'll see that their head is down ***in*** the water, always. That's important. If you pull your head up above the water for a breath, it will fall down and go way under. Makes for very awkward swimming. The real guys keep their head down and roll to the side. You can try it standing or kneeling still in the pool. Lay your torso and head in the water. Now roll your head and shoulders to one side until your mouth is in the air. Inhale. Roll your face down. Exhale. Repeat.

Your shoulders naturally roll as you stroke. You can try it in the air. (Not ***completely*** in the air: you can't fly. Remain sitting or standing. Safety tip.) Pretend you are swimming, with your arms stroking. Your shoulders have to roll. (If someone sees you and asks what you are doing, tell them it's "classified".) You may continue breathing during this exercise. You might even think about breathing while your mouth is sort of ***up***.

Lesson 2: Get swimming lessons

There's probably a YMCA near you. Hopefully they have a pool. If they don't have a pool, you can't swim there. Go somewhere else.

Assuming you find a Y with a pool, tell them you want to learn to swim, and you'd like a little help. It's amazing how nice some people can be.

I felt really bad when I got TM. The best I've felt since then was when I discovered I could still swim. I can still do something athletic. I'm okay. In fact, I can swim better than my wife.

John is not the only person with TM who swims and loves to swim. Netta Gaynor is a TMA member from Israel. Netta is quadriplegic and she has figured out a way to swim without the use of her legs or her arms. Of course, Netta has also figured out how to paint without her arms and hands; and her paintings are beautiful. As you know from the last newsletter, Cody Unser and Pauline are scuba divers and Paula goes snorkeling. Pauline has always loved the water. Her most effective physical therapy and most enjoyable therapy has been in the water. She is able to achieve greater range of motion in her exercise and she has no gravity to deal with and so movement is easier. And she's just a total babe in a bathing suit. In order to get her scuba certification, she had to swim 25 laps in the pool. She did and it was a wonderful accomplishment. Try swimming. Try exercising in the water. You might really like it. And as with all exercise and activity of this nature, please talk to your doctor before you try it, and be sure there is a really great looking lifeguard vigilantly scanning the pool before you get into the water.

Dysfunctional Bowel: Members Helping Members

After publishing the Editor's column on bowel issues in the last newsletter, I received letters and messages from a number of members who shared some personal advice about how they handle their own bowel issues. I wanted to share this information with our members, as I thought their suggestions were great. Thanks to those of you who took the time and effort to help others in our community. Your generosity and your care is very much appreciated!

December 26, 2002

Good article on dysfunctional bowel symptoms. I have used Imodium since 1983 and it has worked with the diarrhea and the stomach cramps. When I first started, it was a prescription. Then it went to an over-the-counter and now there are generic brands. Thanks for the article. It really hit home for the past 31 years.

December 27, 2002

I was sure glad about your article about bowel training. I thought I would tell you how I am handling this situation. I am on a training program.

Every evening at 8 PM, we start getting ready to go to a commode. My aide transfers me and my husband uses a very small enema called enemeez. It works almost right away and may take up to ten minutes (this is for me - others may take longer). Also, for breakfast, I drink a chocolate drink with miralax in it and so the stools are soft and leave the body easily. Once in a while, I do have an accident, but we regulate the miralax and that seems to control them. I am sure there is not an easy way, but this works pretty good for me. Hope this will help someone.

January 02, 2003

I just finished reading the latest newsletter. I enjoyed all of it, but was really interested in your lead article concerning "accidents." I've had my share of them, and I'm sure I'll have more, but there are a few things that I do to help minimize them. In addition to your suggestions of carrying a change of clothing, wet wipes, and plastic baggies (which I do), I have what I call an emergency bag in my vehicle. It is actually just a small travel bag that is made to pack shaving supplies. Since it is small, it easily fits under the seat. In it I have a spare pair of underwear, packets of wet wipes, a partial roll of toilet paper, small sample size of powder, and plastic baggies. That way I always have it with me when I'm out somewhere.

However, the most important thing I travel with is a small porta-potty, which I bought in the sporting goods/ camping section at Wal-mart. It is small and very lightweight. It is discreetly made, and most people wouldn't even know what it was. When I lift the top off, it has an insert which holds a roll of toilet paper. I've lined the inner bucket with plastic trash bags, so that if I have to use it, I can just lift out the trash bag. If there is no place to dispose of it, a package of dry powder chemicals, which came with the porta-potty, can be used.

We have a Honda Odyssey van, and the third seat just folds down so that the back section is completely level. I keep the potty there. If we have to have the third seat up, there is still plenty of room for the potty in the back luggage area. The Odyssey has a walk-thru aisle between the captain seats, and I can easily walk to the back of the van while still inside. If I'm in a rural area, especially if it is night time, I can just set the potty outside if I need to go. However, sometimes there has been too much traffic to do that, so we pull over, my husband steps out for a minute, and I proceed to the back of the van and use the potty. The van has dark tinted privacy glass all around so other motorist could not see in as they passed by. I carry a small travel size spray of Clorox or Lysol air freshener in my emergency bag, so I can freshen the van afterwards. I also carry the waterless antibiotic hand cleaner with me.

We live in a rural part of the country, and it is not always possible to find a public restroom. (And sometimes there is just not enough time to find one). I fall into the category of knowing that I'm about to have a bowel movement, but cannot hold it very long.

Having the van and porta-potty has brought so much peace of mind to me when I travel.
I just thought I would write and tell you what worked for me. Perhaps you can pass the porta-potty suggestion along to others. I realize that it would not work for everyone, but it is very helpful to me.

Thanks again for your hard work and dedication.
Warmest Regards

March 3, 2003

I just read your article about bowel incontinence and feel compelled to share my experiences on the subject. I'm 48 and have been dealing with TM since I turned 40. I'm an incomplete quad and rely on a power wheelchair for mobility. Aside from that, I'm completely self-sufficient. Since my diagnosis, one of the biggest issues I've had to deal with is the bowel situation. Sometimes I felt like working on the bowel issues was far more frustrating than being paralyzed and dealing with TM itself. That said, I'd like to share my story to further encourage the attitude you prescribed and let people know that there is hope.

When I started having accidents, the humiliation was pretty hard to deal with. I'm an Assistant Vice President in a very conservative industry, which sometimes includes making customer calls. I somewhat manage the situation by meeting with customers at my own office where I have a more controlled environment and friends to help when necessary. At first, I didn't think my co-workers would understand my situation which made me consider taking disability. Once I let the ones I knew the best in "on my dirty little secret," I found them to be exactly as you described, sympathetic, supportive and, to my surprise, extremely proud of me. I've developed a sense of humor about it all, and gone from being humiliated to being a "hero" and having some incredibly close friendships (nothing builds intimacy like having someone help with bowel accidents). I've discovered that most people are pretty compassionate, if they understand what you're going through and it's up to us to educate them. Otherwise, they have no way of knowing what our life involves.

Like your suggestion, I also carry an

extra pair of clothes in my van in order to decrease the time and embarrassment an accident can create; however, I haven't needed them in over a year. I not only have trouble controlling my bowels, but I also deal with a nervous stomach and lactose intolerance, both of which exacerbate the problem and leave me with excruciating stomach aches. Over the past few years, I found a solution that has not only given me freedom from worry, but also far less pain.

You're right, a regimen and scheduled bowel evacuation are critical to leading a semi-normal life when it concerns dysfunctional bowels. I used to have a movement about every 7th day, which creates quite a backup and much less ability to control the outcome (no pun intended). After working with my doctors and **much** experimentation on my part, I finally found the perfect combination without adding more meds to my body.

First and foremost, I make sure that every day I allow at least an extra half hour to my preparation time. That gives me the time to relax after I eat breakfast (which I do by playing computer games) and take care of my morning "constitutional." I found this to be one of the most important steps. If I don't take the time to relax, things don't happen. I've added a liquid fiber supplement to my diet (at night) since its nearly impossible to get what you need from food. I avoid caffeine and any foods that are diuretics in order to maximize the benefit of drinking fluids and eliminate the unpredictability they can add to your body's systems. Since I'm lactose intolerant, I read the labels on **everything** I eat and avoid anything with milk in it. By doing all of these things, I'm probably more regular than most of my able-bodied friends and I feel so much better than I used to on a daily basis, both physically and emotionally. It sounds like a lot of work, but once you find what works for you and make it part of your routine, it ends up saving a great deal of time and embarrassment in your life. I've also found that being regular and avoiding foods that don't agree with you has helped cut down on gassy stomach, etc. problems.

I'm sharing this extremely personal information because, quite frankly, I'm very excited about it. Now every morning, instead of being bloated, uncomfortable and often in pain and nauseated, I feel like throwing a celebration party. It took me years to stumble across the right combination. I truly hope that you can share this with your readers and it not only offers some ideas but also affirms that the right attitude and regimen can make all of the difference.

Sincerely,
Regular in Seattle (-:

A Resource for Assistive Technology

William T. Darling
Associate Director, Assistive Technology of Ohio

For many people with disabilities, the difference between 'yes' and 'no' rests often between the presence or absence of technology. Assistive technology is for many people with disabilities the bridge that spans the divide between a world of frustration and isolation and a world of inclusion and participation.

The purpose of assistive technology is to allow people with disabilities the opportunity to use their abilities to their fullest extent, and to allow them a chance to work, to learn, and to live independently.

What exactly is assistive technology? Assistive technology (AT) is a term that was coined by the U.S. Congress with the passage in 1988 of a law known as the "Tech Act." AT is defined in the law as "any item, piece of equipment, or product system… that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities."

AT can range from clamps to help you pull up your sock, to ramps to your front door, to futuristic robots that can bring you your iced tea. Any piece of equipment that makes life easier for people with disabilities will likely fall under the definition of AT.

The Tech Act was passed to help promote assistive technology for people with disabilities. **One of the ways they accomplish this is to set up an assistive technology agency in every state and U.S. territory.** These agencies are given the charge of promoting and administering programs that make it easier for people with disabilities to acquire the AT they need.

Examples of such programs are AT low-interest loan programs, adaptive toy lending libraries, and computer refurbish and recycle programs.

For many people with disabilities, the technology they need is not covered by insurance. In many cases, health conditions can lead to poor credit ratings, if even one hospital stay is not covered. Low-interest loan programs allow people with disabilities - even those with bad credit - the opportunity to take out loans at low interest rates for the assistive technology they need.

There is an entire industry devoted to making toys and educational software for children with disabilities. For parents, it can be difficult to find a toy their child can "connect" with and enjoy. Additionally, these toys can be expensive, and are often found only in catalogs or on the Internet. An adaptive toy lending library, often oper-

ated out of local county libraries, is a place where parents can check out special toys and see if they are right for their child. This gives parents access to more toys and allows them to make more informed decisions on purchases.

Computer refurbish and recycle programs are programs where people can donate computers that are then upgraded and made available to people with disabilities at little or no cost. These computers can be equipped with special software to meet the needs of people with disabilities.

These are examples of only a few types of programs that may be available in your state. The Tech Act agencies can often be a most valuable asset to people with disabilities who have technology needs. These agencies are set up to be a resource and to try and meet the assistive technology needs of people in their state. To find out information about the Tech Act agency in your state, please go to: **http://www.resna.org/taproject/at/statecontacts.html** and click on your state or territory. For more information, please call (703) 524-6686.

The AmTryke® Therapeutic Tricycle Project

National AMBUCS™, Inc. is a non-profit service organization whose mission outreach is "to help provide opportunities for independence for people with disabilities." In 1996, as part of that mission outreach, National AMBUCS™ started the AmBility™ Program, the cornerstone of which is the AmTryke® Therapeutic Tricycle Project. Since 1996 National AMBUCS™ has provided over 5000 'trykes' to children across the United States and several foreign countries.

A physical therapist was looking for a way to motivate her pediatric clients in therapy and asked an AMBUCS™ chapter to help her provide a tricycle that would help with muscular development, tone, build self-esteem, and give them the experience of the thrill of riding. The Longview, Texas chapter took up the challenge and the AmTryke® therapeutic tricycle was born. The AmTryke® therapeutic tricycle is special in that the continuous chain mechanism works both the arms and legs together letting the stronger limbs help the weaker in propelling the tryke. This tricycle can benefit children with low muscle tone (such as spina bifida) and children with high tone (such as cerebral palsy). Children with coordination, balance, or strength problems can benefit from the tryke.

The AmTryke® Therapeutic Tricycle

At present there are three sizes of trykes in production. The **Regular** 12" front wheel tricycle is for children approximately 4 to 8 years of age, with a height of 36 to 41 inches, and an inseam of 17 to 21 inches in length. The **Large** 16" front wheel tricycle is for children approximately 8 years of age and older, with a height of 41 inches and taller, and an inseam of 21 to 31 inches in length. Both of these tricycles have a steering control pin that provides graduated steering of straight ahead, 20 degrees right or left, and free motion. The **All Terrain** tricycle has the large pneumatic tires like an ATV. This tricycle is not for everyone, since the tires make the tryke heavier and it has free steering like a regular tricycle. This tricycle is for children approximately 9 to 12 years of age, 38 to 42 inches in height, and an inseam measurement of 19 to 24 inches. We will add a new style of tricycle to our line in mid-October. The **Toddler** will be for children approximately 2 to 5 years of age, up to 36 inches in height, and an inseam of 15 to 18 inches.

Before you make any decision about the AmTryke® therapeutic tricycle or any other piece of mobility equipment, we recommend you speak with your child's therapist concerning the piece of equipment. National AMBUCS™, Inc. and AmTryke®, LLC believe in therapist intervention with the 'trykes.'

The Wish List Process

The ability to pay for an AmTryke® therapeutic tricycle is not a determining factor in obtaining one. The Wish List is for those parents that are unable to afford the cost of the "tryke." To place a child's name on our Wish List requires a therapist's evaluation and agreement that the child will benefit from an AmTryke® therapeutic tricycle. These evaluations can be performed by a therapist at one of our Demonstration Sites throughout the county where your child will be able to try out the tricycle. You can check to see if there is a Demonstration Site in your area by going to our website or you can call the AMBUCS™ Resource Center at (336)869-2166. The site has the necessary paperwork that you will be required to submit. You will need to send the forms to your local AMBUCS® chapter or to the AMBUCS™ Resource Center. If there is not a Demonstration Site near you, your therapist or physician can perform the assessment for you. The forms you will need to submit can be obtained online at www.ambucs.com/Amtryke. You will need to fill out the **Request Form** and have your therapist or physician fill out and sign off on the **Assessment Form.** We can also mail you these forms be contacting Pam Burleson at the AMBUCS™ Resource Center. **All forms must be received before a child's name can be placed on the Wish List.** If the

assessment is not being performed by one of the Demonstration Sites, it is important that the arm length and inseam measurements are done properly as this is how the correct size tryke is chosen for your child.

Once a child's name is placed on the Wish List, it remains there until a chapter can raise the funds to purchase and provide the tryke for that child. National AMBUCS™, Inc. is a service organization and each chapter raises funds within their community to provide trykes for children. Depending on the availability of funds and the length of the list, it may take as long as a year to provide a tryke. But each child will get one. For those parents requesting the AmTryke® therapeutic tricycle outside the United States, covering the shipping costs would be helpful.

Purchasing an AmTryke® Therapeutic Tricycle

For those parents that can afford to purchase the AmTryke® therapeutic tricycle, the **Regular** tricycle is **$399**, the **Large** is $599, and the **All Terrain** is **$499**. All have a **$33 shipping/handling** fee for shipment within the continental United States. Shipping can be arranged to areas outside the continental United States, but shipping quotes will be on an individual basis.

In the effort to make the AmTryke® therapeutic tricycle as adaptable as possible for an individual child's needs, an **accessory line** has been developed. All trykes and accessories can be viewed at **www.ambucs.com**, click on AmTrykes®. Accessory items are shipped from the AMBUCS™ Resource Center located in High Point, North Carolina. For shipment within the continental US, there is a minimum shipping/handling fee of $10.00. Shipping costs outside of the US would have to be determined. Please contact Pam Burleson, AmTryke® Coordinator, by email at **pamb@ambucs.com** or call (336) 869-2166 for further information or answers to specific questions. Giving children smiles as they take their first ride on their own "set of wheels" is a great way to achieve our mission.

The USDOT Hotline for Air Travelers

The US Department of Transportation has a toll free hotline for air travelers with disabilities. The hotline has been in operation since August 2002 and is available for callers seven days a week from 7 AM to 11 PM Eastern Standard Time. The hotline offers educational information and provides assistance in resolving disability-related air travel problems.

Many disabled air travelers are not aware of their rights. The hotline exists as an educational service to inform air travelers with disabilities about their rights under the Air Carrier Access Act and the Department's implementing regulations 14 CFR Part 382. Hotline operators can provide callers with information about the rights of air travelers with disabilities. The hotline operators can also respond to requests for printed consumer information about the air travel rights of the disabled.

The hotline can also assist with the resolution of real time or upcoming issues with air carriers. The purpose of real-time assistance is to facilitate airline compliance with DOT's rules by suggesting to the passenger and the airline involved alternative customer-service solutions to any problems. The airline remains responsible for deciding what action will be taken to resolve the issue in accordance with the ACAA and Part 382. Generally, if a caller has a real time problem or an upcoming issue with an air carrier, a Hotline Duty Officer will contact that air carrier and attempt to resolve the issue. For example, there have been a number of incidents in which Hotline Duty Officers have convinced air carriers to accept service animals and electric wheelchairs on board flights, to stow folding wheelchairs in the cabin, and to provide requested wheelchair assistance.

Air travelers who want information about the rights of persons with disabilities in air travel or who experience disability-related air travel service problems may call the hotline to obtain assistance at:
(800) 778-4838 (voice) or (800) 455-9880 (TTY).

Air travelers who want DOT to investigate a complaint about a disability-related issue must still submit their complaint in writing via e-mail at **aircconsumer@ost.dot.gov** or by postal service to: Aviation Consumer Protection Division, US Department of Transportation, 400 7th Street, SW, Washington, D.C. 20590.

How do students with disabilities pay for college?

We are gathering input from students with disabilities of all types regarding financial aid for higher education. We need your feedback! You can help other youth with disabilities by sending us a brief e-mail.

My name is Rebecca Moore and I am writing on behalf of the Youth Advisory Committee (YAC) to the National Council on Disability (NCD). The Youth Advisory Committee (YAC) is composed of young adults with disabilities who advise the National Council on Disability (NCD)

about issues faced by children, adolescents, and young adults with disabilities. Members of the YAC know how important it is for people with disabilities to succeed in college and are considering ways that the federal government can address related concerns. Advice from the YAC helps NCD to make recommendations to the President and Congress on disability issues such as special education, the transition to adulthood and independence, independent travel, rehabilitation, higher education, employment, health care, and other topics.

There is little information from people with disabilities about their higher education experiences, including financial challenges, barriers, and level of success. Stories from students affiliated with The Transverse Myelitis Association will help us expand what is known about these issues, so the support services provided to students with disabilities can be improved.

We want to hear from students about financial aid and disability experiences. We need for students with disabilities to write to us at youthfeedback@yahoo.com so we can understand how disability and financial aid have affected their college or graduate school experience. We will use your anonymous quotes to help illustrate the obstacles students overcome and to support policy recommendations.

Written responses may also be submitted to:

Dr. Gerrie Hawkins
Youth Advisory Committee
National Council on Disability
1331 F St., NW, Suite 850
Washington, DC 20004

Please return your comments by October 30, 2003.

Students: Are you wondering what to write about? Sharing a brief, informal note about your story will be a big help. We invite you to share as much of your story as is needed to explain your circumstances and the relationships between your disability expenses, college financial aid, vocational rehabilitation services, and other sources of support.

These are optional, guiding questions to help you think of stories, concerns, or suggestions to share in your brief e-mail. Writing about just one story or concern could be a big help to us.

1. If you disclosed your disability to your college, did this information affect your financial aid package? To what extent did your financial aid increase or decrease as a result of disclosing your disability?

2. What stories or suggestions could you share about how you have paid for school?

3. What stories or suggestions could you share about these concerns and their effect on your financial aid?

- Are you physically and mentally able to attend school at least half time?
- Can you meet your school's requirements for satisfactory academic progress?
- If you must take a reduced course load because of your disability, will you run out of eligibility for Pell Grants before you finish school?
- Are you physically and mentally able to participate in your college's work-study programs?

4. From where have you requested financial assistance for college? For example, do you have stories about working with resources such as any of the following:

- Offices at your college (financial aid office, disability services, student support services, etc.)
- Your state vocational rehabilitation agencies
- Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)
- SSA Plan to Achieve Self-Support (PASS)
- The SSA Ticket to Work Program and its rehabilitation agencies
- Educational Opportunity Programs (EOPs)
- TRIO outreach, retention, and student support programs

5. Have concerns about your disability affected your decisions about student loans? For example, some students are reluctant to borrow money for school because they wonder if they will be able to work and repay their loans.

6. What additional expenses did you face as a student with a disability?

- Please describe services or accommodations that your college funded. Examples: TTYs, speech recognition software, screen reading software, note takers, readers, sign language interpreters, transportation, personal assistants

- For what disability-related expenses have you *not* been able to receive funding from your college, vocational rehabilitation agency, or health insurance provider?

7. How do all of the support services you utilize work together? For example, what is the relationship between the assistance you receive from your college and the help available from vocational rehabilitation agencies?

8. If you are considering attending graduate school, from where will you seek financial support?

We will use your comments in a report advising the National Council on Disability about the concerns and needs of college and graduate students with disabilities. To receive a copy of this report subscribe to our Yahoo news list at http://groups.yahoo.com/group/ncdyacnews

You can help us by sending just one paragraph about a financial aid issue

or concern that matters to you. We want to hear from you, so keep your notes short and send them soon! Thank you.

Sincerely,
Rebecca C. Moore
rebeccamoore@optonline.net
Co-Vice Chair, Youth Advisory Committee
National Council on Disability
1331 F Street, NW Suite 850 Washington, DC 20004
202-272-2004 Voice*
202-272-2074 TTY*
202-272-2022 FAX*
www.ncd.gov *
youthfeedback@yahoo.com

In Their Own Words

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

Learning to walk … again.

Molly Barrett
St. Paul Minnesota

I may just look like an ordinary 8th grade girl who goes to Hazel Park, but really I'm different in many ways, mainly through the lessons I have learned in life.

December 5, 2000 was one of the most painful and shocking days of my life. It was the day the virus, which is Transverse Myelitis, hit my spinal cord. It was a normal day when I was walking back from SEM class and going to my regular class. All of a sudden my legs felt as heavy as bricks. It also felt like a thousand knives were stabbing me in the legs. I started to cry when the pain became unbearable.

My teacher asked, "Are you okay, Molly? Do you need help on math? I can show you how to do it."

"No," I said in a shaky voice.

At this point I did not know what was happening. My teacher wanted me to go to the nurse, but I said I couldn't get up. Then she said, "Try." So, I did, and just as I figured, I collapsed. So they wheeled me to the nurse's office and called my dad. My dad came and he had to carry me to the car, because I was paralyzed and could not walk. That night I went to the hospital unaware that it would be my home for the next few weeks.

The hospital for most kids would be good, because they would think it meant no school and presents. Well, of course, that's what I got, and plenty of visitors, but what I really wanted was to walk again and to be home for the holidays. The days and nights in the hospital seemed like they were never ending. It seemed while everyone was getting ready for Christmas, I was all alone by myself, although physically my mom and dad were there with me every night. The doctors and nurses I had were so nice and encouraging. None of them really knew what I had, at first, since it is so rare.

There were actually some fun things about being in the hospital. I enjoyed watching TV, watching movies, playing bingo, and having two Santa Clauses come and visit me. Even Aaron Gavey from the Minnesota Wild team came to visit me!

If these things make you think the hospital was just fun and games, here are the things I hated. There was the MRI (because it made me feel so claustrophobic), spinal tap, all the blood (because it makes me queasy) and the electrical stimulation test. Those were very painful. And I forgot the immunoglobulin, which in case you don't know, is when they rotate your blood so it gets circulated.

You may think those must have been very hard for me to go through, but actually fitting in when I left the hospital was more important to me. Wearing braces was so hard. People stared at me in the summer time. When I did not wear them, they stared even more 'cause I walked so funny.

Here is where my important lesson comes in. After having to wear braces for a while, I began to think, if people do not like me for who I am, then they are not true friends. So, having this disease helped me to: 1. See who my really true friends are; 2. Have more confidence in myself; 3. See how much people really care about me; and 4. to never take anything for granted, and always think of life as a gift.

That's pretty much how it happened. Out of the blue this disease took my walking ability away from me. Be thankful with what you have, because you never know if it might get taken away.

To this day, I am still struggling with this disease and maybe will be for a very long time. I know crying will not help so, instead, I try to think of this disease in a positive way by looking at the good instead of the bad, because it helps me to accept this better.

I would just like to thank my family, friends and anyone who has helped me go through this the past two years and for always having faith in me when my own faith was gone and, most of all, for helping me learn to walk again!

Jonathan Rock
Derby England

One Step at a Time
By Molly Sena Barrett

The day I got my disease I was scared and afraid,
I was hoping the pain would go and the weakness would begin to fade.
I was puzzled and I was confused I asked G-d, "Why me?"
The reply He gave me was, "just wait and you'll see."
For each day I prayed and hoped that I would walk again,
And each time I said, "Oh, why did this have to happen?"
But one day I got it, I finally understood,
I began to look at only the good.
I thanked G-d I was alive and that I could breath and talk,
And at that moment, it didn't matter if I could run or even walk.
I was thankful for every inch and every step that I took,
I finally was seeing what was in front of me all I needed to do was look.

Every day G-d helped me and is still ever more
Because for every inch he gave me, I made it so much more.
I made one inch a yard and every yard was a mile,
And every time I took a step it all seemed worth while.
In the long run it's not who finishes the race first,
But who takes what they've been given and makes it the best, even if they were given the worst!

The End

Being a relatively fit and active 28-year-old who enjoys all outdoor activities from surfing, snowboarding to walking and soccer, I never thought I would succumb to such a debilitating syndrome or illness or however you would classify TM.

It all started less than a month ago. It is only with the power of hindsight that I am able to give this experience any sense of form or order. At the end of August 2002, I was enjoying a fantastic holiday with around 20 friends, camping in a glorious part of Wales. However, as the weather was so good, the surf was poor, which led to a fairly hectic drinking schedule. After a solid week of beach parties and a day on the beach in glorious sunshine, we decided to go fishing to catch our supper. After an hour of high octane mackerel fishing off some sheltered rocks, I began to feel a little ill. A long walk back to the tent completely exhausted me and I dived straight into my sleeping bag thinking it was nothing more than a little sunstroke. After a feverish night, I awoke the next day with swollen spotty tonsils and an unsightly cold sore developing on my lip. None of this was that unusual for me, being such a slave to the sun and beer.

I fought the illness off and by the following day was feeling back to normal, apart from the blister on my lip. I returned to work the next day. The following weekend, I enjoyed a fantastic weekend with my friends, ending with a wonderful concert in the open air, and my enjoyment fuelled with a bottle of quality red wine.

From here, things took a strange course which may mirror your experiences. On Monday, 2 September 02, I noticed a strange sensation on my stomach and thighs which felt like sunburn. Having clothes next to my skin felt very uncomfortable. However, I carried on at work, putting it all down to my hedonistic lifestyle.

The following day the sensations worsened, but still I carried on working. Finally, I decided to call it a day early to allow my body a bit of time to recover. After a little sleep, I felt a little feverish and noticed my body aching all over. I put it down to nothing more than a brush with flu. Expecting my body to correct the imbalance itself, as it had done many times before, I went to bed thinking little more of it.

However, on waking on Wednesday, things had gone very strange. It felt like I was wearing a thick winter wetsuit as all feeling on my legs and stomach had been numbed. Not painful, just not right. I also noticed I had the shakes quite badly and was walking more like a 78-year-old than a 28-year-old. By now, I had decided a trip to my General Practitioner was required. Upon seeing him, he noted from the presenting symptoms that it was probably nothing more than a strain of influenza. I mentioned I had concerns with it being in my spine or back. I do not know why I thought this, but it just seemed to be so. I was sent away with antibiotics and told to give blood and urine samples and return the following week.

After the visit, things started going rapidly downhill. Firstly, I found it impossible to pass water and throughout the night, the pain was becoming more and more unbearable. I had tried to sleep everywhere, including in the bath and on the toilet, so if I needed to go, I did not have to worry about stumbling around my house. The relief never came, so at 11:00 AM on Thursday, I called in the emergency doctor. I was then presented as an in-patient on the urological ward at Derby City Hospital. Not a pleasant experience for a young man to be catherterised and placed in a ward where the average age was well over 60. Nurses gave me strange looks and the sympathy vote was certainly wooing the young ladies. You will notice that at all stages, I managed to find humour in all situations, which I believe has helped my recovery thus far and is a must for all sufferers.

Numerous tests were carried out on every part of my body; blood tests, urine samples, ultrasounds, x-rays and physical examinations, as you will all well know. Everything came back clear. With no forthcoming explanation, I was beginning to think the symptoms were psychosomatic, but as my strength was weakening along with an inability to walk, I was still sure it was a spinal problem. I kept pushing for an MRI scan. But it was only when all other avenues were exhausted, did they grant me my wish. Finally, on Saturday, 7 September, I was given an MRI scan, following which the attitude of the doctors and nurses changed. I have always asked lots of questions so I know what is going on, but now people had stopped answering them. I knew it was something bad, but still had no clue as to how bad or what it was. After hassling the SHO's and registrars, someone finally told me I possibly had a condition known as Transverse Myelitis or Guillian Barre. However, as both of these were so rare, no doctors had come across it before. Therefore, they were unable to give me answers other than it is serious and there is a chance I may never recover.

The bottom fell out of my world. I was planning a snowboarding trip, my job running a rally driving school, my surf trips, my walking holiday in the Polish Mountains, all gone and for what; for something that no one knew anything about. Words cannot explain the low I felt. But I am sure many of you know what I was feeling.

However, I am a stubborn fellow and refused to believe this was it; game, set and match to some bastard who had decided he did not want me to play anymore. Literally within hours, I had decided what I needed to do; look at the worst possible outcome, look for the positives, and then anything on top of that was a bonus. I am lucky in that I have the best group of family and friends any man can have. They were all willing to stick by me and helped me laugh. OK, I could not surf, but I could get in a canoe (as any surfer knows, canoists are our mortal enemies; to go to the other side was not an option). I could not snowboard, but I was always in awe of the crazy dudes who sped down the mountain on their backsides and skis on their arms. My friends could wheel me around the pubs and clubs. Hey, who knows, the wheelchair would certainly be an icebreaker in talking to all of the beautiful women. My life had changed, but I was determined to make the best of it.

I knew throughout every bad experience in my life that you always had to look on the bright side. No one achieved anything by being miserable and dwelling on ifs and buts. You had to look at what was going on and alter life accordingly.

Things moved quickly from here on in. I was transferred to the Neurological Department of the Queens Medical Centre in Nottingham and was immediately given a lumbar puncture; not a pleasant experience as they had to do it three times to get enough spinal fluid. The results were through in a matter of hours and it seemed likely that it was post infectious TM and IV steroids were administered immediately. The staff there were brilliant, answering all my questions honestly. I realised now that at least things were not going to get any worse. The tests continued, and they informed me they needed to check all avenues, including HIV, syphilis, MS, etc. Again, all

very scary, especially due to my wayward time at university, but at least I knew I was in good hands.

Saturday night, Sunday and Monday were all a blur with so many visitors, doctors and medical students and having to explain the unexplainable to all. Although not technically paralysed, lesions has been noted at T6 and so feeling from the chest down was limited. The pins and needles in my arms had reduced and my lung capacity and breathing had not been affected. I now know how lucky I was.

The more information I was given, the more I could cope with my situation and tried to draw on all the positive aspects. I cannot stress enough the importance of a strong positive attitude. I was determined to prove people wrong. I was expected to see improvements from about two weeks after the three day steroid treatment. I was still catheterised and had not opened my bowels for a week. On Tuesday, I asked for a wheelchair so I could familiarise myself with how my life could be. Not too bad, I thought, but it was not good enough. The physiotherapist gave me exercises to prevent more muscle wastage and DVT. These were done on my bed. I practised these until I was exhausted.

As more and more tests came back clear, the original diagnosis of post-infectious TM seemed to be correct. My spirits, although never dropping, were rising and I asked for more exercises to help me walk. By Wednesday, I was able to walk, albeit shakily behind the wheelchair and much to the amazement of the professionals around me. Every little step seemed like a miracle and made me push harder. The staff and other patients in the ward were excellent. They never smothered me with sympathy, but treated me as a normal person and joked at my wobbily walk, my catheter, and the amount of laxatives I was taking. One nurse said she was even looking forward to giving me an enema. My friends and family also remained strong and continued to treat me as a normal person. These were all vital, I believe, to the recovery I have made thus far.

Thursday, 12 September, and another patient asked to borrow my wheelchair for an hour. No problem I thought, I could just lie in bed and snooze. However, after a few minutes, my curiosity got the better of me. I had amazed the doctors thus far. I had been building the strength in my legs and thought I would give walking unaided a go. What is the worst that could happen? I could fall down and hurt my pride, or the laxatives might kick in and may land me with an unwanted present. I put my legs on the floor and felt confident when they held my weight. I slowly let go of the windowsill and slowly shuffled unaided. What a feeling, ecstasy, unbound joy, pure thrill as I began to stumble around the ward. With plenty of encouragement from the other patients, I was almost in tears. At last, I realised that things were going to be far better than I had ever imagined. Less than a week ago, I was told I may never walk again. But here I was, like bambi on ice, and it was the best feeling in the world.

There were still the down times. Although I knew I was lucky, I still felt like asking, why me? I have never done anything bad. I was fit and healthy, and despite a few vices, I saw myself as a good, honest, genuine, caring person. Why not afflict the criminals who harm others? But then I realised this would not help me. There were other bad times, as when the laxatives kicked in, boy did they kick in. The first couple of visits were fine, but then I got a little cocky, left it a little too long and left a nice present in the medical bin of soiled underwear. Times like these made me cry and sob. But I knew I had to snap out of it and sharing the embarrassing times, and hearing the laughter, soon made me feel better. Another hard time was having the catheter removed and waiting for that first urine to pass through. After 12 hours and many attempts, the first dribble was applauded throughout the ward. Although not brilliant, I knew when I had to go and this was a relief. All that I needed to do was to learn how to be more relaxed and not try too hard. Something which I have yet to perfect, but every visit to the toilet makes me realise how lucky I am. This all may sound strange, but for all of those who have suffered, you will know exactly what I mean.

On Friday the good news just kept rolling in. I was HIV negative, the blood bands showed it was very unlikely to be MS and everything was clear. These may appear small things to many, but to me, I took every bit of news as a boost to my confidence. I knew that my positive outlook and confidence were going to play a major part in my recovery, and I know this has been the case for many others. I was also told that I could return home. Even though I live on my own, to be back among the people I love was the best feeling of all.

It has been two weeks now since I have been home and I will not lie and say it has been easy. Every little pain or ailment scares the living daylights out of me. I have not been to a doctor for many years, but have been on the phone almost every other day. Once after celebrating my release with friends, I drank far too much diet pepsi instead of water and caused a pain in my kidneys. Yes, I have virtually given up alcohol until further along the recovery trail.

The one thing that has concerned me has been the lack of after care and

physiotherapy. After making such a surprising, speedy recovery, I was pretty much left to fend for myself. I have always pushed myself in everything I do to achieve excellence and this was my downfall a few days ago. After reading advice on websites, I thought it best to get in the gym and build myself up. However, rowing 1500 metres, cycling 4.5 km and swimming 1000 metres was a little too much and has set my recovery back a little. It is still hard for me to accept this affliction and the limitations I must impose on myself. My balance has suffered a little, although at this present time, I believe this to be due to congestion in the right side of my face and I feel all bunged up. However, I know now that I must take each step a little at a time. I love my job and wanted to get back to work, but know I must wait. My company have been excellent. Prodrive Motorsport has their own fitness and well-being guru to help with the racing drivers and they have offered me his services. He has experience working with Guillian Barre and other spinal conditions, so I know I am in good hands.

I know it may be many years, if ever, until I recover, but I know that the love of my family and friends, the support of all the health workers, patients and the understanding of my work colleagues will help push me as far as I can go. They have all done so much; much more than I could ever have expected, and for this reason, I am forever in their debt.

There is one more person who is vital in making as full a recovery from this as possible and this is myself. All of you that have been here and for all those who will be here, always believe in yourself, never say if and but, accept this condition for what it is, but never ever give up hope. The human mind and body are incredible instruments that we will never fully understand. They are more powerful than we can comprehend. By having belief in this and by believing in yourself, you can make things better. Even if you are not able to improve physically, at least by coming to terms with things, you can improve your own quality of life and the quality of life of those around you.

Hubert Smith
Rhinelander WI
wheels141@hotmail.com

It was the beginning of the new year, 2001. I had been dating my fiance and we planned on being married on my birthday, January 5th. I would marry my fiance and turn 40 all at the same time. Our wedding night was the nicest day of the week, which included a beautiful sunset.

I had no idea what I would be facing in the next couple of weeks. My thoughts were on us that night and I was really happy. It was my first marriage. My wife, Mary, had been married before and now I have two beautiful step children, 15 and 17. We were married at our church, the Church of Christ in Rhinelander, and we were having a great time.

We went on a short honeymoon. Soon after that we were settling into our new home. We were working on the house to get it ready for the kids to move in. A couple of weeks later, Mary got sick and then I got sick. I then got pneumonia.

I had planned for a special night for Valentine's Day. I had made reservations for dinner for us at one of our local restaurants. I had been going to a chiropractor for some upper back and neck problems. The doctor had helped me with adjustments.

Two days before Valentine's Day, my upper right arm and my upper back were hurting me when I woke up. I was getting really weak. My wife was taking the children to school. I asked her to come back to take me to the clinic. On our way to the clinic, I was hurting so badly that we changed our minds and went to the emergency room.

While I had just gotten over the pneumonia, my lungs were still congested. I had an elevated temperature and I was in severe pain. The doctors gave me Tylenol for my temperature. They never really had any reason to keep me in the emergency room. They gave me pain shots and my temperature came down. They also prescribed me some additional medication for the pain in my back and neck.

After they discharged me, I went home. My wife went to work. I went to sleep, because I work the night shift and was planning on going into work that night. Later in the afternoon, I woke up feeling better. I was moving around okay. I was expecting my wife home soon with the children. She was also picking up my medicine on the way home. At 4 PM, my wife had dropped off the medicine and left right away to take one of the children to the library. I was about to take some pain medicine and I realized that pain was shooting in my right arm, upper back and neck and also my left arm.

I was quickly getting very weak. Being alone and not knowing when my wife was going to return, I called the emergency number. When the ambulance crew arrived, I could barely stand up. I managed to put on the flannel shirt Mary had bought me while we were dating. They put me on a stretcher and carried me to the ambulance. I was on my way to the hospital in an ambulance and I didn't know what was happening to me. I had been in fairly good health. We

had just gotten married and life was supposed to be all good.

My wife came in shortly after I arrived at the hospital. She saw them picking me up at our house and was wondering what was going on with her husband. I had decreased movement in my arms and I was tremendously weak. I told the nurse that I needed to go to the restroom, but then discovered that it was difficult to go.

The nurse immediately put me on an IV for fluids. I couldn't feel a thing when they inserted the needle. I wasn't numb, but it didn't bother me. I did not understand what was happening to me. The doctor said that I needed to stay in the hospital for further tests. They admitted me to St. Mary's Hospital. They took blood samples from me and ran many tests. I was exhausted. There was extreme tingling in my arms and legs. I was beginning to lose movement in my right leg. My arms were hardly moving. They ordered a MRI scan the next morning. The scan indicated marks on my spinal cord in the lower back region and in my neck. They put me into intensive care where they could monitor my condition more closely. They put me on antibiotics and steroids.

The results from a spinal tap were negative, and the MRI scan results were positive. They said that I had Transverse Myelitis and they explained that it was an infection of my spinal cord. I suffer from diabetes, which I have had for some time and have learned how to deal with. Now I had to learn how to deal with this, too? Wow!

I was in ICU wondering when this was going to end. They had a neurologist examine me. The doctor told me that my recovery depended on my immune system and they said that it could take months. They also said that it could turn into MS.

I had some set backs due to my lungs that were really congested from the pneumonia. I was beginning to eat. I could hardly swallow. I was only on a liquid diet, and I lost some weight. The staff in the ICU was really courteous and they really wanted me to get better. I had to say a lot of prayers. My family visited me, as did members of our church. I wasn't alone through this experience. I thank every one for being there. I needed a lot of encouragement and support and love.

I managed to get better. I still could hardly move my legs and I was barely moving my arms and hands. But I was making progress. The doctors were looking for a rehab facility for me. I was transported by ambulance to the rehab unit at Saint Joesph's on February 23rd.

Slowly, I was getting better. It was painful, tedious, anxious, frustrating, sad and happy. You go through so many emotions when you are wondering what your future is going to hold. This has been hard on my wife especially, because we had just gotten married earlier in the year. She also has had health problems. I felt sorry many times when me and my wife had disagreements while I was in the hospital. I didn't know what to do or say. I wanted to express my love to her, but I couldn't. I was just very frustrated. The doctors and the therapy departments were saying that I would be in the rehab unit for about three months.

I did have more set backs. I had blood clots form and a pulminary embolism. I was moved to a medical unit until the healing process was completed. They said that I was a prime candidate for a green field filter to be placed in my main veins or artery. So, I had to go through that operation, as well. The filter would help to prevent more blood clots forming. I have to take lots of medicine now, including blood thinners. I knew that the good Lord was in control. I soon got better. They discharged me from the medical unit and I was put back in the rehab unit. My lungs were getting better so they took me off some of the medications.

I was slowly getting stronger again. They allowed me to go to a local church to help me get used to going out in the community. I couldn't walk and I could barely move my arms. We take so much for granted. I couldn't scratch myself when I had an itch. That is frustrating. I couldn't feed myself and that was hard to accept. In occupational therapy they were teaching me to use a hand lifting device so that I would be able to feed myself. That process was sad and frustrating. I kept dropping my food and it was hard to scoop my food up on a spoon.

The therapy department was really respectful. They understood my frustration and anger. I knew they were well trained and knew how to deal with me. Until you are in a hospital like this, you don't think about the many different diseases, accidents and general health problems people suffer from.

I began to think about what I would do when I got out of rehab. I have an art background and I was thinking that I could continue with it, if I got better. So, I kept this in mind. My family and my wife started to bring me drawing materials as a way to help me get the frustrations of TM off of my mind. I was able to do some drawing, and I was getting better at moving my arms and hands. I was

even able to feed myself again. Oh, boy! Yeah! Amen! I was thanking the Lord. My prayers at the local church were for the hospital staff, my wife and everyone that was there for me. I started with a standing machine with a hydraulic lift on it. It made me sick to stand. I was wondering whether I would be able to get my strength back to stand and walk again?

I managed to progress. I met a lot of nice people in the hospital. I made it through Easter. My family took me and my wife out for dinner and we put our problems out of our minds for that day. The hospital had a nice activity program, which also helped. We made decorations for Easter. I even made some decorations for their therapy bulletin board. I was regaining most of my strength back. I still had trouble going to the restroom. I was developing a better attitude and I knew that I could only get better. With TM you can feel better on some days and then on some days, you feel worse.

Just after Mother's Day, the hospital staff met with us and decided it was time for me to be discharged. I was getting better. I still had a lot of pain in my stomach area. I decided that this was going to put too much stress on my wife and I decided to go into a nursing home until we had arranged for home health care. My wife didn't understand why I wanted to do this, but I knew it was the right approach. I had to focus on getting better, so I could go home. I stayed at the nursing home for about a month and a half. I went home in the middle of July.

The pain in my stomach has gotten better. I still have set backs. I was going to outpatient rehabilitation. I was thinking more positively and I was gaining confidence about being home. I have in-home health care nursing aides that help me. This has been so hard on my wife. She helps me, she has to take care of herself, she cares for the children, and she is also going to school. TM has been a trauma in my life; and it has been so traumatic for the people I love.

I'm getting better but I have frequent muscle spasms in my lower back and constantly in my legs. My hands are much better, but they feel like wood. They have a slight tingling affect to them. I always had feeling, but my sensations were off a bit. It is hard to determine hot and cold sensations around my legs and hands. When I shower, I have to test the water temperature on my shoulders.

I can use a walker now and a quad cane for short distances. The physical therapy and the occupational departments now have me on exercise programs that I can do at home. I use a wheel chair for long distances. I have to be grateful at this point in my life. When I first got TM, I was not able to do anything.

I miss the company of my wife. It is hard on us. I hope she can come to understand that adjusting to my illness has been a new process in my life. I don't fully understand what she is going through. Getting to know her is part of the process of marriage. I just hope and pray we can have peace and contentment with each other and that we can be at each other's side again. Our church is helping us to better cope with our current health problems and finances. We have a nice church. I miss having my wife here and I love her a lot.

It is now January, 12th 2002. It is past our first anniversary. I'm presently taking an at-home course on computer graphics. It is a two-year course and I am three-quarters of the way finished. I just hope my health continues to get better. I'm also in a graphic arts program at my local college. I would like to complete this program. All I can do, all anyone can do, is to have hope and trust in the Lord to keep going.

This has been my experience with my past year with TM. It has been a year of change and learning how to cope with all of the changes.

Jon Spatz
Las Vegas NV

January 10, 2003

Happy New Year. This being the first holiday season with TM, we had to pace our activities slowly due to Jon's reduced energy levels. The things you take for granted before TM!

Let me introduce you to Jon and our family. Jon is 35 years old. He has lived his life in Las Vegas, NV since he was 3 years old. Jon is a local golf professional, working at Lake Las Vegas Resort as the tournament director and golf instructor. Jon and I have been married 12 years this October, and we have two beautiful daughters, Amanda, nine years, and Emily, four years. I work as a clinical exercise specialist for a private gym, and had previously been an emergency medical technician with specialized training for cardiac conditions at a local hospital. Prior to his diagnosis of ATM, he was rarely sick. Jon leads a healthy lifestyle, watching his diet and exercises regularly.

I'm sure that Jon's onset of TM is similar to the others in the Association. Please humor me as I dive into all of the sordid details. Jon and our family celebrated his 35th

birthday, February 17, 2002. He had been fighting a sinus infection for approximately two weeks prior to his birthday. I had encouraged him to go to his doctor after over-the-counter self-medicating wasn't working. Being the typical man, he refused. He assured me that it would be over soon. One week into the sinus infection, he had returned from his daily bike ride complaining that his feet were numb. He got a flat tire shortly after his departure, and had walked the bike home in his biking shoes. Being the "expert," I commented that my feet would be numb also if I had walked home in those shoes. The shoes were for biking, not walking, and he had walked the bike home for several miles. The numbness continued throughout the day. By the next morning, Jon complained that his legs also felt numb. He went off to work that morning. I checked in with him later that day, and again encouraged him to visit his doctor. He visited his doctor that afternoon. The doctor did not seemed concerned with the numbness, and agreed that the numbness was due to the long walk home, hunched over the bike, in the wrong shoes. He was sure that the sinus infection had run its course, and had backed his diagnosis with lab work. No medication was prescribed, and the lab work was negative.

Jon continued to work throughout the week, although the numbness had progressed up his torso. By this time, I was worried. My work as an EMT had taught me to trust my gut, and my medical education was working against the portion of my brain that said, everything will be okay, the lab work was negative. In the back of my mind, I was concerned that this could be the beginning of Guillain-Barre. I pleaded with Jon to get a second opinion at our urgent care facility. The physician on-call agreed with me that the sinus infection needed to be addressed. I had mentioned my concerns, and he calmed my fears by prescribing a decongestant and a three-day course of steroids. We had the prescriptions filled immediately, and by the next morning, the numbness had improved. He insisted to go to work against my better judgment, and after checking in with him later that day, I was shocked to learn that Jon had taken the entire three-day course of steroids that day. It seemed that Jon was "out-of-it." The logical Jon seemed to disappear and a spaced-out impostor had replaced him. The next day we celebrated his birthday and the numbness had returned, and now his hands were affected. Jon's demeanor had completely changed. He confessed that he was now in pain, and concerned that something was wrong.

One day after his 35th birthday, February 18, 2002, our lives were changed forever. He had agreed to take the day off of work. The numbness had increased, and his hands were curled over in pain. I was terrified when he was unable to eat his lunch, because his hands would not cooperate. I fed him that afternoon, and my fear of Guillain-Barre had returned. I went to work that evening, after Jon insisting that he was feeling okay. Shortly into my shift, I called Jon at home. His voice was filled with fear, the numbness was worse, and a band sensation had set in at his chest, and he complained that it was difficult to breathe. I called my supervisor, asked permission to shut the gym down, and raced home. I called Jon's mother and asked her to meet me at the house to convince Jon that he must go to the emergency room. He agreed, and we went to the hospital in our neighborhood. I informed the triage nurse of my concern of Guillain-Barre, and after a short conversation with Jon during his work-up, she agreed with me. Jon was now having difficulty breathing, and was placed as priority one patient in the emergency room.

After an introduction with the on-call physician, he listened to the details of Jon's past two weeks. He disagreed with my diagnosis of Guillain-Barre, and reminded me that although I had a higher than average knowledge of medical conditions, I was not a doctor. He was working Jon up as a chest pain patient, and did not seem concerned with the numbness and pain. Jon began the many tests for cardiac conditions. He was given Nitroglycerin for the band sensation in his chest, and as you could probably guess, there was no relief. Now, the emergency room had a new problem. Jon's blood pressure had dropped to a dangerous level due to the Nitroglycerin. The on-call emergency room physician was confused after all of the cardiac tests were negative, and the band sensation around his chest persisted. We were informed that Jon was going to spend the night as they continued more tests.

The next morning, Jon continued with more cardiac tests. I was pleading with the emergency room doctor for a neurological consult. He gave in later that day after all of the cardiac tests returned with a negative result. Jon was admitted to the cardiac intensive care unit, and we met with the assigned internal medicine physician on-call. He carefully listened to Jon's story, and my concerns of Guillain-Barre. He agreed with me, and now Jon was almost completely immobile. His legs were completely numb, but he was still able to walk, although his gait resembled Frankenstein. The band sensation around his chest had increased, but the nursing staff was able to keep Jon breathing comfortably with painkillers and muscle relaxants. Jon was unable to use his hands, as they were curled

over with pain. He had no reflexes from his elbows down. The on-call neurologist was brought in.

Jon began the several tests the neurologist ordered. Soon, we had a preliminary result of a brain and spine MRI. There was a shadow at C2. The internal medicine physician sat me down to discuss the results. The news was not good. The radiologist had read the report as possible neoplastic tumor at C2. They were calling in a neurosurgeon for a second opinion and continued with more tests. I met with the neurosurgeon later that day. He and the neurologist had consulted with each other, and agreed that this was not GuillainBarre, but possibly MS or a tumor around the spinal cord. They were going to continue more advanced tests, and informed me that Jon's condition was worsening. They were faced with putting Jon on the ventilator that evening if his breathing continued to grow labored. I was told by the neurosurgeon if we had a family priest or rabbi, I should call him or her now. They were also going to try a course of steroids because Jon seemed to respond to this medication after the urgent care visit, but I was told that if this was a tumor, Jon would not respond.

It seemed as if the neurosurgeon, the neurologist, and the internal medicine physician were completely confused. Jon's symptoms did not fit into any diagnosis that they were familiar with. The neurosurgeon was concerned with the shadow on the MRI, and informed me that although he was the only gamma-knife surgeon in our state, he would not perform a biopsy due to the position of C2. My mother called our priest and he met me with our friends and family around Jon's intensive care bed. Our priest performed the Annointment of the Sick. We all received Communion and told Jon how much we loved and cared about him. We tried not to frighten Jon, but knew that we could be saying our last good-byes. Our priest and friends left and the nursing staff brought in the ventilator to Jon's room to save time in case of a breathing emergency. Jon's mother and I began the night watch over Jon fearing the worst.

The next morning, Jon had improved dramatically. The numbness persisted, but the band sensation had left his chest. His breathing was no longer labored. He was alert, and for the first time in about a week and half, he was no longer "out-of-it." Jon was moved out of the cardiac intensive care unit to a medical floor. They continued with testing, mainly lumbar puncture, and increased the dosage of steroids. Jon continued to improve. His reflexes had returned in his arms, and the mobility of his hands increased, especially after a course of steroids. We were told that the lumbar puncture was negative for protein, but the hospital was sending the test to a separate out-of-state laboratory for a second opinion. We were given the option of home health care, which the doctors encouraged. We agreed that this was best for our family, as we have two children that were unable to see their father during this ordeal. Jon was anxious to get home. We left the hospital not knowing Jon's diagnosis. The neurologist and neurosurgeon were baffled, but decided that it was either a tumor or MS. They informed Jon to starting thinking of a new line of work.

We soon had a hospital setting in our home along with two wonderful nurses. Jon was able to be with his daughters, and being home created a sense of well being. Jon continued his course of steroids and improved daily. We said goodbye to the nurses a week and half later. Jon and I had decided not to continue his care with the hospital neurologist, but had a follow-up visit with the neurosurgeon in his office.

The second laboratory test results were in from the lumbar puncture at the neurosurgeon's office. No protein present. Once again, the doctor was baffled at the results, but encouraged us to see another neurologist for a second opinion. We soon met with the second neurologist. He reviewed all of Jon's tests and hospital notes. We finally were given a diagnosis. Acute Transverse Myelitis. Jon continued with more testing in the neurologist's office to rule out a first episode of MS. The tests were negative. ATM was confirmed. We were given the facts of ATM, and were finally able to make some sense of what Jon had been through.

Jon continued to improve although the neurologist had informed us that Jon suffered a demylenation in both of his forearms and fingers. We were told that the next three months would be critical in Jon's recovery, if he was lucky enough to experience it. The lower body numbness was gone, but the numbness and pain persisted in his hands. Jon was prescribed painkillers and continued with outpatient spine and brain MRI's to watch the inflammation at C2.

The next month, the numbness only persisted at the tips of his fingers. The pain in his hands also improved, although his energy level was low. He was able to return to light duty at work. The MRI's confirmed Jon's improvement, the inflammation had decreased. Jon was encouraged to receive physical therapy for his hands. Jon agreed, but did not attend. The neurologist gave Jon exercises for his hands that he could do on his own, and urged him to slowly return to his previous exercise habits.

Slowly Jon's energy levels returned, and the numbness and pain in his hands significantly improved. If he does too much, the pain returns. If Jon is sick, the symptoms return, numbness and pain in his hands. Luckily Jon hasn't been sick often. The last MRI shows no inflammation at C2.

We have been extremely blessed and lucky that Jon's TM has improved. I understand now that it was the timing of the steroids at the hospital although the neurologist and neurosurgeon had never mentioned TM to us aloud, or in their hospital notes. I truly believe that there was a higher power watching over Jon at the time, as he was receiving physical and spiritual care at a Catholic hospital. It was a trying time for our faith, but we both had an overwhehning feeling that it was going to be okay.

Jon has been able to return to his beloved golf game and teaching with no lingering problems. He has good days and bad days. I'm sure that you know all about this!

We are still learning about TM and appreciate all the information your organization has provided us. Jon's neurologist and I are encouraging him to attend physical therapy. The literature you provided also is nudging Jon in this direction. We take each day at a time. We spend as much time as possible with our friends and family and learned how to stop and smell the roses. I don't know why this has happened to our family, but know in my heart that all things happen for a reason.

Wishing you health and happiness this New Year.
Jon and Tammy Spatz

Diane C. Vecchione
Garden Grove CA

July 8, 2001

We had just completed our long anticipated trip to the Grand Canyon and were on our way back to Las Vegas with our friends, Barbara and Irene. We had stopped at the Casino at the state-line for a potty break and were waiting for Barb to bring the car up to the front door. I was waiting with Irene and Jerry when all of a sudden my left side went numb; from my waist to my foot. I almost lost my balance and grabbed onto Jerry's arm. I thought I had pinched a nerve or something like that in my back. We all got back in the car for the last hour and a half ride to Vegas. My leg was still numb but kind of tingly - like it fell asleep - a pins and needles sensation. I tried to move around into different positions in the car and rubbed my leg and even dragged the ice chest up to put my foot up on it. But my whole leg was still numb from the waist to my toes.

When we reached the house, I had to hold onto the car and Jerry to get inside. I felt like I couldn't control my leg and I was really off-balance. I laid down on the floor for about a half hour but it didn't seem to help. We were taking Irene to the ER, because she had not been feeling well on the trip and we were worried about her heart. So, off we went to the emergency room. It was about noon and my leg was still not "waking up."

We sat in the waiting room at the ER while they took Irene in. I put my left leg up on the coffee table to see if that would help. After about a half-hour, my right foot went numb! I really started to get worried. I tried to stand up to check in and couldn't put any weight on my left leg. It was like it wasn't there! I had no feeling in it at all. They put me in a wheelchair and checked me in and took my medical history. I told them about my asthma, my breast cancer surgery, my hysterectomy and the drugs I was taking for my asthma. The ER doctor thought I was having a stroke or aneurysm, so they ordered a CAT scan of my head and stomach. This all took a couple of hours. They both came back negative. At about 6 pm, the doctor ordered a spinal MRI. As it was after-hours, we had to wait for a tech to come in. While we were waiting, the ER doctor started me on an IV of Decadron. He said it would hopefully help to stop the inflammation or whatever was happening. By now my left leg was totally "dead;" it felt really heavy and I couldn't move it at all. The numbness in my right leg was moving up to my hip. Jerry said that about this time the ER doctor was looking things up in medical books and then he knew that something serious must be going on with my body.

After having the MRI about 10 pm, I was admitted to the hospital and was told the neurosurgeon would be looking at the MRI in the morning and that maybe he would have to do surgery! The tech thought they were looking for a crushed disk, but he really couldn't tell me anything more.

July 9, 2001

The neurosurgeon examined me in the morning and said there were no pinched nerves and everything looked normal in the MRI. He saw no need for surgery and would refer me to a neurologist. My left leg was involuntarily "jumping" all through the night. I can't make it move at all, but it "kicks" all by itself.

The neurologist came in later that morning and I had to explain all over again what had happened to me. He checked my legs for sensations with a paper-clip. He went up and down each leg poking me with the open end to see if I could feel anything. Both legs were numb and I couldn't feel anything at all. Then he pulled me up to a sitting position with my legs hanging off the bed and checked my reflexes. My reflexes were OK. He ordered a brain MRI. He thought I might have an infection in my spinal column from either Guillan Barre or MS, or an unusual infection of the spine, or a tumor pressing on the brain stem! Some choices! I had't been sick in ages - how come this all of a sudden?

July 10, 2001

The ER doctor and neurologist told me that the brain MRI was clear. They ordered a spinal tap. They then ruled out a stroke. The neurologist did not think it was Guillan Barre. Then they were going to check the blood vessels to my spine to be sure none were broken or that a clot had not formed in them.

July 11, 2001

All three doctors ordered tests and the lab tech came in throughout the day to take more than fifteen tubes of blood. The neurologist now told me that he saw a lesion in the cervical area from the MRI and he suspected MS. He was now going to order a lumbar puncture with MS panel; which they did later that afternoon. The Kaiser liaison lady came in and said they may have to fly us home to Orange County! Boy, I must have been really sick for Kaiser to be even thinking of doing that. The night nurse told me that my chart said 'suspected transverse myelitis'?

July 12, 2001

I called my daughter who is a pediatric nurse and she said that she was going to try to find some information about Transverse Myelitis. The neurologist came in during the evening and said that I have MS and that he wanted to start a five-day course of high-dose I-V steroids immediately! I told him I wanted to talk it over with my husband and family first then with the other two doctors. And I asked about the results of the spinal tap. He blew up. Who did I think I was questioning him; he's the doctor and he told me he knew from the very beginning that I had MS and he didn't need the test results to tell him that! But I said I refused to start any treatment tonight until I had at least discussed it with the other doctors and my family. He walked out and I called my husband to come back to the hospital. I then called my daughter and asked her opinion and she wanted to know when was Kaiser sending me back to California; and maybe if it was in a day or two I could just wait till I got back home to start the treatments.

My husband talked to one of doctors who also said that he didn't like the idea of us rushing into treatments and then he asked for another doctor to see me for a second opinion. The neurologist really got mad and walked out again. Then we talked to the ER doctor who said that he would get another neurologist to come see me in the morning for a second opinion.

I didn't understand how this one neurologist could be so sure of MS when not all of the test results were back. What happened to his diagnosis of Transverse Myelitis? It just seemed that everything was happening too fast for me to comprehend and I didn't want to rush into any treatment that I really didn't need. The ER doctor said that he was going to recommend that Kaiser fly us home; it would be really hard for me to have to be sitting or trying to lay down in a car for a five to six hour drive back to Orange County. I was still receiving shots of the Decadron every six hours or so. The nurses even said that it was good that I was getting some kind of steroid into my system.

July 13, 2001

Kaiser decided to fly me back to Orange County the next day. The ER doctor decided to let the doctors back home decide what should be done. My other children drove to Vegas to check on me and their Dad. They had some information on Transverse Myelitis from the internet. It didn't sound like anything I would want to have. The information he brought on MS said that it usually starts when you are in your 20's to 30's. I never thought I'd be glad to be too old for something, but at 58, I guess that made it a little less likely that I had MS.

The PT came in and stretched my legs and moved both of them around to try and keep them loose. They gave me a booklet of exercises to do; that was not going to be easy as I could only move my right leg a little and the left leg not at all, except for the jumping.

July 14, 2001

I took the 50 minute flight back to Orange County in a Lear Jet with my husband, the flight nurse and an EMT. It was an hour ride in an ambulance from the airport to Kaiser Hospital in Orange County.

A neurology intern took a detailed history and did a thorough exam. I had more movement in my right leg; she said that was a good sign. My left leg jumped toward the end of her examination and she said that she was

shocked at the force of movement in my leg. She ordered another MRI of the cervical and thoracic areas, as I was numb at the T- 10 level and down. She thought that if the lesions were MS related, I should have upper body problems, but I was okay from the waist up. She thought it might be a "spinal stroke" from a break of a blood vessel in my spine; but usually both legs are not involved.

They took another upper body and cervical MRI. The doctor also took me off Decadron shots; she wanted to see what, if anything, would happen. She ordered B-12 shots. She said they may do the I-V steroids, but only if the test results show a need. She ordered heparin shots for blood clots in my legs as I was not able to get out of bed.

July 15, 2001

I had a bad night; I couldn't get comfortable. My legs felt weird like they are swelling from the inside out! And my leg bones (inside) felt very cold; but the skin on the outside was warm to the touch; it is a very weird sensation. My left leg was still jumping; it goes on for hours and then it just stops. There is also some feeling of "pressure" in the center of my back; not really pain, just an uncomfortable feeling. My right leg seemed to be moving a little more, which was great.

When the intern came in to check me, my left big toe moved! My right leg had been moving more every day, but this was the first time anything on my left side moved. The neurologist came in with a large group of interns. She ordered physical therapy to come in and get me out of bed. Hurrah! I hadn't sat up in over a week.

I also got the best medicine; my grandkids came to visit! I told the doctor I needed for her to get me out of bed so that I could play with them again. Casey just jumped right up on the bed with me. I thought all the tubes and stuff would bother her, but she didn't even notice; she just wanted to give me a hug and kiss. And little brother, Daniel, wanted out of his stroller so Grandma could give him a kiss and hug, too! The PT came back and sat me up again for an hour this time; I never knew sitting was so strenuous. I was exhausted!

July 16, 2001

The PT came and got me out of bed. I sat up in the chair and ate my lunch. It feels great to be up and out of that bed, but also very tiring. He said I was not to get out of bed alone, to get help from PT. I was to call them whenever I felt like getting up or getting back into bed.

The neurologist came and checked me over again, She still thinks it was a spinal stroke incident; they are waiting for the spinal tap results. She said as long as I was continuing to improve a little bit more every day on my own, she would not do the steroid treatments. I was able to "push" back a little bit with my left leg. I was also able to feel the coldness more intensely between my shin and hip. When I asked her about my chances for recovery, she said that I had good incentive to work at the physical therapy and should get as far as I was willing to work.

July 17, 2001

I had a better night's sleep. My legs feel so "cold" inside. The nurse puts socks on me and even a heated blanket and in a few minutes my feet were cold again. My left leg jumped for about an hour without stopping. My right leg seems to be waking up; it is more tingly and I can move it a lot more. I did some of the heel dragging exercises the PT showed me and it seemed to help.
The intern came in and checked me over again. I had more sensations in my left foot, but I still cannot tell which direction they are pointing my big toe. Things are improving everywhere. It's got to be from all the prayers and good wishes and phone calls I have been getting. All of our families and friends and co-workers have been just wonderful, sending cards and calling and putting me on prayer lists. It's so overwhelming, I just lay here and cry. I need to know just what this is and how to make it better and get to work on getting out of this bed and home again.

The intern told me that the neurologist and the other consulting doctors have been discussing my case and have decided to move me to a rehab center as they feel there is nothing else that can be done for me in the hospital. I need more PT than they can provide. They want me in a rehab facility with physiatrists.

The doctor ordered a measurement of urine output. I have been going on the bed pan, but cannot feel that I am going; I can hear the release into the bedpan. They need to know how much I'm emptying out my bladder. They will catheterize me after every output to see how much is left. I have been going 350 to 400 ml at a time. I have still not had a bowel movement!

During the night, I try to move my right leg as much as possible. I move my left foot up and down and if I really concentrate, I can move my left knee up just a teeny tiny bit! Hurrah, something is working. I'm only sleeping about two hours at a time.

July 18, 2001

I have still not had a bowel movement; I feel like I could explode. They ordered milk of magnesia and a

suppository. The doctor from the rehab center came in to check me over; he thinks I'm a good candidate for their program and they are going to set up the transfer. They think I'll need about three weeks of therapy at the rehab center. They will work on my bladder and bowel function and, of course, getting me back on my feet. The plan is to then get me a couple of months of outpatient therapy there and finally at the Kaiser facility.

That night I was moved in an ambulance to the rehab center. I no longer have a room to myself; there are three beds in each room and people are everywhere. I am right by the door, the middle bed is empty, and the lady in the last bed has about ten people walking up and down and back and forth. And here I am in my little hospital johnnie! I don't know if I'm going to like it here. I like my personal business to be mine; not sharing it with everyone in the room and in the hall.

A nurse came in and began asking me some of the weirdest questions: did I think I was abused, either at home or at the other hospital; did I have any bruises or marks on my body; have I fallen since I've been in the hospital? What kind of place is this? I began to cry. I had to repeat the whole story again and added in all of last weeks happenings at the regular hospital. I hadn't urinated all afternoon and there was still no bowel movement!

That evening, they moved the woman to a different room. I was going to have more privacy. I was going to start potting training tomorrow. I finally had a bowel movement, involuntarily, in the middle of the night. G-d bless these nurses. I seem to be crying all the time. This is just so humiliating, to be a grown person and not be able to control my body. The night nurse said to get a good

Kathy Kerby
Grantsville WV

night's sleep as I would be having lots of evaluation testing in the morning.
I want to thank you and all of the other TMA officers for all of the hard work and time you devote to this cause. **Everything** I know about Transverse Myelitis came from your information on the internet.

I was stricken with TM while on vacation in Florida in October 1998 at the age of 46. I was taken to Celebration Hospital in Kissimmee. I did not know what was happening to me, and neither did the ER physician. I was totally misdiagnosed as having an inflammation in the lining of my lungs. Even though I could not walk when I left the ER twelve hours later, I thought it was a result of too much muscle relaxing medication.

After returning to my home in West Virginia, I visited my family doctor. She did not have any idea what was wrong and sent me to a neurologist. He thought I had MS. After the usual tests (the MRI and the spinal tap), MS was ruled out, but no one seemed to know what was wrong.

I began to suspect that the ER physician or nurse from the Florida hospital had given me too much muscle relaxer or had damaged a nerve when injecting it. I was referred to a doctor who specializes in pain and rehabilitation therapy in Parkersburg WV. As soon as this doctor examined me, he said, "you have Transverse Myelitis," but didn't give me much information about it. He wanted to do more tests to determine the amount of nerve damage. I declined, but I did take the series of steroids which did not help. It was probably too late, since three months had now passed.

It was a shame that it took three months for me to find out what was wrong, but I am thankful that at least I finally did learn the truth. I raced home and searched 'Transverse Myelitis' on the internet. What a surprise I was in for as I saw all of my symptoms described to a 'T.' I spent a lot of hours on the internet; I had a lot of learning to do. Thank, G-d, for Deanne Gilmur for founding the TMA, and for you and others who serve to make this information available to us. I always look forward to the newsletters.

I did not make a full recovery from TM, but I did make a partial recovery, for which I am very thankful. When I was stricken, a minister from our church came and prayed for me. Also, my husband began immediately pouring large doses of vitamins and minerals into my system to help my immune system (even though he did not know what was actually wrong with me). He figured my immune system needed help.

Warmest Regards,

Patricia A. Crockett
New Mexico

Kathy Kerby
kathy_kerby@yahoo.com

The fingers on my left hand tingled, went numb; then the hand, then the right fingers, hand, and both arms. I could no longer pass baby shower gifts along to the next person. I was in normal health going to the shower, but in two hours, my arms, hands and fingers were numb. This was September 9, 2001.

Gerry, my husband, walked me to the car, and we drove 200 miles home. An evening emergency call to our family

physician service resulted in a call back by the physician on call, who, after hearing the story, believed it was an allergic reaction to Benedryl. He didn't think he had to see me.

The second day I went to the local hospital emergency room. Without a clue about the numbness, the hospital sent me home. I tried that day to call my local physician without success.

On the third day, I did not reach my local physician, but contacted her nurse who said, "if I were you, I would go immediately to Albuquerque. I did, and checked in at the University of New Mexico Medical Center. I took this 200-mile drive on the day the planes crashed into the World Trade Towers. We thought we were experiencing a bit of our own terrorism, as well. Upon arrival, I could not walk from the car to the emergency room. Once in the emergency room, the doctor did a spinal tap and a CAT Scan. The doctors were not sure about what was going on. I was admitted to the neurology wing for more tests.

On the fourth day, the neurologists found inflammation in the C 4 through 7 vertebrae area of the neck and they found an increase of white cells from the spinal tap. There was no impact on the spine, so the inflammation was a mystery. After analysis of a urine sample, I was given antibiotics for a yeast infection.

The fifth day began with a MRI and further bed rest. I walked the hallway, but was very weak. My fingers and hands were weak, but I was able to feed myself.

On the sixth day, there was more bed rest and walking the hallways. I recall my fingers could not work the TV switches on the bed rail.

On the seventh day, I was sent home. I was given a diagnosis that the discs in the C 4 to 7 area were swollen, and in time, I would either get better or worse. That evening at home, I walked from one end of the house to the other, with relative normalcy, but I was weak.

The eighth and ninth days were relatively normal days, doing normal activities, but I remained weak.

On the tenth day, I got up to go to the bathroom at 2:00 AM, and I felt hot and sticky, and a little light headed. I asked Gerry to fix me a cold cloth, and I couldn't hold it in my hands. My legs were very weak, but with assistance from my husband, I walked back to bed. I stayed in bed with numb hands, arms, and legs. When I had to try to get to the bathroom at about 2:00 PM, my legs wouldn't support me and I melted to the floor like a snowman. The paramedics took me to the local hospital, where they didn't have the foggiest idea what to do with me. My local physician said she would arrange ambulance transportation to Albuquerque. I stayed the night at the local hospital.

On the eleventh day, my husband woke me at 7:00 AM. I was dead cold from my chest to my toes. My skin was physically dead cold. He massaged me to try to get warmth in my limbs. My blood pressure had fallen way, way down. It was then that I realized I was totally paralyzed from the neck down. Back to UNMMC where I was put into acute neurology ICU. They did another spinal tap, started a five-day 1000 mg intravenous drip, and monitored my heart pulse, which fell to thirteen one night. I took oxygen when I slept. It was at this time that I was given the diagnosis of Transverse Myelitis. Multiple Sclerosis was ruled out when the brain scan was normal for a lady of 53 years of age.

After the steroids, the doctors decided to do six sessions of plasma exchange. The clear portion of my blood was thrown out and replaced with the "super juice" as they affectionately called it. It was supposed to restart the immune system with all fresh juice, while the tainted portion, which may have been doing the wrong thing, was eliminated. All of this time, I felt, and still feel, hot and cold patches in my arms, legs and throughout the torso. I was quadriplegic for two months, and now, after thirteen months, I can walk. I go to the supermarket. I can raise my arms. I can drive. I am still weak, cautious and deliberate with all movements. And I remain blessed with a hand with fingers resembling a back scratcher or claw.

The key to the doctor's diagnosis was that the left arm and the right leg were the slightly stronger limbs, thus "Transverse," and "Myelitis," spinal cord inflammation.

I take no medicines, though I tried Nortriptylin for relief of the hot and cold sensations. The side-effects of dizzyness, and a general rummy-dummy feeling, made it not worth while for me. Over all, I have been pain free. An occasional sensation of "The Ring" will cause some discomfort, but that pain below the rib cage doesn't last too long. It is not the pain, it is the numbness, weakness, and disfigured fingers that make life a new challenge. And, heck, I'm one of the lucky ones who have had at least an 85% recovery. Thank You, Lord!!! There is even a funny side to the whole thing. When I point to something, people don't know whether to go in the direction of my finger or go in the direction of my arm. One of my very first therapy sessions was to reach out, grasp a potato chip, and get it to my mouth.

Inexplicably, I remained calm throughout all that went on. I was

helped through this time of trials by an uplifting attitude, and a fighting spirit that wouldn't give in to the negative side.

At UNMMC, the doctors put pulsing air bag leggings on my legs to help against getting blood clots. I believe these leggings are the reason why my legs improved better than my arms and hands. If only I could have had them on my arms, as well, during that motionless period. Perhaps the forced blood circulation would have saved more of my arm and finger muscle mass. But we didn't know about that at the time.

Thank, G-d, I went to a University Medical Center where the doctors are use to looking in books and searching the Internet for solutions to new and exotic 'syndromes;' five weeks at UNMMC, followed by five weeks at Roswell New Mexico Rehabilitation Center.

UNMMC, doctors and The Transverse Myelitis Association,
THANK YOU!!!

Patricia A. Crockett

Paula Cook
Medina TN

pgcrockett@aol.com

January 8, 2003

I was diagnosed with TM in February 1998. I am 60 years young; I was 56 years old at the time on my diagnosis. On February 8th, which was a Sunday, I got up and was feeling fine, I thought.... I walked down to the mailbox to get our Sunday paper about 8 AM. We live in a rural area and our house sets more than 200 feet from the road. Returning to the house (our driveway has a good incline), I felt short of breath (I walk two or three times a day) and felt kind of weird. I went
into our den and sat down on the sofa. At that time, I had two stabbing pains in my back (level T5). I sat there for a few minutes to let this feeling kind of pass.

I decided to get up and fix breakfast, as my husband was having his coffee. I told him how strange I felt and the more I moved, I noticed my left leg was sort of dragging. I began to have spasms in my left leg. I got through breakfast. My husband was to meet our son that morning , as they had planned an outing. I told him that I would be fine and I didn't want him to miss his trip, as they don't get to do things together often because of their work schedules. It had been almost two hours since this all started with me. The leg spasms had not stopped and they are getting stronger. So, I went to lie down thinking, if I get off my legs and feet that it might stop.

Our youngest daughter, who lives close to us, called when her dad told her that I was having these
spasms. She came over right away. She wanted to take me to the ER. I agreed to go and told my husband to go on and meet our son as planned. I was able to walk to the car, but got sick to my stomach driving to the highway, which is about two miles from our house. My leg would not stop the spasms.

We got to the ER at about 11 AM. I had to have a wheelchair to get into the ER as I could not stand up properly. As I was waiting to see the doctor, sitting there in the wheelchair, my left leg was getting numb, starting at my foot. The ER doctor, after performing a very cursory exam, wanted to send me home. He said that I just had a cramp in my leg. He told me to see my family doctor the next day. I knew I wasn't having a stroke, as I had had a stroke in 1991. The stroke left me with left sided weakness, but I was able to walk okay. My daughter said that we were not leaving until we found out what was going on with me. So, the nurse called my family practice clinic, and the doctor on call admitted me.

By the time they got me to a room, I was not able to move from my breast down. It took three people to get me on the bed. By the end of the week, I had many tests done, blood work, EMG, CT, MRI and a spinal tap. The neurosurgeon said I didn't have any brain problems. The neurologist tagged me with TM and said that I had a lesion at T5. I lost bladder and bowel control. I was in the hospital for ten days. I was given the three day treatment of IV corticosteroids for two hours each day. I started having a little movement in my toes on my right foot. I was paralyzed from my breast down. I had good strength in my upper body.

The physiatrist sent me to the Rehab unit in the hospital, on February 19th. I started a strict daily regime of PT and OT. I had to learn how to use a transfer board and wheelchair. And my daily routine of PT and OT was quite vigorous. I was not in any pain. Everyone in this Rehab unit had to rise and be at breakfast at 7 AM to start our day. We had either 30 minutes of PT or OT and an hour for the other with a break in between. Lunch was at 12 PM. After lunch there were two more sessions of PT and OT. It was hard to get much information on TM from anyone.

My attitude was good, as I am a spiritual person and know that God has a plan for each of us. So, I was standing on His promises that I would be healed, and I would do all I could to help myself. I had to learn to self-cath, and also give myself shots in my stomach, a blood thinner. After four

weeks of Rehab, I was sent home on March 20th.
I could not stand alone, but I was getting some feeling back in my legs. I had home health and rehab three times a week. I was able to use a walker by the end of May. I was then sent to out-patient Rehab three times a week. By December, I was going twice a week. I was doing both upper and lower body strengthening using gym equipment, mat exercises, and an exercise bike. I worked out for two hours. By February 1999, I was walking some with a cane. Over the course of this year, I had several bouts with a horrible attack of burping and thoracic spasms, which no one could identify for me. They lasted for as long as ten hours without stopping. I would take everything I could to stop the pain and agony, but nothing helped. I would have one of these attacks about every five to six weeks from the beginning of my intense workouts. No one would associate these attacks with my workouts. I would tell the therapists and my doctors, and they had no answers. I finally decided after having several of these bad attacks that I would ask my doctor for a script for a pain pill so I would have it when I had one. This was after having my longest and worst attack which lasted from 10 PM to 3 PM the next day. I have not had an attack in about six months.

By February 1999, I thought I was doing really good. But then I started having these bad spasms in my leg again. I was afraid I would become paralyzed. I saw my neurologist and he sent me to have an MRI and he started the steroid treatment again for three days. When they read my MRI, I had a disk herniated at T5-T6 and T6-T7, with compression on the cord. I wondered if this was caused by physical therapy. I needed surgery, and was sent to Memphis to see a surgeon. He did a myelogram and thoracic CT scan. He also looked at my MRI's and compared them, as they were done at different hospitals. The one from February 1998 showed a lesion; the one from 1999 showed the herniated disk.

I had surgery to get the pressure off my cord, so that I would not be paralyzed or wheelchair bound. But I may have permanent damage since it had been a year with compression on my cord. I had to have a thoracotomy by a cardiac surgeon to get to my herniated disk, where the neurosurgeon did the disksectomy and spinal fusion, using part of my 5th rib, bone from the Florida bone bank, and pins and dowels. I was in surgery for over 12 hours.

This was April 1999. I have had more pain and have been more uncomfortable since I had the surgery. But I am thankful that I am not wheelchair bound. I can use my walker or cane in the house. I have become weaker in my legs this past year and also have found that I have more degeneration in my spine.
I have much to be thankful for. I try not to take anything for pain; I have enough daily meds to take.

I do thank G-d everyday for the good as well as the bad. I made up my mind that I would not let my bladder and bowel problems keep me a prisoner at home. I have never been in fear of what may happen. We can only take one day at a time and make it the best we can. I have had several bowel accidents in public places, and needed help to get cleaned up. I was usually with one of my daughters, and once was at rehab. I now have bladder incontinence, and only have to do self cath twice a day. I try to be careful not to get bladder infections. I use my wheelchair when I go out since I can only walk with my walker short distances. I do get depressed occasionally, but won't let it take a grip for long; maybe a couple of hours. I will not let it control me. I am positive and try not to dwell on the things I can no longer do.

Be good to yourself, love yourself and try to find the peace and joy that you desire in your life. Share your memories good and bad, with others. Laugh a lot and Cry some. Don't dwell on yesterday and be wondering about tomorrow. If we can get through today, that will be enough.

Thanks to Deanne Gilmur for sending me the information on TM and the TM Association. I spoke with Deanne in December 1998.

Thanks to Sandy Siegel for the unconditional love and support he has given to all of us; in trying to let us know how many have this challenging disease. And keeping us informed with the Newsletters. And thanks to the others who are on the staff. May you all be richly blessed for all your efforts. Prayers to all of you. Don't forget to call on your Angels to help you and protect you and your loved ones, as they need to be loved back for all the care they give to us. Smile, Jesus loves you and so do I.

Paula Cook

cook633@aol.com

Family caregivers play a vital, but often unrecognized, role in caring for chronically ill, disabled or aged loved ones. The goal of NFC Month is to build caregiver self-esteem, expand caregiver self-awareness, and teach

caregivers to become their own advocates.
NFC Month is sponsored by the National Family Caregivers Association (NFCA), the nation's leading family caregiver constituency organization. The TMA supports this effort to Share the Caring and acknowledges NFC Month as an opportunity to provide community-based activities in support of family caregivers.

For information on NFC Month and the National Family Caregivers Story Project, please contact NFCA.

National Family Caregivers Association
10400 Connecticut Avenue
Kensington, MD 20895
(800) 896-3650
www.nfcacares.org

The Transverse Myelitis Association is a proud member of the National Family Caregivers Association. Our sponsorship of NFC Month is our way of recognizing that our community has the most outstanding and dedicated caregivers!

Strategic Planning Meeting in Seattle

The Transverse Myelitis Association held its first strategic planning meeting on Thursday, July 17 through Saturday, July 19, 2003 in Seattle, Washington. This was the first time in the history of the Association that the TMA board, the TMA Medical Advisory Board, physicians from the TM Consortium and support group leaders from across the country gathered to discuss and plan the future activities and goals surrounding the support, education and information, medical care, research and advocacy that we offer to the TM community. It was a watershed event for the TMA, for the Johns Hopkins TM Center and for the TM consortium. We believe that the results of this three day session will create far reaching and very significant benefits for the TM community. As the TMA has limited resources to carry out the many services we offer to our members, it is difficult for the Association to fund an activity such as this planning meeting. The Association would like to thank all of the Medical Advisory Board and consortium physicians, board members, support group leaders and TMA members who funded their own travel and hotel costs from their personal resources. We are so grateful for your generosity! The Association would also like to thank the Chafetz-Hampton and the Lazzeri families for holding fundraisers that covered the costs of this important event. Finally, we would like to thank UROMED for the generous grant which helped us with some of the costs of the meeting. This meeting was also made possible by the hard work of Paula Lazzeri who devoted much time and effort in making all of the meeting arrangements. Thank you, Paula! We would also like to thank Debbie Capen for all of the work she put into planning and organizing the meeting, and for the hours of transcribing she is engaged in to prepare the formal report of this meeting. And thanks to Paula's family for transporting the crowd for the wonderful pizza party on Wednesday night.

Dr. Douglas Kerr and Dr. Adam Kaplin made presentations regarding the most recent research on TM. There were also very important discussions with Dr. Nancy Cutter and Dr. Tim Vollmer from the Barrows Neurological Institute involving future plans for collaborative research with the JHTMC and other physicians in the TM Consortium.

In addition to the very exciting presentations and discussions about research, there were extensive discussions about the expansion and development of support groups around the country and around the world. Other topics covered during the meeting included, the development of a strategic plan for the consortium of medical centers involved in the treatment of TM patients; planning the 2004 Symposium in Baltimore, development of an awareness and education effort for emergency room physicians, general practitioners and pediatricians; the development of a formal referral list of neurologists, physiatrists and urologists who can care for people who have the neuroimmunologic conditions; and the establishment of a children's recreation camp program

One of the most important discussions we engaged in concerned the fundraising efforts of the TMA. After learning about the current research, as well as the collaborative projects that will be conducted this year, there was tremendous enthusiasm for raising the money required to attract more physicians and scientists into the study of TM, recurrent TM, ADEM and Devics. As there is no NIH funding of this research, it became even more obvious to the attendees that we bear a critical obligation to raise the money to keep this research going and to encourage new and long-term projects. In addition to the commitment to raising research funds, the planning discussions increased the urgency of fundraising efforts for the 2004 Symposium. Stephen Miller was asked to head up a committee which will focus on foundation grants and other fundraising efforts.

A symposium planning committee was established which is headed by Dr. Kerr and is composed of physicians from the medical advisory board and TM consortium, as well as TMA members. Dr. Kerr is going to take the lead in developing the program agenda for the symposium.

Meeting for three days to discuss such

important issues for our Association was exhilarating, energizing and exhausting. The discussions and the results of the meeting made it apparent to all of us that we need to take the opportunity to do this planning much more often than once a decade. These meetings are difficult to arrange as we are asking people to donate their time and their personal resources in order to participate, but the fact that we had more than 30 people attend should provide our members with some sense of the commitment and dedication that is reflected in our board, medical advisory board, our support group leaders and by our general membership. It was a very humbling experience for me.

To fully appreciate the significance of this event, I need to provide you with some history. The TMA Board of Directors meets once a year to formally conduct business. Our administrative reality is that the officers have virtual and long-distance conversations to conduct the TMA's business every single day. We allow Paula to take a vacation every once in a while, but we do ask her for the email addresses of the family members she is going to be visiting. The Board has a formal meeting once a year to review and adopt minutes, to review and discuss our financial status, and to discuss business that is most effectively handled in a face-to-face meeting. As we pay our own travel expenses, we have linked these meetings to other occasions which bring us together. We have had board meetings the day or night before symposia and workshops, and we even held a board meeting the night before Pauline's and my wedding.

There is no one who puts in more hours or devotes more energy and creativity to the TMA than Jim Lubin. Jim is a tireless advocate for the TM community and is the person most responsible for making our information and support as widely available to the world as it is – and I can attest to just how widely available it is from the phone calls and emails I receive daily from around the world. And yet, while Jim is ***virtually*** everywhere, he is rarely able to leave his home due to his dependence on the ventilator. Jim handles his life circumstances with grace, with dignity, with courage and with a very healthy dose of fatalism. I cry about Jim's situation – a lot. I'm trying to be more courageous, Jim. My crying is a bit irritating for Jim.

Jim is the geek's geek. Jim is one with his technology. It is a world that he loves, and thank, G-d, it is a world that has connected him to the rest of the world that we all live in to various degrees. So, Jim is amazingly productive, he is happy, and he is one of the most emotionally healthy people I know. But Jim still doesn't get out of his house. In fact, when Jim came to the first day of the meetings, that was the first time he had been out of his house in more than a year. And that last trip out of the house was to a doctor appointment.

Before the children's workshop last summer, I promised Jim that the next TMA Board meeting would be in Seattle so that he would be able to participate. During the children's workshop a discussion I had with Dr. Kerr grew this board meeting into the strategic planning meeting.

The meeting was incredible. I was really gratified to have so many people attend and to get so much important work accomplished. But the most important aspect of this weekend for me was being able to spend three days in a room with Jim. I loved talking to him, laughing at his incredibly dry sense of humor, watching him eat and touching his hands. It was cosmic. It made me realize, once again, what a special gift the TMA has in Jim – and what a special blessing he is in my life. I'm not shy; I tell this to Jim all the time. He knows I love him. He knows how much he means to me. He knows that he is my hero. But I am way too sappy for Jim, so he doesn't pay much attention to me anymore when I get into my emotional mode. And he regularly delivers his witty remarks about my crying with his very dry sense of humor. Jim is a very funny guy.

At the end of the meetings, everyone took their turns talking to Jim and saying good-bye. I was not the only person overwhelmed with his presence at these meetings. I happened to be with Chitra while she was talking to Jim. And Chitra told Jim that he was her hero. In addition to being really smart and creative and organized and highly motivated, Chitra is a truly beautiful twenty-something. Jim really blushed. Jim was so touched by her words that I've decided that from now on, if I want for Jim to take me seriously, I'm going to hold a photograph of Chitra in front of my face while I'm talking to him.

You are so amazing, Jim. I didn't take a vote, but I know that I was not the only person at the meeting in Seattle who defined the best part of their trip as the time they had to spend with you. It was a great meeting. We have so much important work to do. I feel incredibly confident that we will get it done and we will get it done well – because we have Jim helping us with all of it.

Nancy and Alla, thank you for getting Jim to the meetings and thank you for taking such good care of Jim during the meetings. You are such good friends to Jim and Joe and Helena. You made a very special weekend possible for Jim and for all of us who were graced by his presence for those

The TMA Youth Advisory Board

three wonderful days.

Eve Hampton is initiating a Youth Advisory Board for The Transverse Myelitis Association. If you are a young adult or teen, please get in touch with Eve and she will get you involved. The purpose of the Youth Advisory Board will be to develop and carry out fundraising and awareness projects for the TMA, to help the TMA organize the children's recreation camp program, and to assure that the youth in our Association have their opinions fully represented in our activities and decisions.

Eve is a wonderful sixteen year old from Seattle, Washington. Eve has it all going for her; she is very bright, she is kind and gregarious, she is a great communicator and she is very athletic. Eve is also very charming and very pretty. The TMA is absolutely thrilled to have Eve involved and willing to take on this leadership position.

If you are a young person interested in becoming a member of the Youth Advisory Board, please get in touch with Eve. Jim will work with the YAB to set up your own bulletin board, list-serve or chat on our web site. You may be located hundreds or thousands of miles away from each other, but Jim can effectively facilitate your communications. Membership on the Youth Advisory Board is open to all of our young people from across the United States and from around the world. Please get involved in this important role in our Association. You can help to make a difference for yourselves and for each other.

If you are interested in becoming a member of the Youth Advisory Board, please send an email to Eve Hampton at: evehampton@hotmail.com; or you can call me (614)766-1806 and I will provide your name and contact information to Eve. Thank you for getting involved; you are the future of the TMA!

Disability Advocate for the TMA

Cossy Hough

The Transverse Myelitis Association would like to let members know about a new service available. I have agreed to take on the role of disability advocate for the TMA. In this role, I am available to give members information on how to apply for disability benefits, as well as provide information on how to qualify for benefits as quickly as possible. The disability determination process can be overwhelming and sometimes some small tips are what you need to get things moving.

A little about myself; My name is Cossy Hough. I am a Licensed Master of Social Worker-Advanced Clinical Practitioner in Austin, Texas. I worked for several years as a medical social worker in a home health/hospice agency. My experience also includes working with clients with mental illnesses and in the family planning field. I currently work with a Medicaid program for children and pregnant women at the Texas Department of Health. I was diagnosed with TM in January 2000. I am married and mom to two, wonderful pug dogs.

Information on Applying for Social Security Disability

You can find this and additional information on the TMA website. You can find basic information on how to apply for Social Security Disability at the Social Security Administration (SSA) website at **http://www.ssa.gov/disability.html**

You will need to call for an initial appointment at **1-(800) 772-1213.** Most of these initial appointments are telephone interviews. You can request an in-person interview, but this can take longer to set up. At this point it is important for you to start to gather together your paperwork. The social security website, identified above, has a good list of the documentation you should include.

You will be mailed an application to fill out. This application is long so please don't become discouraged. Once you have applied and sent in your paperwork, you will be assigned a disability determination worker in your area and the process begins.

Important Tips

The social security 1-800 number is least busy first thing in the morning. You should always expect some hold time, but the mornings may only be a few minutes while the afternoons can be much longer.

You will be asked to sign releases for the SSA to request your medical records. Sign the releases, but realize it will take a lot longer if your disability determination worker requests the records for you. Call your physician(s) offices and find out how to request your records yourself (or have a family member or friend help you). It may be a hassle to get all your records yourself, but it saves valuable time.

Once you have your medical records, make a couple of copies! You can send a copy in with your SSA application, but know that some of the records may be lost and you may have to resend them. Just be prepared for that and expect to have to resend some

or all of them to your disability determination worker.
Give detailed information on your application. Don't be afraid to write too much.

Ask SSA for the phone number to your area disability determination office or look it up in the phone book. Then, start calling the office after your application has been sent in to find out if your case has been assigned. Keep in touch with your disability determination worker. Make sure they have everything they need to process your case.

It is difficult, but not impossible, for other people to talk to SSA and disability determination workers on your behalf. Ask about the acceptance of written consent if you feel you will need help with the process from someone else.

The disability process can take a long time; oftentimes, up to a year or longer. Applications are often denied. **You need to appeal the denials**. Many cases are denied twice and get to the stage of having a hearing before they are approved.

Finally, and most important, get your Senator or Representative involved in your case. Don't wait to do this. Getting their involvement at the beginning of your case is most effective. Call and ask to speak with whomever their local office has assisting people in your area. They will most likely need a letter from you asking for their help and getting your consent for them to advocate on your behalf. Make sure to include information on how your disability is affecting you and how the time waiting for a decision on your disability application will impact you financially. A letter from your physician is also helpful at this time. A short letter from your physician explaining your condition and how it will impact you in the long term can help a lot.

If you need additional information or have questions, you can contact Cossy at **cossyh@yahoo.com** or by phone at (512) 420-0904. Weekends

TMA Children's and Family Network Directory

are the best time to reach me.

Mary Troup is continuing to collect information to organize the Children's and Family Network Directory. We know that there is a great need for this directory, because the TMA is contacted regularly by parents who are seeking support and networking opportunities with other families who have a child with TM. Mary has received a response to our request for this information that is very small as compared to the number of families we know are a part of our community. Please send Mary your information as soon as possible so that we can complete the directory.

The TMA will publish and mail the directory. In order to protect the children in the TM community, we will not mail a directory to anyone who does not have their own child listed in the directory. Your child should be eighteen years old or younger to be included in the directory.

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

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

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

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

Please also remember to send any changes in your information to Mary Troup as we will try to update the directory annually as we do with the general TMA Directory.

We are very appreciative for Mary's willingness to take on this important project.

ADEM, Devics, Recurrent TM: Networking and Support

There is currently no way for people in our membership to identify the members in the TMA who have ADEM, Devics or Recurrent TM. It is important that you are able to find each other to share information and support.

I am going to compile a list for each of these conditions, and then when I am contacted by a person who has either ADEM, Devics or Recurrent TM, I will offer them a copy of the list so that they can find others in our community who share their conditions and their experiences. If you would like to be included on this list and also if you would like to receive the names and the contact information of others, you may send me the following information:

Identity of your disorder: ADEM or Devics or Recurrent TM

Full Name
Street Address
City, State/Province
Country, Zip or Postal Code
Home and Work Phone and Fax: include country and city code if international
Email Address
Date of Birth (for age)
Age at Onset/Year of Onset

Please send the information by email to:
ssiegel@myelitis.org
or via the postal service to:

Sanford J. Siegel
The Transverse Myelitis Association
1787 Sutter Parkway
Powell OH 43065

I do not intend to publish this information. I will provide it to people when I am contacted by someone seeking this information. And I will provide the list of names and contact information only to those who provide me with their own information. I'm writing this article for Jim, because he's too busy doing the important work of the TMA to be spending time writing an article for the newsletter. As I have noted in the past, Jim is constantly on the hunt for new ways for all of us to be communicating with each other and sharing information. I know he takes breaks to eat and sleep, because I've seen him eating and sleeping. And he does watch a lot of movies. Otherwise, Jim's working. And his work has improved the quality of life for all of us in the TM community.

New and Improved TMA Message Forum

Jim Lubin and Sandy

Our Information Technology Director has discovered a new bulletin board system. The bulletin board software is produced, released and is copyrighted by phpBB Group. It is made available under the GNU General Public License. The system is easy to use, it looks great, and it has some really wonderful features. You can get to the bulletin board by clicking on the link ***Message Forums*** from the main page of our web site or by going to:

http://www.myelitis.net/phpBB2/

The system includes a very detailed and descriptive index of topics which explain how to use the bulletin board. The topics are listed under frequently asked questions or FAQs. There is a registration process which allows access to more sophisticated bulletin board features, including private messaging and emailing to fellow users. You can use the forum without registering, if all you are going to do is read and post messages.

Jim is the TMA Forum Administrator; he controls the bulletin board operation. Jim also serves as the moderator for most of the forums, although in the future, we are going to want other people to take responsibility for different topical sections of the bulletin board. Moderators are individuals (or groups of individuals) whose job it is to look after the running of the forums from day to day.

The message forum represents an incredible potential for facilitating communication and the sharing of information on a wide variety of subjects. Jim has established a really comprehensive index of topics for the TMA message forum. The topics reflect Jim's thorough understanding of the issues in our community, his desire to assist people in finding answers to their questions, as well as providing an outlet for their need to share their experiences.

Jim has set up forums which cover all of the symptom categories that are possible from all of the neuroimmunologic conditions. There is a forum to discuss research. For parents who are seeking a vehicle to share ideas about their children's experiences with TM, there is a forum for children with TM. There is a separate forum for parents and caregivers.

There is a forum for Social Security and Insurance Issues. Cossy Hough will be regularly checking in on this site to respond to posted messages and to offer advice.

Jim has also set up a separate message forum for recurrent TM, ADEM, Recurrent Optic Neuritis and Devics. The message forums are a great way for people with these conditions in our membership to find each other and to share information.

There is a message forum for Pregnancy and Delivery Issues with TM. Paula Lazzeri will be regularly checking in on this board to respond to questions. We have a group of women who have experience with pregnancy and delivery with TM. We also have women in our community who have been parents of infants and young children while having TM. We would strongly encourage you to check in on this message forum. There are women who regularly seek advice about pregnancy, delivery and raising children with TM, and you have an important perspective and experiences that you can share.

The range of message forum topics is extensive. Information may be shared on everything from going back to work with TM to offering assistance for and announcing fundraising events for the TMA.

The message forum can also serve as an important tool for the state and

country support groups. Jim has a separate message forum set up for each of the currently established support groups. Support group leaders can encourage their members to regularly check these forums; it is a great way to communicate with your members. You can share information on everything from local resources to announcements of meetings or fundraising events. For those of you who do not have a support group in your area, Jim has set up forums which cover different geographic regions.

The message forum has a search capability. As with the transverse myelitis internet club which also has a search function, the forums can become an important archive of information on a wide variety of subjects.

The last time I checked in, there were 82 registered users in The Transverse Myelitis Association Forum. The value of this message forum will be commensurate with the numbers of people who participate and the quality of information that is posted. We would encourage all of you with a computer and internet access to get involved. Everyone will have experiences and information to share and that information could dramatically improve the quality of life for someone who desperately needs an answer. We are in great need of information about the most complicated issues and the most basic issues. You have become experts on everything from how to travel to where to find programs that will assist people in purchasing a van with a lift. The message forums provide a great way to share your expert knowledge with people who want to learn from you.

It is very important to keep in mind while participating in this message forum that it is not a private forum; it can be accessed by anyone. You should never post personal information that you would not be comfortable sharing with others.

Thanks, Jim, for once again finding a great way for us to communicate with each other. You have found such wonderful ways for us to transform our global community into a very intimate and friendly neighborhood.

Support Groups

Issues of Privacy and Confidentiality in a Support Group

Pam Schechter

People are very sensitive about their medical information; and for very good reason. A person's medical history can impact their health and medical insurance, their life and long-term care insurance, their employment, and their personal relationships. The handling of medical information has become a topic of very serious debate and discussion and has been and continues to be the focus of important legislation on the national and state levels.

Support groups invariably will discuss people's most personal medical histories and information. That is one of the most important reasons for our existence. People need to be able to talk about their experiences. Given this important purpose for support groups, support group leaders carry a critical obligation to conduct their support groups in such a way as to offer the greatest respect to people's personal lives and information and to be very sensitive to their member's concerns about privacy and the handling of medical information.

Support group leaders have an obligation to provide information about the issues of privacy and confidentiality to their members. Assuring members' rights to privacy and confidentiality is an issue that should be introduced at the beginning of the meetings, especially when new members attend. Members can by word and deed, demonstrate that they can keep confidential what they know about other members.

In our support groups, the leader cannot guarantee that members will protect each other's privacy, but we can explain and discuss the issue with the group and work towards establishing a norm that specifies what we mean by privacy, as well as attempting to define the mutual expectations we have about confidentiality. Members ought to decide what information they will keep confidential and what information can be shared with family and friends. After all, if members are having a good experience at the meeting, it is natural and appropriate that they will talk about this experience with their family and friends. The issue of privacy and confidentiality concerns sharing the meeting experience without revealing sensitive information about other members.

Another relevant issue concerns how to protect confidentiality without unduly limiting self-expression. Members often come to groups with some fear of the other members. One common fear is that the other members will violate the member's right to privacy by revealing to others what is known about them and that these revelations might be detrimental to them. Thus, dealing with these fears is essential and needs to be addressed at future meetings so that all members have a common understanding of the issues of privacy and confidentiality.

A unique feature of support/self-help groups is peer interaction and sharing of experiences, which can create a

common denominator or bonding among the group members. This interaction and sharing can be therapeutic and lead to self-awareness and self-determination. However, group pressure may sometimes escalate for members to reveal more and more intimate information about themselves. This openness may stimulate other group members to do the same. In either case, the member may feel coerced and yield control to the group by sharing very personal or sensitive information. Whether such information remains in the group or is communicated outside depends on the cooperation of co-members and how well they understand and respect the rules of privacy and confidentiality. The leader should also stress the need to conform to those rules; member's self-disclosures should not be discussed outside the group in private conversations.

A fundamental aspect of groups is participation by every group member. One task of the group leader is to deemphasize his or her own role and stress the value of inter-member relations within the group. The quality of participation is not the issue. The mere act of participating may be more crucial; it can reduce the possibility of members dropping out. Initial participation often leads to additional and deeper self-disclosures. Therefore, a common characteristic of groups is that an environment is eventually created in which members feel safe and protected about the sharing of very personal information.

After a feeling of trust in the group is developed, members begin to disclose more and more of their lives as members participate more freely and openly with the group. As secret, private information is made more public, that "public self" is enlarged and members are less guarded in what they reveal about themselves. The implication of more shared information about ourselves is that the greater the feedback from the other members, the more therapeutic the results will be.

In this "public" atmosphere, it is important that the feelings of trust that the members have created not be violated, because there is always a risk in the self-disclosure of intimate information. It is important to emphasize that the group leaders and members not pay lip service to the issues of privacy and confidentiality. Respect for privacy and confidentiality should be a matter of practice; what is said within the group should remain there.

In conclusion, privacy and confidentiality are a basic requirement for all support groups. Groups should establish a policy on these issues and ensure that information which might personally identify a group member not be revealed or discussed outside the group.

The "Lupus Foundation of America, Inc. Support Group Manual," offers some good suggestions regarding confidentiality. These include, not releasing names, addresses or phone numbers of group members to anyone outside of the group. If the group chooses to have a roster of names and addresses, which are available to all group members, it should be made clear that no one is required to be on it and that all members who have a copy will not give this information to outsiders. This policy may be especially important to newcomers who have not shared their diagnosis with others, such as friends or employers. All group members should agree that any personal problems, such as divorce, emotional or financial problems that are discussed in the group not be shared outside of the group. It is appropriate and beneficial for the group to share information about community resources, which might be of benefit to the individual, but it is up to the individual to contact the resource. We should not contact the resource on behalf of a person or provide the name of an individual to a community resource unless we have been asked by the person to do so.

If any questions or situations concerning privacy and confidentiality arise which are not well defined or clearly understood by the group, these should be presented and resolved at a future meeting. If you have an interest or a need for further advice or suggestions about this subject or any issues surrounding the implementation, development or conduct of support groups, you should always feel free to contact me at:

Regards to all!

Pam Schechter

Providing Information and Support Without Offering Medical Advice

Sandy Siegel

Littleprincess900@hotmail.com

I receive phone calls and email messages on a daily basis. Most of these contacts are from people desperately seeking answers to their questions. So much about having TM is a mental and emotional challenge. People who get TM know nothing about it. The medical community has only a very partial understanding of it. So little research has been done and there is very little that can be said that is definitive about causes or treatments. People are loaded with questions.

I am regularly faced with the challenge of providing information to people without offering them medical advice. I have been giving serious thought as to how I could provide a set of guidelines to people about how to accomplish this goal, because there

are none of us without medical training who should be providing medical advice to people. And a medical professional would not provide specific advice to a patient without collecting a complete medical history and without performing a thorough evaluation of the person. And that is certainly not what is being done on the telephone or on the internet. How information can be provided and how questions can be responded to in lay terms and without offering medical advice is a critical issue for people who are leading support groups around the country and around the world. But it is also an important consideration for those who communicate with other people who have TM, including people who participate in the tmic and on our bulletin boards.

I have discussed this issue with some of the other support group leaders. I am not smart enough to distill all of my thoughts on this subject down to a concise code of conduct that would serve as guidelines. So, I will employ my usual approach; I'll just ramble on in a systematic fashion, and hopefully by the end of the article, you'll figure out what I'm getting at. Okay, if you're up for this, I'll get started. Try to keep up.

When I am responding to inquiries from a caller, the first thing I communicate is that I am not a physician and that I have absolutely no medical training. I let them know that my wife, Pauline, has TM and that she is the reason for my involvement in the TMA. As some of them hear me referred to as "doctor" on my voicemail message, I clarify for them immediately that I am the wrong kind of doctor. I tell them that I have a Ph.D. in cultural anthropology, the science of esoteric and irrelevant stuff. I also tell them that I am talking to them from the international headquarters of the TMA, which also happens to be my kitchen.

I believe that my introduction serves to place me in the proper role and social context. After we have talked for a while and they have heard me say "neuroimmunologic" and "demyelinating" and "parasthesias" a few times, I repeat that I am not a medical doctor and that they are hearing all of this free information from some guy in Ohio standing in his kitchen; the reminder is important in the event the caller is being lulled into a sense of seriousness through my use of these multi-syllabic terms.

I have been responding to questions about TM for nine years, and have developed some experience at this part of the job. This job has lots of different parts. I have learned a lot about TM. I have learned a lot as the newsletter editor; editing articles and working with specialists in order to get the best information about TM and the other neuroimmunologic disorders to our membership. I have read medical journal articles. I communicate regularly with physicians who treat people with TM. I have administered and have been analyzing the TMA survey which has had more than 740 respondents. I have attended all of the symposia and workshops and have listened to hours and hours of presentations about TM. And I have been through the experiences that I share with Pauline. I am in daily communication with people from all over the world who have TM and I share in their experiences. I read the tmic and the bulletin boards regularly. There is a lot I can say to people who call me and ask me questions. But I am not an expert and I am not a medical professional. I try to provide them with as much information as I am able; but I am as vigilant as possible about my status and consciously attempt not to provide them with medical advice.

I draw kinship diagrams and try to figure out what satellite dishes have done to the Dugum Dani and Yanomamo. I don't diagnose disease and I do not prescribe treatment.

My first focus in a conversation is on the kinds of questions I am being asked. There are just no definitive answers to some of their questions. I often get a phone call from someone who has had TM for a short time and they want to know if they are going to recover. My approach with people who ask questions to which there are no answers is to help them to feel comfortable with the uncertainty. I talk about the possibilities for recovery that are published in the literature and the relation of those possibilities to time. I remind people that every case is different, and that while there are these published incidences, these are general ways of thinking about what is possible, and no predictor of what is going to happen in their case. I also strongly encourage a positive attitude; I do summersaults to encourage them to be positive – whether they get a good recovery, a fair recovery or no recovery. I talk about people I know who have a life after TM in every instance. And I get them plugged into the network of support which exists around the world – literally and virtually. I let them know that they do not have to go through this experience alone.

I talk to them about how overwhelmed they might be by all of what is going on and encourage them to be honest with themselves about whether they need help or if it would be easier for them to handle if they sought help from a professional. And I talk to them about accepting help from their family and friends. Our members around the world may be posting signs up in front of their homes asking for help; in America, we are fiercely independent, and accepting help from

friends and even our closest relatives is difficult sometimes. I try to help people to acknowledge that not only do they need this help; they are doing those who want to help a favor. People need a way to show their concern. Allowing your neighbor to watch the kids for you and to help prepare meals is something they need to do for you. You are taking something away from them by not permitting them this opportunity. Relax about it. They feel good about helping you, and they will get access to the electric hedge clippers and snow blower in your garage until the end of time. That's the way reciprocity works.

I sometimes get calls from people who have not yet received a diagnosis and want to know if I think they have TM. Some of these people visited an emergency room or a general practitioner and were sent home after no cause of their symptoms was identified. After they tell me that they have not urinated since yesterday at 4:00 in the afternoon, I ask them to print Dr. Kerr's articles from the 'about TM' link on the TMA web site which includes a decision chart enumerating the steps to a diagnosis of TM. Then I tell them that if there is a medical school nearby to go to their emergency room. I also let them know that the neurologists who best understand TM are those who specialize in MS – encourage the emergency physicians to find one of those. I also tell them about the Johns Hopkins TM Center and indicate that if the physicians are having a difficult time figuring out what is wrong or what to do, if they do figure out that it is TM, that they should consult with Dr. Kerr immediately.

I also receive phone calls from people who have had a TM diagnosis and they think their symptoms are getting worse. They call me to get an opinion about what they should do about it, or they tell me that they have seen their doctor and their doctor is not taking them seriously about their symptoms. Okay, this is dicey stuff for me. I have learned from anecdotal experience that the symptoms a person experiences with TM can become exacerbated under certain circumstances. For instance, a person who is sick with the flu or some other infection, who is experiencing unusual amounts of stress, who has had some other health problems, is not getting sufficient sleep, may also experience a worsening of their TM symptoms. If muscles are weak, there may be a greater weakening; if they have bladder or bowel urgency, under these circumstances, the urgency can become worse. Nerve pain or fatigue or spasticity may be intensified. Everyone with TM faces the challenge of having to learn when they are experiencing an explainable exacerbation of symptoms, and when they are experiencing something that should trigger a different and more elevated cause for concern. And this is what I try to get to in my conversation. If a person begins to experience a set of symptoms that they did not previously experience or experience symptoms at a level that was not previsously experienced, my concern goes to something more than an exacerbation of symptoms. Fortunately, this happens very infrequently, but it happens. It happens to people who have recurrent TM or who have a second episode which becomes MS or to people who have Devics. And it also happens to people who have a demyelinating attack which is taking a long time to resolve.

If they have any doubts, I encourage them to go back to their doctor. It does them no good at all to be at home worrying about what is happening to their body; and I am not going to get it resolved for them over the telephone or, for that matter, if they were in my kitchen with me. Now, this is even dicier stuff, because if their neurologist told them there is nothing going on, you need to go home and relax, this person is faced with having to go back to this neurologist to tell them that the idiot in his kitchen in Ohio told me to come back to you for another look, or they have to call another neurologist and wait for two months to establish in this practice. But they have to do one or the other.

If I have any concern at all that they could be having a new demyelinating attack, I send them to the emergency room at the medical school with the three articles by Dr. Kerr from our web site.

Chitra, Phylis, and Dr. Kerr and I have worked out a process for getting assistance to people who contact me and who seem to be experiencing a demyelinating attack. I am able to get the family in touch with the JHTMC and we are able to get the physicians caring for the patient in communication and consulting with Dr. Kerr as quickly as possible. However, if a person is not having a demyelinating attack, but wants an evaluation, they are going to have to make an appointment at the JHTMC. And no one is going to get past Phylis without getting into the queue on the calendar and also without the proper insurance. And Phylis makes no exceptions for anyone; the President and the Pope will be treated in exactly the same fashion as you and I. Phylis is the gatekeeper's gatekeeper. And I mean that in the most respectful and positive sense of the concept, Phylis.

I often receive phone calls or email messages from people who are seeking a diagnosis. They have a collection of symptoms and have not been provided with a diagnosis or they have been offered a tentative diagnosis, but the physician is not certain. They provide me with a description of their

symptoms and a history of their illness and their experience with the medical community. I let them know that it is imperative that they get a definitive diagnosis for their condition. I recommend them to a neurologist who specializes in MS. I recommend them to one of our medical advisory board physicians or one of the TM consortium physicians, if there is one in their area. I also tell them that if they can get it covered by their insurance, it would be worth their trip to the Johns Hopkins TM Center in order to have TM definitively ruled in or out. Most of these people have very challenging cases, i.e., there has been a gradual development of their symptoms without the identification of an underlying cause; or the person was in a car accident or sustained a back injury at work; or they had some type of back surgery which preceded the onset of their symptoms; or their symptoms began after receiving an epidural. I tell the person that there are many different conditions and diseases that are associated with the symptoms of TM. I remind them that I am not a doctor and am not able to make a diagnosis, and that even if I was a doctor, they wouldn't want for me to make a diagnosis over the telephone or internet. When this happens to a person in a major metropolitan area, I know they are going to have a challenging time getting their condition diagnosed. When they live in a small rural community, I know that they are going to need to travel in order to have a challenging time getting diagnosed. And some of these people are not covered by health insurance. Have I mentioned that my job becomes overwhelming at times.

And then I get a lot of questions for which there are answers, but for some reason the person asking me the questions doesn't have any of the answers or they are not satisfied with the answers they are getting. I then begin the process of figuring out the nature of the issues involved.

If the person describes the responses they are getting to a question or questions from their doctor, and this information makes sense, I try to get a sense from the caller as to why they have doubts about what they are hearing. First, how do I decide that the information makes sense? I base my decision on what I have read in the journal articles, what I have read in the newsletters, what the physicians have told me, and what I have learned from the symposia. I always repeat what I have been told or read; that is the only basis I have for this decision.

There are people who shop for an answer when the answer they get is not what they want to hear. If a person has had the demyelinating episode, and during the episode they were treated with steroids and/or plasma exchange, and then their doctor says, "well, that's about all we can do for now; we just have to see what nature does from here," there are some people who do not want to accept that notion. I don't blame them. Who wants to hear, "we have run the course on all of what we know to do to help you; the rest is up to your body's ability to heal and recover and the blessings of a higher power?" So, some people begin a hunt for a better answer. Hey, let's call the guy in the kitchen from Ohio; he'll know. Well, I don't know anything, but you can't have more compassion than I have, and the caller is going to know that I genuinely hurt for them. They get what I do know – which is what I have read and been told by physicians – and I repeat what I have read and what I have been told. I send them to the web site to read Dr. Lynn's Q&A column about the treatments for demyelinating attacks; it is a short list of options. I work my brains out to help them feel comfortable with where they are; I encourage them to get help from their family and friends, from clergy, from a professional, and from the community of people who have been through this same experience. And I extol the great virtues of a positive attitude and how that attitude might actually impact and help their recovery. And I talk about the importance of seeing a physiatrist and physical and occupational therapists to have a rehabilitation program established for them.

And then there are some people who get confusing or incorrect information from their physicians. There is no part of my job that is more difficult or causes me more discomfort than having to disagree with what a physician has told a patient. They have the medical training and knowledge and experience; they are the professionals; I'm an idiot in my kitchen. But it happens.

Some people call me and tell me that they were given a diagnosis of TM by a neurologist, and then they were told that there is nothing more that can be done for them; they just need to deal with their new life and get on with it. The person doing the calling is almost always concerned that they are no longer getting medical care from the neurologist. I ask them when their symptoms began, when they were diagnosed, and their current symptoms. I also do some mental and conversational gymnastics to be sure that they understood their neurologist correctly, that they were being told that they should not come back for another appointment? If I hear that they are certain, we go from there. I am always amazed at what I hear from this group; they aren't urinating or completely emptying their bladders, they have nerve pain, they have spasticity, they have all sorts of issues. Some of them are not taking any medications for their symptoms and some of them have not been referred to any special-

ists, such as urologists or physiatrists. I tell them that they can get treatment for their symptoms and that they need to get treatment for their symptoms. And I provide them with information about getting established with a different neurologist, and the other medical professionals they should rely upon.

And then some of the information people get from their doctors or therapists is both wrong and truly unhelpful. I have received calls from people who have recently completed intensive therapy at a rehab center who have been told that they are never going to walk again. I ask them to describe for me the duration since the onset of their symptoms. It is disheartening to me that a doctor or physical therapist would communicate this statement to a person after only a few weeks or a month or so from the onset of their condition. Of course, the person with TM and their family are dismayed by this pronouncement. Again, I am in the uncomfortable position of having to provide conflicting information to what they are hearing from a medical professional, but as reluctant as I might be about doing so, I cannot in good conscience allow this information to go unchallenged. I tell them that at this stage, no one can really know. I tell them that, at the present time, there are no definitive predictors of outcome for TM. (I've read the stuff about spinal shock, back pain and catastrophic onset being predictors of poor outcome. I know of so many exceptions to this statement, I'm not sure what to do with it). Besides the fact that no one can say whether they are going to walk again or not, what is the point of demoralizing a person who faces months and months of difficult rehabilitation and significant emotional, social and psychological adjustments in their lives. I talk to these people about the possibilities that they might not have a good outcome, but that it is too early for anyone to know. I encourage them to use the possibility that they can have a good outcome as motivation to work hard and I talk about the positive benefits which accrue from physical therapy. And I always communicate the perspective that a positive attitude is going to make a difference for them, regardless of their outcome.

Some people do not receive good information because they are not communicating effectively with their physicians. So, we often explore this area, as well.

The physicians who are treating people with TM often spend a long time examining and talking to their patients, because there are numerous and complicated symptoms associated with this condition. Some people will go through an examination without offering any information to their physician and without asking any questions. The physician is given all of the responsibility for getting it all figured out. It is just not realistic to hold your physician accountable for asking you about every single area of possible concern. You are being treated by a physician with whom you have a relationship, and as with all relationships, you have some responsibilities as well as rights. You need to help them get it figured out.

Some people just do not come prepared for their appointments. It is very important to come to an appointment with your questions and concerns organized and written out. Doing so will facilitate effective communications, you will get more accomplished in a shorter period of time and you will maximize the information you receive from your physician. I go to doctor appointments with a list of questions, and I have never had a doctor either rush me through a list or ask to leave before I completed my list. They are going to appreciate that you took the time to get organized. Given the importance of your appointments, why would you not take the time to get organized.

Some of this organization should be going on during the times between your appointments. In some cases, keeping a journal is an effective approach for remembering any changes in your symptoms. For instance, some people have a very difficult time describing their pain over time, and the circumstances surrounding when their pain is the most and least severe. Keeping a journal about pain or bowel or bladder urgency, or fatigue or spasticity or any of your other symptoms may make it easier for your physician to understand what has been happening to you, and may provide them with significant insights that might result in more effective treatments. Are there times of the day when your pain is worse than others? Is the intensity of pain associated with certain activities or with different temperatures? Is there a relationship between when you take your medications and the intensity of your pain? It may also be a good idea to come up with your own rating system for pain intensity and refer to this rating when you are describing the various circumstances that might influence your pain. How can this information not assist your doctor in providing you with better treatment.

There are people who are so emotionally overwhelmed by their experience, that they cannot get themselves gathered together enough to ask questions. And there are some people who are introverted or timid enough in any social interactions, including with a physician caring for them, that they are uncomfortable asking questions; they'll faithfully and intelligently respond to a question, but they won't ask their own. It is not easy to get to

these issues in a phone conversation with a person who you are speaking to for the first time, but I do get to these issues with some people, and I am able to encourage them to try to be more effective communicators with their doctors. Going in with the list of questions is a good technique for people who are reticent to share their feelings or ask their questions. And I tell them that they can always write questions out neatly and hand them to the doctor to answer for them.

And then there are questions that are very difficult for a person to ask; and there are also issues which some physicians are not entirely comfortable to discuss. Hey, they're human; really, they are. As I noted a few volumes ago, Pauline and I never had sexual dysfunction discussed in a doctor's office until we raised the issue ourselves. There are some subjects you are going to have to initiate if you are going to obtain good information from your physician. My guess is that they will wax philosophic for hours about spasticity, fatigue, nerve pain, and paralysis without your having to say a word. If you want them to discuss your bowel incontinence or your inability to have an orgasm, you might have to take the responsibility for broaching the subject. This information is critical for you; I know it is cause you are talking to me about it, and I'm an idiot. Why not discuss these issues with someone who went through medical school?

We filter all of life experience through our own experiences; that is one of the more significant ways that we make sense of any experience and give it meaning. This is also a way that we bias how we apply meaning to experience. My most intimate experience with TM is Pauline's experience. It is a very natural and normal tendency for me to make sense of everyone's TM experience by comparing their experiences to the experiences that Pauline has had with TM. I can use Pauline's and my experience with TM to feel empathy and compassion. I resist as much as I am able the comparison of all experiences with TM to Pauline's experience. What happened to Pauline does not happen to everyone with TM. What treatments have worked for Pauline are not going to work for everyone with TM. She cannot be the model by which I think of everyone who calls with questions. If I constrict other people's situations into Pauline's experiences, I am taking a biased, limited and perhaps incorrect perspective on their experiences.

I receive more calls about pain and pain management than any other symptom. It would be very easy for me to talk to people about Pauline's pain, which can be severe at times, and how she is being treated. That is, of course, always the first thing that comes to mind in these conversations. But I resist focusing on Pauline's experiences, because in the first place, I have no idea what is causing the caller's pain. How could I possibly think about or suggest a treatment. And, even if I could be certain about the cause of their pain, what treatment works for one person, may not work at all for another. We do talk about Pauline's experiences, because I believe that sharing anecdotal experiences is important. But the focus of my conversation with them concerns the reasons as to why they are not being effectively treated for pain by their physician. We talk about various options for receiving medical treatment for pain, including from neurologists and pain centers. And I direct the caller to the many sources of information on the TMA web site that address pain management. I communicate that it is important that once the cause of their pain has been identified, the more they know about treatment options, the better they can advocate for their care. And I implore the caller to find a physician who will take the time to work with them to find effective treatments for their pain.

When I am called by people who are experiencing bladder problems, I encourage them to discuss their issues with their neurologist and to seek an evaluation with a urologist. I don't automatically assume I understand the cause of their bladder problems; it could be from nerve damage caused by their demyelinating attack, or it could be that their prostate is the size of a grapefruit. How would I know? I tell them that there is excellent information on our web site about bladder issues, I direct them to this information, and I talk through with them how to find the best medical care for their bladder issues.

People get TM from infancy into old age. Completely healthy people get TM, and people with previous health problems get TM. A physician doing an evaluation, medical history and examination is going to assess the whole person, not just their spinal cord. I can't treat symptoms, because I do not know the cause of the symptoms, and I'm not a doctor, so the only thing I am comfortable prescribing are good techniques for finding a doctor and communicating with a doctor.

I also receive phone calls and email messages from people seeking advice about alternative treatments for their symptoms. The questions involve everything from acupuncture for the treatment of parasthesias and pain, to any benefits that might accrue from going to a chiropractor to the use of supplements that have an influence on the immune system. Pauline is my wife; I am perfectly comfortable offering her my opinions about her reliance on other-than-medical treatments for her symptoms. She has benefited greatly from taking tai chi, and she is

planning to sign up for a yoga class this summer. I believe that she will derive great benefits from taking yoga; any opportunity she takes to focus on her body as opposed to focusing on all of the things I have done to irritate her during the week is a very healthy use of her time. If she wanted to take a supplement that would somehow influence her immune system, that would make me really uncomfortable. The primary function of the immune system is to distinguish between self and non-self. For some reason, Pauline's immune system did not function properly and it attacked self. No one presently understands why it did that. Why would I be comfortable with Pauline wanting to treat her own immune system? If she is going to devote her life to curing something, she might want to start with my neuroses and leave her immune system to the medical professionals who do research that is ripped to shreds in a peer review process.

I strongly suggest to people that before they incorporate any kind of alternative therapies into their treatment regimens, they should discuss it thoroughly with their physicians. My guess is that most doctors will not wholeheartedly endorse some therapy for which there is no evidence that there is an effective benefit. If the therapy is, at its worst, benign, they may be all right about you trying it. But they will give you some feedback on whether it could cause you some potential harm; and you need to hear that from your doctor. I recommend to people that they shouldn't make these decisions on their own without consulting their doctor.

I try to remind myself that I get a lot of phone calls because people with TM and their families are often frightened and confused, they are seeking the answers to their many questions, and my telephone number is very easy to find. If they could call their doctor every time they had questions or concerns, they wouldn't be calling me. When was the last time you called your doctor's office and had the doctor answer the phone? There are so many gatekeepers in doctor's offices today, that you have to go through a gatekeeper to get to the person who mails you the bill. I remind myself every day that I am in demand not because I know; I am in demand because I answer the phone.

So, let's review my focused and concise list of guidelines for providing information without offering medical advice:

Do not diagnose disease or disorders.

Do not prescribe medication or treatments.

Remind people that you do not have medical training and the more authoritative and credible you sound, the more often you need to remind them of your amateur status.

If you do have medical training, be sure to communicate to people that while you are a medical professional, it is not professional to provide specific advice to people without taking a medical history and conducting an examination.

Be sure to communicate that there is great variability between the different neuroimmunologic disorders and between the various manifestation of symptoms. While there are similarities between individual cases, your case is not the model for all cases, and the treatments that have been effective for you are not going to work for everyone. There is not a one-size-fits-all approach to the treatment of symptoms; there is often much trial and error involved.

We should help people to be more effective advocates for their treatment and care. One of the best ways to accomplish this is to become a well informed patient. We should be focused on providing people with information we know is good information about TM. Have people thoroughly review the information on the TMA and the JHTMC web sites. If you are going to talk to people about specific symptom management issues, it would be a good idea for you to know what information is available on the web sites, so that you can direct people to specific articles or presentations.

We should be helping people find good medical treatment from medical professionals. If you are receiving good care from your neurologist and they know TM, sharing that reference with the others in your support group is a great idea. It is also a good idea for you to know the names and locations of the physicians on the TMA medical advisory board and the TM consortium; we should be referring people who are seeking good medical care to these physicians. The TM consortium physicians are identified in the TM Consortium Working Group article, "Proposed diagnostic criteria and nosology of acute transverse myelitis." A copy of this article was reprinted in the TMA Volume 5 Issue 1 Special Section.

We should help people to be more effective communicators with their physicians. Any advice we can offer to assist them in that process is going to be of tremendous benefit to the person with TM and their caregivers.

Help people find good information. Help people to understand that just because they read it on the internet, it doesn't mean it is correct or accurate. Always evaluate the source of the information and always weigh its value against its source, as well as the process that surrounds testing the veracity of the information being presented;

i.e., information published in a peer reviewed medical journal vs. information posted on a bulletin board.

Please don't tell people stuff to do like you heard it at the burning bush this morning.

Be sure that people understand the full range of medical professionals that can be involved in the management of symptoms, i.e., neurologists, urologists, physiatrists, physical and occupational therapists. And be sure that people know that the physicians who understand TM best are neurologists who specialize in the treatment of MS.

Remind people that not everything that is happening to their bodies can be explained by their neuroimmunologic condition. They still need to have a regular examination, for instance, by their GP or gynecologist or pediatrician.

Sharing experiences is important and helpful, showing empathy and compassion is critical. Help people to understand that they do not have to go through this difficult experience alone. Be sure they know that there are thousands of people across the country and around the world who are offering each other support and encouragement. They are providing this support in their local communities, on the tmic, on our bulletin boards, in our support groups and at our workshops and symposia. Be sure that they join The Transverse Myelitis Association. Tell them its free, there are no membership fees. And then tell them that it would be a great idea and we would be eternally grateful, if they would raise millions of dollars for TM research.

The First South Africa Support Group Meeting

The South Africa Support Group is led by one of the most wonderful and amazing people I have met in my life, Tanishka du Plessis. Tanishka announced the initiation of the SA TM support group in March 2001. She organized the first South Africa support group meeting in the fall 2002. As the members of the SA TM support group live all across the country, organizing this meeting and getting everyone together was quite a feat. Tanishka was even able to get a grant to assist the group with their travel to the meeting.

For those of you who do not remember Tanishka's story in the newsletter, she is a smart, beautiful, and charming 28-year old from East London in the Eastern Cape Province of South Africa. She is the Senior Communications Officer of the Eastern Cape Provincial Legislature. Tanishka was diagnosed with TM in March 1999 and was paralyzed below the T8 level. Tanishka also has Crohn's disease, Lupus and osteoarthritis. Challenges are nothing new to Tanishka who grew up in a children's home.

I have been regularly communicating with Tanishka for the past three years. I have never heard her complain about anything. She has the most wonderful sense of humor and the most positive and uplifting attitude about life.

Tanishka and Johan are going to be getting married this spring. Everyone who knows Tanishka and Johan are absolutely thrilled with this great event. We are so happy for both of you. Please bring plenty of rhino and monkey repellent to the ceremony so that they don't ruin the festivities.

Tanishka has been very sick and has been hospitalized over the past few months with a lupus episode. It has been very difficult for her and for those who care for her. About a month ago, I spoke to Tanishka for the first time on the telephone. What a thrill that was! I was totally amazed that she had a telephone in her mud hut on the grasslands. She is improving slowly, and we are hoping and praying that she is back to her vibrant self in time to celebrate this great event with Johan!

I wanted for Tanishka to send me an article about their first support group meeting. As she was just not up to the task, I am, instead, publishing her email message to me about the meeting.

In her article introducing the SA support group, Tanishka made the following proclamation:

"We are not here to see through each other, but to see each other through." So, watch out world… the South African support group is here to stay!

We are going to hold you to that promise, Tanishka. And we want to thank Jenny Moss and Alet Uys for helping to keep the support group going during your recovery. Take care and be well, Tanishka!

Re: Support Group Meeting
11/19/02 11:49:32 AM
tanishka@otpmleg1.ecape.gov.za
srulyoself@aol.com

Hi Sandy.

It is about 17h00 here, and if my calculations are right, it should still be early afternoon for you.

A **HUGE** thank you, I did get those letters for the Legislature. The members are going to be so stoked! I am fram-

ing it with a big photo of our TM group and handing it over during a Rules Committee meeting (our highest executive committee in the Legislature) on the 2 December. They have been good to me. I am really lucky; not many people get such support at work.

Sandy, now to tell you about the TM meeting. Firstly, I was a bundle of nerves, my tummy ached so much the night before because I was just so anxious and excited about everything. But all my worries and tummy-ache was for nothing!!! We all got on like a house on fire. People were at first a bit shy, but everybody soon realised that we all had the same worries and that no one had to feel uncomfortable about anything. We had organised this huge holiday house on the edge of the Vaal River. People were jetskiing. We all went on a long boat cruise down the river when the sun set and had sun-downers and toasted our blessings and our friendships. It was the ideal setting to park off and just relax. At night we had braai's (barbecues) and sat around huge bonfires till after midnight - just talking and laughing. I read your letter to our group on Saturday night after supper. I choked up a couple of times while reading it, especially where you wrote that you were there with us in spirit. Don't write such tear-jerkers! Our group really appreciated the letter. I made copies of it so that everybody could take it home. Hey, Sandy, you know that you are pretty special to all of us here?! Your caring nature blesses our association again and again and again...

I had organised a neurologist to address us on Saturday, but she wasn't able to make it. I tried in vain to get somebody else, but people declined because most of them were attending a conference. Ag, but there is always next year. And anyway, I think that we know more about TM then most doctors. So, we shared what we knew and what we had read regarding the latest research.

Every day and every night that I spent with everybody that weekend was so special. It was so hard to say goodbye on Sunday afternoon when the first group of people had to leave. I don't think any of us could stop crying. I think that many spots in my little heart were healed during that weekend. Everybody had incredible stories to share. True stories of pure courage and the strength of the human spirit when faced with challenges. Every story touched me deep. I am so grateful to have had this opportunity to meet everybody.

What an incredible week!!!!!
So, in a nutshell, that is that. I could write so much more….
Sandy, take care of yourself. Our love to Pauline.

UK Support Group

Tanishka

I received an unwelcome letter at the beginning of the year. It informed me that I had been chosen at random for a reassessment of my DLA award and that a staff member would be visiting me at home. This made me apprehensive as my original assessment had been made ten years before and I had no idea how the regulations had changed. The man arrived carrying a 36 page questionnaire. However, he was very helpful and after two hours, we had completed the form. Hence, the next letter from the DLA office was a surprise; they had insufficient information and now needed an examination by a doctor! In due course, a private doctor arrived from 40 miles away bearing another 36 page questionnaire. Two hours and a physical examination later, it was all completed. If you are singled out for reassessment, don't be too alarmed. My allowance ended up being doubled.

During the year we have set up a database of children in the UK who are suffering from TM. The objective is to enable parents to identify other families with similar problems whom they can contact to compare notes. If you have a child with TM and would like to be included in this database, please contact me. Note that the information is only available to others who are on the database and it is not available over the internet.

Geoff Treglown
geoff.treglown@btinternet.com
015394 34 677

In an earlier Newsletter I described members' experiences with alternative forms of treatment. Sandy Smith has contacted me to share his experiences with acupuncture which I include below.

Treatment with Acupuncture

My initial attack of TM occurred in 1988 and recovery during the next year involved a wide variety of different sensations. These included pins and needles and muscle spasms amongst others, but the worst, by far, was bouts of very severe white-hot pain. The bouts of pain lasted for approx 20 – 25 minutes and occurred up to four times a day over a period of several months. The pain was so intense that I often passed out for a few minutes. Doctors tried various combinations of drugs to control the pain, but nothing seemed to work.

About nine months after the initial attack, despite having no feeling in the lower half of my body, I was able to drag myself around on elbow crutches for short distances. I then saw a consultant neurologist who told me that my walking probably wouldn't improve further and I would "just have to learn to live with the pain." I was then referred to a different hospital as this prognosis might be easier to accept from a second source.

My wife and I both refused to accept this situation and, as I had used acupuncture for back pain, long before it was officially recognised by the health service, I decided I had nothing to lose by trying it again. I attended a private clinic for two years. Acupuncture did not take the pain away completely, but it certainly reduced it to a more manageable level and I never did pass out again. Because the pain level was reduced, I was more able to concentrate on learning to walk again.

I eventually almost had to force our GP to have me referred to a pain management clinic at our local hospital. The staff at the clinic is exceptionally good and I now have 20-minute sessions of acupuncture on a monthly basis, which is as often as the hospital budget will allow. I am one of the few people who suffers from recurrent bouts of TM, and have actually had a home visit from the pain clinic when acupuncture reduced the tension in my spine within 15 minutes of the needles being inserted.

I realise acupuncture isn't a cure and it certainly doesn't take the pain away completely, but for me, it keeps it at a more manageable level and this, in turn, helps me to remain mobile. All I can say to other TM sufferers is, don't give up, even when the doctors appear to give up on you. Anything is worth a try.

If you would like to discuss this with Sandy, his phone number is 01333-

Southern California Support Group Meeting

311 671.
Our little group is growing. I can remember when we had only two or three people getting together at the Abilities Expo in Long Beach, CA. During our latest meeting which was held on May 31, 2003, we had 19 participants. Our group includes caregivers, as well as people with TM. We offer a means of "venting," comparing medical treatments, comparing medications used for our varying symptoms, our frustrations with the "outside world" that does not understand what we are living with daily. The main topic of discussion during this meeting was offering small ideas of how to make daily life a little simpler. One suggestion was to have several "grabbers" located throughout the house, such as one in the kitchen for items placed too high, another one in the laundry room to take clothing out of the washing machine, and one in the living room to grab a paper off the floor.

We do **not** suggest any of our medications or treatments be taken without the advice of our own physicians. What we do offer is options that can be taken back to our doctors, to ask if a particular treatment option would work in our individual case.

We had several new members come to the last meeting, and we had several "regulars" that were not able to come, and we did miss them. We have become close friends. When somebody does not come, questions are asked, "Have you heard from so-and-so? Are they doing okay?" Please, if you are unable to attend our meetings, just keep in touch with us so that we know you are doing well.

During our last meeting, we were very surprised to see Lou and Luna arrive with their 10-week old new baby son. We had all been anxiously waiting to hear any of the latest news from them and were so happy to see the beautiful baby. Our next exciting arrival was Rick and Bob. Rick had become paralyzed a second time during the Christmas holidays and was struggling to reach the level of improvement prior to his relapse. At the last meeting, Rick was still in a chair. This time, he ***walked*** into our meeting room and he received a standing ovation and cheers. Rick credits his improvement to grueling physical therapy and a lot of pressure from Bob to keep going when Rick couldn't keep going.

We had a silent auction that went on during our lunch meeting. Several items had been donated by merchants and TMA members. We put these items on a table outside of the conference room for inspection and opportunities to bid on the items. At the end of the meeting, we announced the winners of the items. The money that was raised during the silent auction was donated to the TMA to cover costs for the Seattle Strategic Planning Meeting. After the winners of the merchandise were announced, we had the raffle drawing for Ann's quilt. Although the winner was not one of our members who were present, we knew that the quilt was going to a home where it would be much loved.

Our meetings are held in Garden Grove, California. We do understand that there are so many people who are unable to drive that distance to attend, and we would like to see more locations for meetings in Northern California, the San Diego area, and the greater Los Angeles area. If anybody lives in these areas, please contact either Cindy or me at the numbers or email addresses below, and we will do whatever we can as far as suggestions or ideas to set up support groups that will be available to all people with TM and their caregivers in all areas of California.

We are not your typical support group. We are people living with TM, and once we meet for the first time, we develop friendships that just continue to

grow. Please think about this, and if there is no support group in your area, please consider taking the initiative to start one on your own. If you contact Cindy or myself, or any of the other support group leaders that are organizing in the U.S. and around the world, any one of us would be more than happy to share our experiences on how to make a support group happen.

By the way, if you have Internet access, please take a look at the latest picture of our smiling group that was taken during our last meeting. The webpage address is: **http://www.myelitis.org/local/california/index.htm**

Deborah Capen
dcapen@myelitis.org
(909)658-2689

Cindy McLeroy
cindymcleroy@sbcglobal.net
(714)638-5493

Finally, a TM Support Group in Idaho

We have a lot in common, you and I.

We have shared a lot: experience, knowledge, understanding, compassion. Now that we have these, we can give them away.

I'd been told that it would help to talk with someone else who has it. (Who?) I discovered TMA (can't remember how) when I'd had TM for about 2 years. I got in touch, asked what I could do to help. Sandy said, "Start a support group for Idaho." You might know that compared to the rest of the states, nobody lives here! OK, we have more people than Wyoming. In fact, if you combine Idaho and Wyoming you have enough people for a decent size city anywhere else. None the less … Idaho now has a support group!

John Craven
889 N. Watson Way
Eagle, ID 83616
(208) 939-7968
jscraven@msn.com

After a number of contacts with Sandy, he told me that I **need** to start one. He and a few others pointed out that I was teetering on the edge of depression. It helps tremendously to be able to help someone else.

I contacted a few TM-ers in ID. (Some of us don't have phones or paved roads. Most have email). It really is remarkable how connected we felt, right away! None of us had ever talked to "another" before. We talked for hours. I feel better. (If you haven't, do it now! Call Anybody!)

I thought I should write this on an "up" day. I'm not up today. In fact, this is just one of those days. You and I share that. We don't need to fake it. If you are having a better day today, celebrate! Enjoy every moment. I'm just struggling deep in Round 3. Here's ***my*** blow-by-blow.

Round 1: May 9, 1999 I was paragliding along the edge of the Snake River Canyon. It is like hang gliding, but the wing is a skinny parachute. It's fabulous. I used to do everything. I was very active. I made three beginner mistakes that day. I landed sitting and broke some bones. The important one was L1, a "burst fracture" that crushed and penetrated my spinal cord. They used **glue** to seal it! The bones healed, with a bunch of re-bar. The numbness lasted four months. Then the pain started: awful! We finally tried a morphine pump. **No pain** for three days. We kept increasing the dose until …

Round 2: Mary was my favorite nurse, from my first pain clinic. I went to lots. Seven months later I learned that she was single! In the fall we got married. Then funny symptoms started. After three weeks I dropped, paralyzed. The pain stopped! So did everything else. Lying in the dark that first night was awful. We stopped the morphine too quickly, so I had withdrawal too.

The doctors knew nothing! Actually, they knew to call Karin, soon to be my neurologist. She knew immediately. TM. Scared? Overwhelmed.

Physical therapy was amazing. They told me I could walk. What? Just try it. I am! Then one magic day, Dave said, "You couldn't have done that with your arms." It was working!
I got about 50% nerve recovery, motor and sensory. Official diagnosis: probable MS. Theory: high morphine dose triggered latent MS. Months later the tingling started, and grew, and the spasms, and the pain. Once again, I was immobilized by pain.

We tinkered with meds and other trials and made some good progress. I still didn't move much. Then I started calling "my support group." Robin said, "Try Klonopin! I love it!" I got some on Wednesday. I stood up and walked Thursday. Wonderful!!! It helped foot muscles release, dropping another source of pain. I started driving again. See what TMA did for me! Wow! I restarted my YMCA membership, swimming. Until …

Round 3: An infection in a testicle (which I couldn't feel) has apparently inflamed the nerves around it. After seven months it's still going downhill. I'm immobilized again by pain. I cancelled my YMCA membership.

What can you learn from all this whining? Remember my wife, Mary? She's the director of the hospital pain clinic. She encourages me. We keep talking and trying. My pain doc keeps trying.

My neurologist, too. Five MRIs last week: at least it's not MS. There are many ways to treat pain.

The hardest thing of all is to gain ground, then lose it again. It hasn't killed me, so I guess I'm getting stronger. I've learned to keep trying.

IL Support Group

It's hard to hope.
We will find a way.
My name is Nickie Garrigan and I live in Chicago, Illinois. I read a tmic posting by Tina DeBerge, who lives in nearby Glendale Heights, inquiring whether anyone was interested in starting an Illinois support group. We met less than a week later. After contacting Sandy, Tina and I are moving forward and establishing the IL support group.

I developed Transverse Myelitis at the age of two and was not diagnosed until some months after the onset of symptoms. Until the year 2000, I had not met another person with TM. Although I was 21, I still had outpatient physical therapy at Children's Memorial Hospital in Chicago. A physical therapist who was working with Rachel Dorocak, a young Ohio TM patient, referred her mother, Cathy, to me, because she wanted to meet someone who grew up with TM. Through Cathy and Rachel, I found The Transverse Myelitis Association.

I had two additional episodes of TM, at 10 years and at 18 years of age. All of my episodes have been completely different. The first episode was shortly after receiving immunizations and shortly after having a cold and stomach flu. I went from a normal, active toddler to being able to walk less than three steps. The second episode started with weakness until I could not move from the neck down. The third episode affected the right side of my body more than the left and again I was unable to walk. After lengthy rehab, I was able to walk short distances. Several spinal fusions after I was 18 have further complicated the walking issues. Having Juvenile Rheumatoid Arthritis and Lupus also adds additional issues.

After graduating from high school, I started college, but that has been on hold due to health issues. Continuing my education is one of my goals. After the initial meeting with Cathy and Rachel Dorocak, I attended the 2001 Baltimore Symposium and the 2002 Children's and Family Workshop. Attending these TMA sessions reinforced the feeling of isolation I experienced in Chicago and the need for a local support group.

Tina and I bonded instantly and are looking forward to meeting with other people from the area. One of my priorities is to find a neurologist in the Chicago area who will specialize in the treatment of TM and become a link in the network of regional centers of excellence for Transverse Myelitis. Another priority is fundraising to support research. Two local families, the Hamilton's and the Callahan's, who have young children with TM, have had successful fundraisers. As a group we could offer support to any fundraising projects in place and hopefully initiate fundraisers.

The IL support group has already held several meetings. If you are interested in becoming involved, please call either Tina or myself, and check out the IL page under Support Groups on the TMA web site. We regularly post information about our activities and future meetings. I would also like to thank Jeanne Hamilton who has taken a leadership role in the IL support group. Jeanne's young son, Kevin, developed TM as an infant.

Nickie Garrigan
6121 N. Northwest Hwy., Apt. 407
Chicago, IL 60631
(773)774-6554
duckprincess5778@ameritech.net

My name is Tina Deberge. It was August 7th, 1998 when TM came into my life. A newlywed of six weeks, I was enjoying a family visit when I suddenly felt a lightning bolt-type pain shoot across my neck. The pain was sudden and intense, and by the time my hand reached my neck, the pain vanished. What followed was total numbness in the bottoms of both of my feet. I saw my doctor two days later and was told that I was very sick, that I either had Syphilis, HIV, MS, or a brain or spinal cord tumor. More remarkable than the "diagnosis" was the fact that she sent me home. I drove myself around the first few days while my symptoms progressed! It took another day before I received a normal MRI of the brain, and several days more before an MRI of my spinal cord showed inflammation at C2. I continued to lay in my apartment for another three to four days before seeing a neurologist who performed a spinal tap and blood work.

Soon after, MS was ruled out, so I was told I was diagnosed with TM. It was explained to me that it was not an illness, but a condition with several symptoms that mirrored MS. Basically, I was told I had TM because MS could not be proven at that time. I was assured that I would be diagnosed with MS within the next few years. By this time I had no feeling from the waist down, and felt like a tight band stretched around my entire torso as if I was encased in cement. My arms and hands were becoming numb, and my fingers were curling up into my hands. I could no longer write legibly or hold anything without fear of dropping it. My breathing was shallow, and I felt

like I might be suffocating. It's funny to me now that my husband and I never thought to go to the hospital! Finally 10-12 days after the initial onset, the neurologist prescribed prednisone. Day by day, I became better until I made nearly a full recovery. Today, I still have vibrating, tingling, and numbness sensations throughout most of my body. I also have chronic back pain due to having little physical therapy to regain muscle strength while recovering. I also feel like the luckiest person in the world to have overcome such an event!

The worst part of TM for me was that I felt very alone and not receiving good care. It didn't seem like anyone knew what to do with me, and I was too sick to try and find out for myself. I have never felt so alone, and I hope that no one else ever has to go through this! The best part of TM is that I have learned a lot more about myself, my limitations, my strengths, and I know that I have something positive to offer others. I also get to say I am one in a million and mean it!

I really hope the Illinois support group can be a place where people can turn for support and friendship. We need to get the word out to the medical community, so people with TM receive the best medical care possible. I hope to raise money to help fund research. Please come and join us! I look forward to meeting you!

Tina Deberge
32 Mill Pond Drive
Glendale Heights, IL 60139

The Maryland / DC Area Support Group

(630)690-1684
tina@wideopenwest.com

My name is Kelly Connor and this is the story of the first meeting of the TM support group for the MD/DC area, as well as our story of Transverse Myelitis.

The story is actually about my husband, Alan, who developed TM on October 8, 1999. We were on a plane heading to our first trip to Disney World with our two younger daughters. We gave each other a "high five," as the plane was taking off, because we had saved $150 dollars by not having purchased vacation insurance through the travel agent.

Shortly after take-off, Alan complained of neck pain. We blamed it on the take-off and I gave him Ibuprofen. The pain never really went away all day, but it was bearable. We saw the Animal Kingdom and then later went to the hotel pool. By 9:00 that evening, he had left arm numbness and was feeling exhausted. We blamed the numbness on the neck pain and the fatigue on the fact that we had been up since 4 AM. So, we went to bed. At 11:00 PM, Alan woke me, because he could barely walk on his way back from the bathroom. I called 911 and he was taken to a small community hospital where he was diagnosed with Guillian-Barre.

I breathed a sigh of relief because I knew that Guillian-Barre could get serious but is reversible. By 3:00 AM his respiratory function deteriorated and it became necessary to intubate him. He was placed on a ventilator and transferred to a larger hospital in the Neuro ICU. He was paralyzed from the neck down and had sensory deficit from the shoulders down. He could tell he was being touched, but could not tell if it was hot or cold, sharp or dull. He was only intubated for three days; no one will ever be able to convince me that high dose steroid therapy is not the reason he is not on a ventilator permanently. He had the battery of tests and on the fifth day we got the diagnosis of Transverse Myelitis.

Alan spent the next six days in this unit. Everyone there said that he would be okay. I knew nothing about TM at the time. We had never even heard of it. So, I took their word for it. The social worker there arranged for an air ambulance to get us back to Baltimore to Johns Hopkins Hospital. We were not moved to be at the TM Center; we are from Baltimore and I work at Hopkins. After we arrived at Johns Hopkins, we found out about the TM Center. This is also when I truly learned what TM was and how completely it can affect a person. Alan was put through tests and the diagnosis of TM was confirmed. After seven days at Johns Hopkins, he was transferred to a great rehab center.

The first day of rehab was the first day we even remotely began to relax. When we got there, the nurse said, "Did you bring shorts and tennis shoes? That hospital gown is coming off; you're in rehab now, honey." With physical and occupational therapy, a great team of nurses and doctors, Alan went from barely tolerating sitting in a chair with head support to walking with Canadian crutches in four weeks time.

He had to learn self-intermittent catheterization and learn a bowel regimen. Once Alan returned home, it was yet another adjustment to life with limitations. He turned 40 while he was in rehab and had been very active up to this point. He continued with outpatient PT and is now able to walk short distances with a cane. He uses a wheelchair for long distances. He has been able to continue to do a lot of the things that bring him joy and happiness. He has become a stay- at-home Dad and really has enjoyed being with the girls and they have loved having him at home. Needless to say, we lost

all of the vacation and it was non-refundable, because we did not buy the insurance. We decided we would not "high five" about things; we are convinced something saw us do it and said, "so, you think you are so smart."

I have always wanted to get involved in a support group, but Alan was just not ready to face the reality of this condition being permanent. So, we did nothing for a long time. We went to the TM Symposium in July 2001 and met some really wonderful people. We did have lunch with two couples we met about a year later and then after the next TMA newsletter arrived, we were ready to do something meaningful and productive for other people with TM.

I began by writing a short letter with a questionnaire to everyone in the TMA directory in the MD/DC area. I received several replies and then began to search out places to have the meetings. The final destination was a restaurant that had a small private dining area, which holds about 24 people.

The first meeting of the MD/DC Support Group for TM was held on March 29, 2003 at Snyder's Willow Grove restaurant. There were 12 members in attendance, seven with TM, and five family members. Of the seven members with TM, six were female and one male (this was Alan, he is always the only guy; we have three daughters). The ages ranged from 20 to 65 and the amount of time with the disease ranged from 3 to 32 years. Five of the people had developed TM as adults and two were adolescents. Some people had a long hospital course and others have only been treated as an outpatient. Everyone brought their experiences to the table, some were familiar to everyone, and some were unique to each individual.

We used this first meeting to get to know one another. We also discussed how often to meet, where and when to meet, and what topics people were interested in hearing and learning about. We decided to meet three times per year. The group liked the location, which is central to everyone, so we will return to Snyder's for the next meeting. Some of the topics people wanted to hear more about were: stem cell research, what happens as a person with TM grows older, are there ways to improve physically with TM and are there ways to improve sexual function. We took a group photo and after all was said and done, we said our goodbyes and left in about five different directions.

I cannot wait until the next meeting. There is a sense of kinship when you are sharing experiences with people who not only empathize with you, but also really know what you are feeling. I would like to extend an invitation to anyone in the area to join us. There is no obligation, no fees (except the cost of your lunch) and, hopefully, you will come away with more knowledge about your disease and make a few friends in the process. Please feel free to contact me at: kac61@cablespeed.com or (410) 766-0446.

You can also contact Janice Yoder at: carly@chesapeake.net or (410)326-4016.

Please check out our web page that Jim has designed (Thanks, Jim) on the TMA web site. First click on the support group link and then click on the MD/DC link. We will post summaries for those of you who are unable to attend the meetings. We will also post meeting dates, times and locations for future meetings.

Michigan Support Group

I am pleased to announce that I am initiating a Michigan Support Group for Transverse Myelitis. Our support group will provide members and families with the opportunity to share their advice about living more comfortably with TM. Each person brings their own experiences about living with the disease, and can offer support and friendship. Our mission is to heighten awareness about TM, to offer emotional support and to participate in fundraising efforts focused on research that will bring us closer to a cure for TM.

I joined the Army on my 22nd birthday, back in 1989. Six months later and while I was stationed at Advanced Individual Training, I fractured my C7 vertebrae and injured the muscles down both sides of my spinal cord during a military exercise. I had trouble with both of my legs and arms, loss of feeling and severe pain in my back and neck. I was put on several medications and went through some physical therapy. I was able to regain some of my strength before I was sent overseas and stationed in Heidelberg, Germany. I had another relapse and I saw several doctors, even a German doctor, and went through several sessions of physical therapy and was soon able to walk again. Ever since the accident, I have dealt with severe pain in my neck and back, shooting pains in my legs and arms and severe headaches.

My next relapse happened shortly after I was given an honorable medical discharge from the Army in September 1992. My legs went out from underneath me and they were completely numb again. I was admitted into the VA hospital in Detroit, MI and went through extensive physical therapy

again. After a few months, I was able to regain my strength and start walking once more. Each relapse seemed to be harder on my body, my spinal cord and my spirits.

On September 2002, I was at my desk working when I twisted my back as I was reaching for something out of a drawer. I felt a lot of pain in my mid-lower back, but got up and went to the restroom to shake it off. Within minutes, my legs were going numb and when I sat back down at my desk, I had severe pain in my back and both legs went paralyzed. I thought to myself, "This is it." A month later and after a lot of complaining about not being able to go to the bathroom, the Urologist ran some tests and found out that my sphincter for my bladder wasn't working. I had to wear a catheter for three months, having it changed every two weeks. Finally, they took it out and now I just self-catheterize. The doctors diagnosed me as having Osteoarthritis throughout my entire spine, Musculoskeletal Disorder and possible Transverse Myelitis during my two-week hospital stay in September 2002. Each of the doctors I have seen since this time have agreed with these diagnoses.

Due to all of these experiences, I lost my job and now live with my brother, his wife and kids in Michigan. I will be moving into a new house on my own next year. In another week, I will be able to drive using hand controls in my car. That will make me feel like a huge part of my independence is back.

In April 2003, I went to the VA hospital in Milwaukee, WI for Physical Rehab and went through several tests to see if there was anything they could do to help me. They told me that I have Transverse Myelitis and there was nothing they could do for there was not a cure. My current medications are: Morphine, Gabapentin, Rabeprazole, Lorazepam, Prochlorperazine, Baclofen, Lidoderm patches, Fluxetine, Acetaminophen, Docusate, and Tizanidine.

I have gone through several bouts of depression since September 2002. The time it hit me the hardest was about May and June of this year. I was told that what I was going through was very normal. I began to feel myself wanting to just sleep, not wanting to be a part of anything, going over in my mind all of the mistakes I had made in my life, and feeling sorry for myself that I am paralyzed and that there was no progress in my condition. I am on depression medication to help with the issue and it does seem to give me some support. I feel as though I have come through the worst of it. I am working on getting my life together and working on dealing with being paralyzed. Just over this past month I have made some progress with my right leg. It has feeling and is getting stronger. My left leg is still numb and there is no sign of any sensations at all. But I have hope.

That is why I want to be there for others who are going through the same thing and whatever other issues people may be experiencing. I can offer support and friendship to others who have TM. I would also like to encourage networking in Michigan so that we can widen the support opportunities in communities all across the state. I feel that making contact with people and having a support group will help everyone. It is often the case that those who work the hardest to offer support also receive the greatest support. So, please get involved. You can help others; and you can also help yourself. Please get in touch with me and please get involved in the Michigan TM Support Group. I would like to hear your story and your concerns. I am here to lean on and know you are not alone.

Mississippi Support Group

Hello, TM Family. My name is Joyce and I have had TM since September 1992. I had just turned forty-two years old when it caught me. I have begun a support group in Mississippi for all of the TMers, their families, caregivers, and friends to come together and be able to discuss our problems and needs with someone that really understands. We have a web page on The Transverse Myelitis Association site; just click on the link for the Mississippi Support Group. Our support group meets once a month; please check our web page regularly for meeting times and locations.

My journey started on September 17, 1992. I had been having problems with numbness in my right hand and arm for a few weeks. I went to the ER, and doctors told me I was tired and stressed out. I worked as a waitress and had been working twelve to sixteen hours a day, seven days a week, because we were short of help. I assumed the doctors knew what they were talking about. Then the numbness started traveling down the right side of my body. In the meantime, the doctor decided it might be carpal tunnel syndrome. I was trying to tell him that the numbness was getting worse and no one would listen. The doctor was setting a date for my carpal tunnel surgery.

I was living in Jackson, MS, and no neurologist would take me sooner than three months. My husband, with whom I was separated at the time, lived in Greenville, MS. I called him and told him I needed a place to stay

for a few days to see a doctor in Greenville. I called a neurologist there, and he worked me in within a week. I went to Greenville a few days early, because the numbness was traveling faster down my right side. My appointment was for September 21, 1992. On September 20, as I was walking across the floor, my feet literally quit working. I panicked.

I went to the hospital, and was immediately put on liquid steroids. The doctors started doing many tests, and I was scared half to death. I had never been sick a single day in my life. I kept telling the doctor just to give me something to fix it, that I needed to get back to work. By then I was paralyzed from the breast down with some numbness in my hands and arms. My doctor was a superb doctor, but he had no bedside manner. After several days of tests he told me, "I have good news and I have bad news. The good news is that I know what you have, and it is called Transverse Myelitis. The bad news is that if the steroids don't start working, as quickly as this is progressing, you'll be dead within six months." He had labeled me a T7-8 paraplegic incomplete. He had determined that I had TM based on the spinal fluid. I remember something about him saying that a normal level is four and mine was twenty-one. I did not have a MRI done, but medical technicians did the Nerve Conductor Test, many x-rays, blood work, and some I have forgotten. In the hospital they started physical therapy. On October 1, 1992, I left the hospital with a wheelchair, potty-chair, and a walker to either get better or die.

Nothing worked right. When I tried to eat, I missed my mouth. My coordination was so off that I wore more of my food than I ate. I had to give myself steroid shots in the muscles; plus, they started me on a lot of medications. The doctor decided to send a physical therapist and nurse out to see me at my home. The nurse had to check the levels of medication in my blood, which meant blood work every week. My physical therapist was one of the sweetest young girls I've ever encountered. I was really angry, but she had the patience of a saint. She encouraged me. With her help, I got to the point of being able to get up on a walker and get around my house.

One day, when I was six months into TM, my husband looked at me, sitting in a wheelchair, and very calmly said, "Joyce, I'm sorry, but I can't handle this." He was nice enough to wait for my disability subsidy to begin. I knew it was time for a change, so I moved. After a time, he came to me and wanted to try to work out the marriage. I guess the shock was a bit much. We tried for several years, off and on, but it just did not work. Finally, in 1995, I divorced him. Today, we are good friends, but we could never be husband and wife again.

I have gone through many neurologists, trying to find one that understands TM. I found one that took another neurologist's MRI and saw something. She sent me for a new MRI and found I had lesions not only at the T7-8 level, but also at the C4-5 level. That finding explained the numbness in both hands. In the meantime, I had had double carpal tunnel releases done. Most of the neurologists I saw continued with the same thing the one before him had been doing. Mississippi does not have a lot of people with TM that know about each other nor doctors that have even heard of TM.

Today, I can walk short distances. I can manage in my home on my feet most days, because there is something near to grab on to if I start to fall. I have to use a wheelchair to go out for any length of time or to do major shopping. I am one of the very fortunate ones, though. I do have some limitations, but I can live independently. I have not been able to work since 1992. I tire easily, and I live with chronic pain 24/7. My balance and coordination are off, and I have to concentrate when I am walking, making sure where my feet are and in which direction they are facing. Otherwise, my feet have a tendency to go where they want and usually end up putting my body on the ground. These difficulties are easy to deal with compared to some of the concerns others have to deal with. Until lately, I managed with a cane for short distances. I have just recently had to go to a back brace and the double arm crutches to be able to walk short distances. These devices help relieve some of the pain that walking with the cane seemed to enhance. With the cane, I seemed to walk leaning more to one side and had less control of my feet. As I write this, the use of these accessories is all new to me. This change in walking devices was another low blow to my ego. Like all things, I get over ego trips and get on with living.

My family and friends have had trouble accepting that I have anything wrong with me, so my support system hasn't been very understanding. I am the youngest in my family, and they want me either 100% OK or totally an invalid. They are extremely good to me and will do anything to help me, but they just don't understand what I go through on a daily basis. I never knew exactly where I fit in -- disabled or "normal," so it was hard to make them understand. I never felt I was one of "them" -- the handicapped. I felt this was temporary, and the doctors would find a way to make me well. For ten years I lived this way. I am in counseling today to learn to accept my limitations. All these years, I kept telling myself I would return to "normal," but I have to learn to accept

that this **is** my normal.

I am back in physical therapy, again. I started having a few problems with my feet burning; my legs are banding more, my balance is off more, and I do not have a lot of energy. My neurologist feels this new round of physical therapy may help. I have to go back for physical therapy about once a year. For some reason, I have more muscle spasms, as well as pain. This condition gets better, and then it gets worse. I have a tendency not to exercise as I need to. I realize this has a lot to do with the muscles getting weaker and my having more spasms. My weight has fluctuated back and forth a lot since I was diagnosed. I gained a lot of weight through the years, but then without trying, I began to lose weight. I found that some of the medications caused me to want to eat more. Another problem for me was depression, and I was not even aware of it.

In the first few years, I trusted the doctors and never questioned anything. Today, before I will take a new medication, I want to know all about it. I have learned through time and trial and error that knowledge is the best tool you can have to help yourself. Exercising is important; keeping one's muscles built up helps the body more than anything else. The old saying, "if you do not use it, you will lose it" is very true.

I do not let myself become discouraged. Life is too short to waste time worrying about what one cannot do. I have a good sense of humor and a strong faith in God. I feel these two traits have helped me to get to where I am today. I have learned that if I cannot do something the way I used to, I should try to find another way. If it is something I just cannot do at all, then it cannot be that important. It can wait till someone else can do it.

I have tried to return to Hinds Community College for the last five years, and I am fifteen hours away from my associate's degree in preparation for becoming a social worker. After that, I have at least two more years to complete the bachelor's degree, and for me it will probably take longer. I have managed to keep good grades and remain a member of Phi Theta Kappa, an international scholastic honor society. I have had to drop out of school many times, because of a minor setbacks (extreme pain or other physical problems), but I will continue until I become a social worker. The most important lesson I have learned is to ***listen to your body***. It will tell you when enough is enough. I may have to give in to some of the symptoms I have from time to time, but I will never give up. Everyone has a purpose in life. We each need to find it and live our lives to the fullest.

Please get involved in the Mississippi TM Support Group. I will look forward to hearing from you.

Joyce Boothe
jboothe@myelitis.org

New York State Support Group Meetings

The New York State Support Group, which focuses on Transverse Myelitis awareness and education, held its eight and ninth luncheon and support group meetings on November 16, 2002 and March 29, 2003 at Ben's Delicatessen and Restaurant in Bayside, Queens.

We hold our meetings at this restaurant, because it is centrally located and adjacent to a major highway in a large, well-known shopping mall. It is accessible to those members who live outside the city. The attendees of both meetings included members, families and friends and numbered about twenty-two to twenty-four persons. Some of the members came from Long Island, Westchester County, New Jersey, as well as New York City.

The meeting on November 16, 2002 was again chaired by Dr. Hope Klopchin, who in the past year obtained her Ph.D. in counseling psychology from the State University at Buffalo. She is a licensed psychologist who specializes in medical and health psychology. Dr. Klopchin led the group in the very important issue of "Stress Management" and as it relates to having Transverse Myelitis. Discovering how to manage stress can enable the members to better handle life's demands, bring more satisfaction and success in their lives, and help them function in a more productive manner. The strategies discussed at the meeting could help members to achieve a better quality of life.

Dr. Klopchin first emphasized the importance of recognizing signs of stress which can be both emotional and physical. Some of the emotional symptoms of stress include anxiety, anger, confusion, frustration and depression. Physical signs of stress include exhaustion, fatigue, pain and energy loss. She explained that illness and disability are some of the most stressful events that we can experience in our lives. A noteworthy point Dr. Klopchin made concerned the everyday stresses that are associated with the environment (inadequate accommodations, inadequate family support, negative attitudes, exclusion/isolation and unaffordable costs for needed services). Dr. Klopchin discussed family relationships, how family may express their feelings about the illness, and how the illness affects the relationship between you and your family. She also said that projecting negative attitudes about ourselves (loss of self-

concept/esteem) affects how others view us and feel about us. She further discussed what she called a "Negative Head Set" or unhelpful thinking and she distributed a document which listed some of the negative thinking we indulge in, such as thinking of past events and feeling it difficult to shift to the present; feeling our difficulties are hopeless which fosters inactivity; having a tendency to blow events out of proportion and over-interpret situations when we don't have all the information.

The discussion finally progressed to the use of "coping mechanisms" in dealing with the stressors of illness and disability. One of the members suggested that we think about all the things we can still do and experience. Dr. Klopchin suggested that this is a healthy way to reaffirm and redefine your identity and will lead to positive affirmations about accomplishments and qualities. The discussion then centered on short-term and long-term, stress-reduction tactics.

Dr. Klopchin distributed a quality of life pamphlet called "Coping With Disability Related Stress." As quoted from the pamphlet, some of the helpful hints to reduce stress quickly include: concentration/focusing, cooking, craft projects, deep muscle relaxation, deep breathing, laughter, movies and popcorn, prayer, reading, newspaper therapy (comics, crossword puzzles, etc), talking to a friend, writing (e.g., a poem or story). Long-term, stress-reduction strategies are used for weeks, months or years. Some helpful hints to reduce stress today and years from now for individuals and their families include advocacy and assertiveness, close relationships, counseling (individual/group), exercising regularly, future planning, healthy life habits (e.g., diet, sleep, moderation), leisure, hobbies, networking with peers, positive attitudes, support groups, socializing, travel and vacations.

At the meeting on March 29, 2003, Ms. Carrie Schauer provided a presentation on the importance of rehabilitation and physical therapy in relation to neuro-muscular disorders such as Transverse Myelitis. Ms. Schauer has a B.S. in physical therapy from Hunter College, a M.S. in physical therapy from Touro College, where she teaches several courses in rehabilitation and physical therapy, and is affiliated with the Department of Rehabilitation Medicine at Mount Sinai Medical Center in New York City.

Ms. Schauer introduced the discussion with a basic overview of Transverse Myelitis. She talked about the role of the physical therapist in managing some of the complications of Transverse Myelitis, which include spasticity, skin issues, flexibility, pain and muscular weakness in arms and legs. She discussed the issues of functional independence, which include bed mobility, ambulation, wheelchair mobility, stairs, everyday tasks (i.e., driving and cleaning) and wheelchair seating and positioning. She presented intervention therapies used for strengthening, stretching, balance, coordination, gait assessment, wheelchair issues, patient and family education and home exercise programs.

Ms. Schauer then discussed what she called "Team Approach" which employed the use of occupational therapy, vocational therapy and mental health care professionals. The occupational therapy approach helps patients learn new ways of performing meaningful, self-directed, goal-oriented, everyday life tasks such as bathing, dressing, house cleaning, and engaging in arts and crafts. The therapists teach people how to develop compensatory strategies, how to make changes in their homes to improve safety and how to change obstacles in their environment that interfere with normal activity. Vocational therapists help develop and promote work skills, identify potential employers, help in job searches and act as mediators to secure reasonable workplace accommodations. Mental health care professionals can help with depression by providing a wide range of medications together with psychotherapeutic treatment. Ms. Schauer also discussed alternative therapy approaches, such as Tai Chi and Qigong. She explained that Tai Chi is a martial arts specializing in maintaining mental and physical balance. Qigong is a system of yoga encompassing physical, mental and spiritual practice aimed at quieting the mind. Another approach is called "The Feldenkrais Method" which teaches awareness through "movement lessons."

During a question and answer period, Ms. Schauer was asked about fatigue resulting from physical therapy. Ms. Schauer suggested that you increase your therapy in small increments so as to avoid doing "too much" and practice energy-conservation techniques. She also suggested ways to improve strength and energy by proper diet, enough rest, relaxation, and healthy life-style, all of which help to maintain the rehabilitation process.

For the next meeting of the NY support group, we are going to invite a therapist practitioner of "Alternative Approaches" to physical therapy.

Pamela Schechter

Western NY Support Group

Too often we focus on the negative. After all, there are plenty of negatives to be found, especially when dealing with TM. TM brings many hardships and struggles, most prominently to the TM patient, but to his or her family, as

well. It comes in without warning, and changes everything in its path. However, TM also brings blessings. The blessings are often not seen until much later, however, they are there waiting for us the entire time. You have to wait through the rain to get to the rainbow.

My sister, Allyson, developed TM on June 25, 2001, my mom's birthday and the day after my college graduation party. She woke up a healthy 11-year-old. By 5:00 PM, she couldn't walk to the bathroom, and when she was carried there, she couldn't go anyway. She spent the next day in the pediatric emergency room and the next three weeks in the hospital. In a matter of hours, my sister had become paralyzed from the waist down. The saddest moment in my entire life was watching my baby sister in a hospital bed, strapped to a backboard, with a neck brace, screaming in pain. During those moments, I couldn't imagine anything positive ever coming out of this horrible experience.

But the horrible experiences have not lasted forever. We all survived that first 48 hours when no one could give us a clue about what was going on in her body. We all survived three weeks of living in the hospital, and having her come home in a wheelchair. Not only did we survive, we have thrived because of it.

The blessings of TM have changed my life, and the lives of my family. My sister is an amazing person. I'm sure she'd have been pretty great without going through TM, but because of it, she is simply wonderful. She knows that since she learned to walk again, she can do absolutely anything. She has compassion for everyone, and enjoys all the little things that too many of us take for granted on a daily basis. In short, she is my hero. My family is a lot closer and stronger since TM. We appreciate every day together, because we know how quickly things can change. We know we can weather any storm as long as we're together, and we're not afraid to cling to each other when the clouds come rolling in. Personally, I've learned that there is no such thing as an insurmountable obstacle and that each storm, no matter how fierce, will pass, and a rainbow will appear.

In honor of the rainbow, as well as the rain, I have created the Western NY Support Group. I look forward to helping newly diagnosed TMers through the worst of the storm, as well as reminding all of us to look for the rainbow. Please get involved in our support group! Please feel free to contact me at any time.

Shannon O'Keefe
75 Orchard Creek Cir.
Rochester, NY 14612
585-889-0059
sjokeefe79@yahoo.com

Ohio TM Support Group

The Spring 2003 Meeting of the Ohio TM Support Group was held on Saturday, May 17 in Worthington. Attendance topped 30 and included people with TM and their family members and friends. Our guest speaker was Karen Shirk, Executive Director of 4 Paws for Ability, a helper dog placement and training organization that is headquartered right here in Ohio.

4 Paws for Ability is a not-for-profit organization that provides assistance dogs for people of all disability levels, including spinal cord deficits. Their dogs are trained to assist with a variety of tasks from helping with laundry and in the kitchen, retrieving dropped items, and even aiding in mobility. They offer great companionship, as well. Karen brought two dogs with her, T.C. and River, and showed a video explaining the details of their program. She also demonstrated some of the tasks the dogs can do and answered questions for nearly the whole afternoon. Several TM'ers left with applications and are planning on getting a helper dog of their own.

Anyone interested in learning more about helper dogs and about 4 Paws for Ability can call Karen Shirk directly at (937)374-0385 or visit their website at **www.4pawsforability.org.** Additional contact information can be found on their website. Be sure to tell her about the TMA connection.

Virginia TM Support Group

The Virginia TM Support Group has been busy since its formation in October 2001. I am amazed at how much can be accomplished by two little words... *I'm new*... on the subject line of an email message! Our group has grown by the proverbial *leaps and bounds* over the past year and a half. We started with me, Ron, Jesse and our spouses. We now have 52 members, including three teenagers and their families. This has been a challenge for me, personally. As a R.N., dealing with sick kids was no problem. As a mom, it was something that you did and it was okay, too. Kids with TM? I was at a loss on how to handle this and as usual, Sandy came through for me.

With our group growing, we have decided to try to set up outlying chapters in an effort to reach people who otherwise would not be able to make support group meetings. While email is our primary mode of support, Drema had an excellent meeting in SW Virginia in April. John did not have such a good response to his meeting in the Charlottesville area in March. I try to stress that it is important not to look at the numbers of people, but at the impact that we make on the lives of

those that do attend. I know how it is to plan for 20 and have four attend, because it has happened to me before. TM is unpredictable! We are going to continue the attempts with the outlying chapters until we get it right. I ***know*** it can work. Drema and I will then coordinate a state-wide meeting. I was looking at my calendar for October. What a great celebration for a two-year anniversary party!

We are also working on a couple of fundraising projects. The first is the inkjet recycling project which several groups are working on with the TMA. I contacted the hospital where I worked, "pre-TM," and they agreed to let me put a box in their storeroom where the cartridges are returned for disposal. They do not get reimbursed for returning them, so they were more than happy to let me do whatever I wanted. Naturally, I volunteered my boys to be responsible for overseeing the project.

The second project remains in the planning stages until my newly graduated college girl, Laura, returns from her trip to Florida. She and her brothers and Buck's daughters are going to coordinate their fundraiser which is entitled, *Virginia Bowls Over TM*. They are going to visit the local bowling alleys, and enlist the owners of the facilities to donate the use of lane time, after giving a brief explanation of TM and what the funds will be used for. The basic idea is to solicit donations based on the number of pins bowled over.

My children are now 22, 18, and almost 16 years old. They know a lot about TM. In his Senior Yearbook, William wrote that his *Secret Desire* was "To find the cures for the diseases that no one cares to put funding towards, especially TM!" They had to grow up fast and I am very proud of them. They have copies of the TM brochure ready to take with them when they meet with the owner of the bowling alley. I hope to coordinate the date so that all of them will be bowling on the same day and also get media coverage for their efforts. They work hard at their fundraising.
God Bless,
Pamela New

Southwest Virginia TM Support Group

On April 19, 2003 we met in Dublin, Virginia for the first meeting of the Southwest Virginia TM Support Group. The meeting started at 10 AM in the conference room of the Comfort Inn. We had until 1:30 PM to get acquainted and share our stories before we moved on to lunch at Shoney's. The time flew by for all of us!

I am Drema O'Dell. Even though I have met others with TM in the past, and even some people from our local community, this day was a dream come true for me. The meeting was attended by four members who have Transverse Myelitis. They were accompanied by family members and friends.

We ran the gamut from weakness to paralysis in the acute phase. Each person took as much time as they wanted to tell their story or ask each other questions. No matter how much time has passed since TM entered your life, retelling your story remains so overwhelming. The newest to TM was a 30-year-old mother of two who was diagnosed in November 2002. The remaining three of us are older; suffice it to say, around 50!

Two of us had very acute initial attacks with chronic ongoing residual effects. One woman in our group has recurrent TM. She also has probable MS. There are several other people from this area of Virginia who contacted me, but were unable to attend this meeting. We hope that they are able to make it to the next. We plan to hold our next meeting in Roanoke, Virginia.

I came to know about Transverse Myelitis on November 20, 1989. I was at the peak of my career in direct sales. I was responsible for a five-county area and with 36 dealers working with me. I had a good income, along with company perks like a minivan and travel awards. Suddenly, it was over. I went to bed around midnight in good health and no preceding virus. I was over-worked and stressed to a small degree. I had a flu shot three weeks prior. I had surgery six months earlier and did have a nagging area of gripping in my side, with some numbness of the skin in the area. I also had a mild case of shingles about three months before. I had a very severe whiplash injury in a car accident a couple of years before. At 3 AM, I woke up with pain in the center of my chest, across my shoulders, and down my left arm. I used a heating pad and took hot soaking baths a few times. I ended up in a recliner with the heating pad and a bottle of ibuprofen by my side. I was just in so much pain.

My husband got up to leave on a hunting trip. I convinced him that I had the world's worst case of bursitis and he should go ahead. The pain had eased some by the time my daughter got up and she went on to school. Just as quickly as the pain in my chest, shoulders and arm eased, it moved down my back. It didn't occur to me that I had not gone to the bathroom for many hours. My right leg began to jerk all around in violent movements and I had strong pain. My daughter arrived home from school and insisted that I go to the doctor. I got up! I could bear weight on my jumpy right leg, but my left foot was drawn up

from the floor and hanging in a droop. My left hand was drawing also.

The ER experience took hours. Since the pain started in my chest, I was placed on a heart monitor behind pulled curtains. My leg continued to jerk around. It was ignored. After four hours, my 16-year-old daughter was asked to get me back home and take me to my family doctor in the morning. When they assisted me off the table, I had no legs to stand on. Back on the table, they decided to admit me. When I arrived on the floor, I was in the room less than five minutes when my neurologist who treated me for migraines and whiplash came in the room. He tried to stand me up. No luck. He then did pin pricks to determine my level of sensation loss. Nearly collar bone. He told me they did not have the treatment options there I would need and I was being transferred to Roanoke. IV's were started while I waited for the ambulance to take me away. Steroids in the drip plus an extra injection for good measure. In Roanoke they told me that the steroids probably kept me off of the ventilator!

I had one good arm. Everything else was affected; bowel and bladder; no walking; no movement of my legs at all. My left arm had movement, but my fingers were drawn inward and the whole arm was so weak I could not really move it. I could rotate my trunk some in the bed. Three weeks later, I got back small movement in my right big toe. I was denied entry into their rehab hospital. Four and one-half weeks in the hospital there and I was sent home in a wheelchair. As movement gradually returned with intensive therapy, I graduated to a brace for the foot drop, knee braces, walker, and a back brace. I eventually traded the walker for a quad cane. I walked with the braces and quad cane for about three months. I used the foot brace for two years. I walked with a limp full time for much longer, even though I did not realize it! Others did.

I am so fortunate to have had such a great recovery. Yes, I have those wonderful residuals. Bowels that would never move without extra motivation. Urinary incontinence. Back pain! Leg spasms. Spasticity when cold or overtired. Leg torment at night. Toes that draw under. Reverse hot/cold sensation. My right side has loss of skin sensation. Left side is weak. Burning and freezing and tingling sensations. I have had several periods of deteriorating symptoms. I have done PT off and on for 13 years. I am currently in a great cardio and strengthening program at the YMCA. My weak leg gives out without warning and I usually can expect to fall several times a year. I never sleep much, because of the pain and spasms. Right now I use baclofen and clonazepam. I have used Neurontin. I have been evaluated for MS. Not proven. I have been to Dr. Kerr at Johns Hopkins twice. He is so nice and works so hard for all of us. I want to go back again soon.

I did not have access to a computer until about 1995. From 1989 until then, I only had limited access to information. I was given the name of Deanne Gilmur through NORD at the time she was getting started with the TMA. I wrote her and received what information she had through the mail in a few days. Still very confused and frustrated by my doctor's belief that I did not have all the problems I knew I did, I called Deanne up on the phone. That conversation has changed my life! What a relief to know I was not a crazy hypochondriac.

I have been to every national meeting the TMA has offered. I have made lifelong friends and learned so much. Deanne, Dick, Sandy, Pauline, Paula, Myk, Debbie, Jim and everyone I have met through the TMA - you are so important to me! I am excited about the research for the future. But to me the most important thing is supporting each other. How great it is that new patients and their families do not have to wait years to get accurate information about what has happened to them. Local support groups are needed to allow us to talk to others who know what we need. I was stunned to hear another lady at our meeting tell of a strange gripping pain in her side that is relieved by holding her arm above her head. I have the same problem. I have literally been laughed at by my doctor when I have told him. But I know - and so does Lois!

If you live in this area of the country, please get involved in our support group. You can contact me by email, by mail or by phone. I would love to hear from you!

Drema O'Dell
3695 Bill Street
Pulaski, VA 24301
(540)980-0286
dho@i-plus.net

The Texas TM Support Group Coalition

The Texas TM Support Group Coalition was established in February of 2003. The Coalition is starting out small, but growing in numbers. Since Texas is so large, we have divided up the state with different contact people in different areas. Our hope is to form a group of people who can be a resource for each other in their local communities, as well as support on a state level. So far, the contact people are:
Cossy Hough, Central Texas

Barbara Lamb, Dallas/Fort Worth
Bob Cook, Houston
Nita Frier, Abilene

There have been two meetings of people with TM in Austin. The first meeting was held in February and the second in May. There were six people with TM who attended each meeting and some attendees brought friends and family members. Attendees have traveled into Austin from as far away as Houston and Waco. We discussed many topics, from how we were diagnosed, to symptoms and limitations, to physicians in the area.

The Texas TM Support Group Coalition established a website in April and plan to expand the site to include more resource information. We also hope to have more meetings this year and to create a system that can advocate for people with TM in Texas.

We are looking for contact people for other areas of the state, including East Texas, The Panhandle, West Texas and the Valley. If you are interested in becoming a contact person, please get in touch with Cossy Hough.

If you would like more information about The Texas TM Support Group Coalition, please go to:

http://texastm.tripod.com/

or you can contact Cossy Hough at:
cossy@yahoo.com
or (512) 420-0904.

You can also find a link to the Texas TM Support Group Coalition web site from the support group page on the TMA web site.

Support Groups Desperately Needed In Brazil, each Province of Canada, India, and Everywhere Else.

This is a call for action: The TMA needs a support group in every state, in every major metropolitan area and in every country where we have a member. Check the support group page on the web site and the membership directory. If you do not have a support group, please volunteer to start a group in your city, state or country.

Okay, so, he calls for action; what gives? He couldn't get Aaron and David to cut the lawn or take out the garbage for the past twenty years, and he thinks he's going to mobilize the development of a worldwide infrastructure for the TMA by his 'call for action.' Hey, as I get older, my doctors continue to incrementally and yet steadily remove every pleasurable activity from my repertoire; please at least leave me my delusions. Thank you.

Local support groups have become a tremendous resource for people with TM and the other neuroimmunologic conditions. The support groups that have formed around the country and around the globe have served to bring a network of emotional connections to people who otherwise would be very isolated in their experiences with these rare conditions. The support groups have also become a great source of information about resources that are available in local communities. These groups exchange information on everything from references to physicians to good places to purchase medical supplies to local social service programs that may assist in purchasing medical equipment. The support groups have also been very actively involved in fundraising and awareness activities. The international organization is never going to be able to provide this level of information to our members. The support groups have become a critical source of local information and support.

People are reticent about getting involved in doing this work, because they are concerned about being overwhelmed with more than they can handle. Please do not be concerned; the work is not overwhelming, and very quickly you will not feel like you are doing work. And here's the big support group secret – the greatest beneficiaries from the support groups are the support group leaders. For every ounce of good you create in the way of helping others, you will be provided with double the good feelings in return. No kidding.

So, what is the job of a support group leader? Well, every support group leader has brought their own personality, talents and experiences to the position, and have created their own specific approach to developing and conducting their support groups. The great benefit for the TMA of the not one-size-fits-all approach has been the generation of lots of creative ideas for providing information and support. And what one person or group does in New York or Ohio or Virginia serves as the source of a new idea or approach that is often adopted by some of the other support groups. The creating and sharing has been one of the more exciting developments for these support groups.

Some of our support groups have started by a person contacting me indicating that they would like to start a support group. Most of the support groups have been initiated by a person calling me and asking me for the support group in their area. My response is usually – there is no support group in your area, but obviously you understand the value of a support group, please let me help you start one. Very

few people have declined the offer. And I will tell you, our support group leaders are really incredible people. All of them have TM and are caregivers. They are an extraordinary group of kind and caring and compassionate people. And they do bring so much intelligence and creativity and skill to these positions. And they come from all walks of life and educational backgrounds and cultural backgrounds. I sometimes think about the group of people who have been brought together by this unfortunate circumstance in their lives and how much good has been created from such a bad thing.

The first thing I ask a person to do when starting a support group is to get into their membership directory and find people in their communities or states or countries and get as many people involved as possible. I often know people in their communities and I suggest people for them to call. I encourage them to share the work as quickly as possible. The support group leaders are facilitators and opportunity creators -- everyone should be doing the work. And this way, no one becomes overwhelmed.

The first job for the support group leader is to write an introduction article for the newsletter so that we can announce that there is now a support group available in this area. And we set up a support group page on the TMA web site. Jim Lubin is wonderful to work with in the process of setting up a web site. People have taken many different approaches in setting up their sites and in the types of information and communication opportunities that are offered.

The primary purpose of the support groups is to be available to offer support. This support is offered in phone calls, via email messages and at support group meetings. Support group leaders provide their contact information on their web pages and also in their newsletter articles. I also identify support group leaders in the membership directory. In addition to these contacts, when a new member registers with the TMA, if they indicate that they want to be listed in the membership directory, and if there is a support group in their state or country, I pass their contact information on to the support group leader. They are then contacted by the support group leaders and are offered emotional support, information about the TMA and our web site and information about the local area support group. The best way to learn about all of the various activities that support groups engage in is to review the articles in the newsletters written by the support group leaders and also by reviewing their web sites.

Some of the support groups have designed their own logos and have worked with Jim to set up items on the Cafepress web site. In addition to my many TMA, Reading for Rachel and Children's Workshop items, I am also the proud owner of Ohio and California support group coffee cups and t-shirts. It is a wonderful way to bring awareness to the TMA and TM and also a great way to create a sense of camaraderie among your group members. Logos and support groups … some day, when I really want to wow you with all of the amazingly esoteric stuff I have rattling around in my brain, I'll write an article for the newsletter about totems. Okay, how many of you just thought, I hope he decides to retire first?

Our international support group leaders do a tremendous job of assisting me with translations. If I receive a message from a person in a language other than English, the international team is able to assist me in effectively communicating with the person. I took five years of Spanish and all I know is *Hola, Paco, que tal, como estas?* Thank goodness, Yvonne and Marina are there to help me communicate with everyone who is not named Paco.

The following are the current requirements for these important leadership positions around the world. You need to be able to listen to people. You need to have compassion and empathy. You need a lot of common sense. You need to know the difference between right and wrong, and then practice what you know. You need a telephone. You need to be able to organize a small meeting. You need a computer with internet access. And you must speak English well enough to understand when I am being sarcastic and are able to comprehend my sense of humor well enough in order to find me absolutely hysterical.

We have relatively large memberships in Canada, India and Brazil, and there are currently no support groups. If you have an interest, please get in touch with me. If you have any concerns about being able to do the work, please get in touch with any of our support group leaders before you contact me. Ask them about the amount of work that is involved and how they handle it. Then please call me or write me an email. We need support group leaders in every province of Canada. We need a support group in India. We need a support group in Brazil. I need a support group leader to alphabetize the Brazilian names for the membership directory. I owe a deep and sincere apology to our Brazilian members for the total mayhem I have created of your names in the directory. Please become a support group leader and help me eradicate the totally embarrassing list I have created of your beautiful names in the directory.

Pam Schechter serves as the support

group coordinator. Pam leads the support group in the New York City area. If you ever have any questions or concerns about your support group or starting a support group, please get in touch with Pam. I would recommend communicating with all of the other support group leaders. They can provide you with great information and advice.

Ultimately, I would like for most of the international mailings to be done by the support groups around the world. As we are in more than sixty countries, our postage costs are becoming quite high. Geoff Treglown has done an amazing job of doing the newsletter and directory mailings with assistance from his group. And they do all of the work from electronic materials. I send them the files and they do a beautiful job of translating all of the information onto the different size paper that is used in the UK. Then they do the entire mailing for Europe. Geoff has also forced me to learn which countries are not in Europe. Hey, give me a break; we have people here who think Alaska is a country. Errol White has not only taken care of the newsletter and directory mailings for Australia and New Zealand, he now also handles the membership packet mailings for these countries when we receive new membership registrations. This approach is going to be able to save the TMA a great deal of money. And every dollar we do not spend on postage is a dollar for the research fund!

I have more returned mailings from Brazil than any other country; envelopes returned with a bad address. These new membership packets cost us $5.70 per each mailing. Can I tell you that when one of these returned envelopes appears in my mailbox, it makes me totally nuts – and like I need any help in that area. If there were a support group in Brazil and someone who could assist me with these mailings, I know that we could minimize these returns and cut down on the waste. Hey, I'm trying to run an efficient operation; and I take spending your money very seriously!

Brazil, Canada, India … please get involved. Please help me. Please help those in your community who need the opportunities to meet and to learn and to share. And Massachusetts? What gives? If you live in a state, country or community that does not currently have a support group, please get in touch with me, and I will help you get started in this important role.

Fundraising and Awareness

Reading For Rachel Update
Cathy Dorocak

It was another successful year for our Reading for Rachel campaign and this coming year promises to be even better with more commitments from new schools to participate. We are very proud of the fact that our reading program has raised approximately $30,000 for TM research since its inception four years ago. What a wonderful gift we are giving to Rachel and to others with TM – the gift of hope!

Participation is easy. We simply contact schools in our area and ask them to have the students participate in our reading program. We do this by involving the PTA leadership to help make this event happen at the school. We have learned that the best time to do this is early in the school year before all of the planning is complete. We ask them to check out the website: **www.readingforrachel.org** to learn more about Rachel and the affect Transverse Myelitis has had on her life. All of the materials needed to participate in the program can be found on the website and it can be modified in any way a school sees fit.

It works like this: Kids are asked to read books, pages, chapters (whatever the school decides is appropriate for the grade level) and they obtain pledges for their reading efforts. At the end of the Reading for Rachel campaign, the kids collect their pledges and turn the money into the school. Cash is converted into a check for The Transverse Myelitis Association and individual checks are sent in as well – noting Reading for Rachel on the memo line. It is exciting to see how each school does and it can really add up. We have been to several of the participating schools, including Pauline Siegel's school (where she is a 2nd grade teacher) and it is so wonderful to see how excited the kids are to help out. It is definitely a win/win situation – the kids are reading and feeling good about it and it helps the research fund of the TMA!

We have had kids read for a day all the way up to a month and we have also received money into the Reading for Rachel fund in a number of other ways, including:

Flat donations: either for kids just participating, via donation bins in school cafeterias, or by someone reading about Rachel's TM and donating from the website information.
Penny Wars: this is a lot of fun and usually raises a lot of money – kids

save pennies which are counted, but other classes put silver into a bucket and this subtracts from the total. The class with the highest net total wins! You can see how this can be fun for the kids trying to sabotage each other's class!

Donations in honor and memory of someone's death: - the Reading for Rachel Program/TMA has become a favorite charity of several people.

Valentine Heart Grams – one school in our area has the children send each other notes on little hearts the entire week of Valentine's Day. Each one costs 25 cents and the kids just love it. It has become an annual tradition at this school and all money raised goes towards Reading for Rachel! A girl scout troop at the school worked on this as their monthly service project this past year.

Sales of Goods/Services – For example, Rachel's Grandpa makes birdhouses and donates the money he makes from that into the fund.

We are hopeful you will get involved in raising money for the TMA and if you need an idea, please consider using the Reading for Rachel Program to do it! Everything is all set up on the web site and you can make the program come to life locally with your own (or your child's) TM experience. In this process, we have reached another local person who had never met anyone else with TM (she is the grandmother of a kindergarten student in our area). Besides the money we have raised, we are grateful to have made the connection with this person. And, we are definitely raising awareness of TM. If you have any questions at all, please contact me and I will be happy to share my ideas with you.

Cathy Dorocak
Reading for Rachel Chairperson
(440) 572-5574

Hello fellow TMer's. My name is

First Annual Texas Roll-A-Thon

Barbara Lamb

Barbara Lamb. I am the TM Support Group contact person for the DFW area in Texas. I am planning a huge fundraiser called the First Annual Texas Roll-A-Thon to raise money for research and awareness for The Transverse Myelitis Association. The event consists of a two-mile trail by The Ballpark In Arlington here in Arlington, Texas. It will be held September 27, 2003. After the event, there will be a barbeque catered by Sonny Bryan Barbeque, which is only for the first 200 people who register. During the barbeque, we will be raffling off a handmade commemorative quilt made by my mother, as well as other items which have been donated.

We hope to make our first year's event a big success, so if you feel like joining us in Texas or live close by, please put us on your schedule. We appreciate all of the volunteers or participants we can get. If you want any additional information, please e-mail me at texasrollathon@yahoo.com.

Given the publication schedule of the TMA Newsletter, I have no way of knowing whether this newsletter is being delivered to you before, during or after Barbara's First Annual Texas Roll-A-Thon. If it is before and you live in Barbara's area, please try to participate and attend. If it is going on right now, please hurry down to the stadium. If it is after September 27th, darn, I was afraid that was going to happen. Barbara, I'm really sorry. But it is not too late for next year. Remember, this is the ***Annual*** *Texas Roll-A-Thon. Please get in touch with Barbara and offer to help her with the planning of next year's event. Please get involved and participate in this wonderful fundraiser. Barbara and I would love to have the Texas TM Community make this into an annual awareness and social event, in addition to becoming a successful fundraiser for the Association.*

Barbara got TM as an infant. She is a quadriplegic. Barbara is a very independent and wonderful and young and vibrant 20-something year old. She is a college student in graphic design. I met Barbara a couple of years ago with an exchange of emails and phone calls. She is a whirlwind, full of great ideas, lots of energy and enthusiasm, and charm and talent. Please get involved in Barbara's work. We owe this to Barbara, and we owe it to the people of the TM community who so much deserve the important research that will be made possible by this great project. Barbara and I are so appreciative of your generosity!

This was truly an experience, taking

Ann's Quilt Raffle

Deborah Capen

on the task of holding an "international" raffle. This started in 2001 when Ann Moran came from Ireland to the Second International TM Symposium in Baltimore, Maryland. Ann presented the TMA with a quilt that she had pieced together with squares that had been made from members around the U.S. and the world. We thought for a long time how to best utilize this opportunity that Ann had given us to raise funds and awareness of TM – actually we thought about it for a little over a year!

It was finally decided that we would have a raffle; sell tickets and ask all of our TMA membership to help by getting involved. I did not know of the intentions of the future winner of the raffle at this time. Beverly Christen-

sen of Sacramento, California had traveled with her daughter, Doreen, to Baltimore to attend the symposium. She met Ann and spent a lot of time with her during the four days in Baltimore. When Ann presented the quilt, Beverly said to herself, "I want to get involved when this happens!"

The raffle was announced in the last newsletter, and Beverly started getting busy. Beverly printed the tickets that we made available on our website. She printed hundreds of tickets. She sold them to her family members, all of her friends, and anybody else who would listen to her. Transverse Myelitis is a name that has been in her family for over 45 years. Her daughter, Doreen, has had TM since she was 19 months old.

When I received the large envelope and letter in the mail, I was overwhelmed. I think I sat in my truck and cried for a little bit, and don't remember the drive home. Beverly is very proud of her daughter, Doreen, and her independence, and living her whole life with TM. I could tell that from the letter that I received.

I do not want to minimize the hard work that was done by so many TMA members. I had a lot of help from my own Southern California TM support group. Without them, I really don't think we would have had as much success as we did. All of the TMA members together sold over 1,000 tickets and we raised a total amount of $2,045.00. This money will be used to support the activities of The Transverse Myelitis Association.

By the way, Beverly was not the official winner of the quilt. Her other daughter, Gail, was the winner. I think that they are a very close-knit family and that the quilt will be enjoyed by all, and I am so very pleased that Ann's quilt was won by the Christensen family. It could not have a better home.

Thank you, again, all of you, for your support and your hard work in making this fundraiser such a success. Most of all, thank you, Ann, for the great opportunity you created for all of us, by creating such a beautiful quilt. You are a treasure in our community, Ann. Thank you!

Pasta with a Purpose Party

Lynne Chafetz and Brad Hampton

On May 31, 2003 with much help from family and friends, we held our first fundraiser for TMA at our home, the ***Pasta with a Purpose Party***. We sent invitations (designed on our computer by our daughter, Eve) to about 125 of our family members, friends and colleagues, asking them to join us for a hearty meal and good company to raise funds in support of The Transverse Myelitis Association. We included a letter with information about the TMA, the support we received when Eve contracted transverse myelitis in May 2000, and the important work the TMA does to provide support and education, as well as to support research. We explained that the TMA was holding an important steering committee meeting in Seattle and that we were raising funds to support that effort, as well as TM research.

About 70 of our invitees attended the party and those who could not attend generously made donations ranging from the "Penne Level" ($50) to the "Cannelloni Level" ($1000). By the day of the party, we had already raised over $5000. Lynne spoke for a few minutes to thank everyone for joining us, followed by very moving words from Paula Lazzeri (the TMA's Treasurer) about her experience contracting TM and the TMA, including its website and webmaster, Jim Lubin. We prepared a simple Italian dinner and many antipasti (prepared by Grandma), pounds of pasta, cans of tomato sauce, heads of lettuce, loaves of garlic bread (prepared by a dear friend), bottles of Italian wine, amaretti cookies and tiramisu cakes later, we had raised a total of over $12,000. While a bit hesitant before this event to ask our family and friends to contribute, once we "made the ask," we found the response overwhelming. As people left the party, they commented on how wonderful it was and asked that we please repeat the event -- so this may become the first annual ***Pasta with a Purpose Party***.

I would be happy to share our party invitations and planning information with anyone wanting to do a similar event.

Lynne Chafetz and Brad Hampton
bradlynne@comcast.net

The Lazzeri TMA Fundraiser

Paula Lazzeri

After hearing the many pleas for raising money from Sandy, I decided it was time to get to work on my own fundraiser. On June 28, 2003, I held a dinner and raffle fundraiser to benefit the TMA. With the help of my friends and family, we put together a plated pasta dinner and charged a set fee. In addition to dinner, we raffled off several items, including Mariner tickets, concert tickets, a kid's toy basket, coffee basket, and note cards. Most of the items raffled were donated by local companies. It was a wonderful evening spending time with all my family and friends while, at the same time, helping a cause so near and dear. Overall, the evening brought in over $4500. The entire evening was very easy to organize and my family and friends were thrilled to be able to help.

They were also glad to have the opportunity to support our Association.

Worthington Estates Elementary

Worthington Estates Students Raise TM Research Funds from Toy Sale and Reading for Rachel

Pauline H. Siegel

School has adopted the Reading for Rachel Program as an annual event. I am really honored to participate in this program as it affords me some wonderful opportunities. We are able to raise money for TM research, which is so important for all of us who have this condition. It allows me to promote reading among my second graders, which is a passion for me. The program helps me to teach my students how important it is to get involved in their community, to participate as good citizens to help make their community a better place. And it helps me to teach lessons about how important and rewarding it is to help others.

One of the best features of the Reading for Rachel Program at our school is that Rachel and Cathy Dorocak are able to come to kick off the month-long reading fundraiser with us. It is a long drive for them to get to Worthington, but their visit leaves such an incredible impression on all of us at our school. Almost the entire day at our elementary school is devoted to Rachel's visit and the reading program. Rachel and Cathy share lunch with some of the children, we visit many of the classrooms during the day and talk to the children about why we are asking them to raise this money. We talk about TM and we explain to them in what ways TM has impacted both Rachel and myself. There is an assembly during which Cathy shows a video about Rachel's therapy sessions and also answers questions for the students. The day is wrapped up with a short meeting with the teachers and staff to describe the program and also to answer any of their questions. It is a very long day for Rachel and Cathy, but their presence makes all the difference in the world to our students, teachers and staff.

Rachel is such a smart and charming person; and she is such a character. The children really develop a concern and care for her, even from the short visit. I have children asking me about her all the time. They want to know when was the last time I saw her, and they want to know how she is doing. During this last visit, Rachel left such an impression on the students, that some of them held a toy sale to raise money for TM research.

These children were third graders, some of whom had been in my class the previous year. Each of them gathered up some of their own toys that they were willing to put up for sale. They held the toy sale over two days. During that time, they rode their bikes all over the neighborhood advertising the toy sale. These students raised more then $75 from their sale, and they donated the money to the TMA research fund! I am so proud of these students. This was such a wonderful thing for them to do. Thank you, Andrew, Steven, Eric, Ruthie, Bryan, Conrad, Evan, and Greg.

Worthington Estate Elementary School raised $2855.13 from the month-long Reading for Rachel Program. Our principal, Dan Williams, and Kimberly Forte from our PTA gave the program their full support and efforts. Coincidentally, Dan was the principal of the elementary school in Strongsville where Cathy's sons initiated the Reading for Rachel Program.

I am very proud of my school, our wonderful students, teachers and staff. Thank you!

The Most Successful Method for Raising Money for Research

The most successful fundraising activities we engage in are those that focus on our friends and family members. I know, I'm sounding like a broken record. Try to get used to it, because I don't plan on quitting. If we want a cure for myelin and nerve damage, we need more research, and if we want research focused on the damage caused by the neuroimmunologic disorders, we need to raise the money. No one else is doing this fundraising and no one else is going to do it.

If we are going to raise this money, the vast majority of it is going to come from you and from your friends and family members. Why? Because they are the only people in the universe who know about these conditions and they are really the only people who care!

I am not comfortable asking my family for money. I am less comfortable asking my friends for money. I am no different than you. But I have learned to do it, because I have come to accept that this is the only way I can make the difference for Pauline and the so many others of you who I have come to love and care about so deeply.

I have an idea which I think might make this easier for you to accomplish. I have written a letter and have posted it on our web site. You can find it from the 'donations' link under the title ***Fundraising Letter for Christmas Cards***. I have included important information about TM and the neuroimmunologic disorders, about the TMA, and why it is important for

the TMA to succeed in raising money for research. The letter is created in Word. Since most people have MSWord on their computers, I am encouraging you to personalize this letter. Please include information in this letter about how TM and the other neuroimmunologic conditions have impacted your lives, and why you need for this research to be done.

When you send your Christmas cards this year, and every year, please include a copy of this letter in your card. Just fold it and put it into the card; it won't cost you a penny more in postage, unless you are sending really fancy shmancy and heavy cards or your letter becomes a book. So, what's a little more postage? And, if you don't celebrate Christmas, you can include the letter with any regular correspondence you have with your family and friends. You can include it in all of the cards you send to people! *Happy Birthday, Uncle Harold; and oh, by the way ….* Or use the letter as a good excuse to communicate with your family and friends. Send all of them a letter to let them know how you are doing; and include this letter with your mailing.

Do it for yourselves and do it for the other children and adults in your community who need this research and the great hope that this research brings for all of us.

~~All donations to The Transverse Myelitis Association may be sent to:~~

Paula Lazzeri
Treasurer
10105 167th Place NE
Redmond WA 98052

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

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

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

As a result of this situation, I have to do a separate and special mailing that is devoted to checking the accuracy of the TMA membership database. The process involves a lot of work, a lot of money and about four months of time to complete. And the cost to the Association is substantial, because until we perform a mailing to correct the address information, the materials we are mailing to a bad address just ferment on some post office floor. These are wasted printing and postage costs.

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

The following tables present The

The Transverse Myelitis Association 2002 Statement of Financial Activities

(in US Dollars)
Paula Lazzeri

Transverse Myelitis Association Annual Financial Report for 2002. 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 2002. This column includes funds/activities reported in the TMA (General) Fund, as well as non-reimbursed expenses paid by members of the Board of Directors. These non-reimbursed expenses also are shown as Donations made by Board of Directors under Revenues. The Donations made by Board of Directors line item presents the amount of funds spent by members of the Board of Directors that were not reimbursed by the TMA (General) Fund.

The Transverse Myelitis Association Treasurer's Annual

Report: 2002

Income	**TMA Funds**	**Total Donations and Expenses to Benefit TMA**
Amazon.com Donations	118	118
CaféPress Donations	1,072	1,072
Children's Workshop Donations	64,945	64,945
Donations made by Board of Directors	0	8,561
Endowment Donations	250	250
Endowment Interest	119	119
General Donations	34,800	34,800
Interest	2,219	2, 219
Research Donations	1,573	1,573
Total Income	**105,096**	**112,466**
Expenses		
Bank Fees (cashier checks, merchant Svcs)	50	50
Board Meeting Expenses	0	2,605
Domain/Web-site/Webhosting	419	419
Internet Service Provider	0	968
Johns Hopkins Coordinator Research Position	25,000	25,000
Membership fees	0	60
Mileage and Parking	0	96
Office Equipment	0	2,238
Office Supplies	0	1,350
Postage	10,128	10,762
Printing	4,216	4,340
Software	131	131
Secretary of State Registrations	490	490
Telephone and Fax	0	447
Workshop Expenses	31,928	31,928
Total Expenses	**72,361**	**80,882**
Net Income	**32,734**	**32,734**

The Transverse Myelitis Association 2002 Statement of Account Balances

Operating Fund	**83,565**
Research Fund	**32,462**
Children's Workshop Fund	**45,368**
Endowment Fund	**9,742**
Endowment Interest	**400**

The Transverse Myelitis Association 2002 Donors

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer the services to our membership; they also make possible the expansion of services to our existing and future members. The following persons and organizations made donations to The Transverse Myelitis Association in 2002. The donations made by members of the Board of Directors include non-reimbursed expenses.

$5-25

Annette Allison
Bruce and Janet Andrews
Msgt. Pio and Elizabeth Arroyo, HQ USAFE/DOTZ
David and Jacqueline Baker
Michael Ball
Michelle Banks
William and Joy Barnes
Don Batchelder
R.J. and Wilma Bartholomew
John and Susan Beck
Beck's Trucking
Emma Louis Benedict
Larry and Susan Bergman
Pearl Bernocchi
Patricia Bernstein
Agustin and Mildren Bigornia
Thomas and Sandra Blacker
Richard Bogard
Donna Bosco
Donna Burkhardt
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Terry and Maureen Jones
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Arthur and Dorothy Lassila
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H. William and Kristin Muller
Thomas and Lois Mulvey
Colonel M.L. and G.H. Ogilvie
J-Paul Parisien
Milree Parsons
Glenn and Barbara Partyka
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Pamela Perry
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Roland and Doris Phinney
Kenneth and Sharon Pipes
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John and Mary Smith
Harold and Ann Sorley
Ralph Spiegel
John Stallard
Margaret Sweeney
Tha Hair Company, Gary and Helen Skinner
Brad and Christine Thwing
Vera Thyes
Ann Tierney
Robert and Doris Trax
Randolph and Marie Walker
Kenneth and Naomi Wegmeyer
Derek Whiteley

Tony and Cheryl Willever
Richard and Jane Zembra

$25-50
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Robert and Hattie Appley
Nevin and Donna Armstrong
William and Bonnie Barnes
Ronald and Susan Batzer
Ted Canterbury
Steven Carter
Paul and Mary Clemmitt
Barbara and Daniel Cole
Gregory and Irene D'Anna
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Lane and Jane Duvel
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Robert Glasser
Margaret Gough Memorial:
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William and Penelope Gray
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Kara Nielsen
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Donald and June Hartwig
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'Lyn Pignon
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Department of Neurology
University of Kentucky
Kentucky Clinic
Wing D, Room L-445
Lexington, KY 40536-0284

James D. Bowen, M.D.
Assistant Professor, Neurology
Multiple Sclerosis Center
University of Washington
Box 356465, Room RR650
19 NE Pacific
Seattle, WA 98195-6465

Dr. Adam I. Kaplin, M.D. Ph.D.
Consulting Psychiatrist, JHTMC
Departments, Psychiatry and Neuroscience
Johns Hopkins Hospital
Meyer 115
600 North Wolfe Street
Baltimore, MD 21287

Douglas Kerr, M.D., Ph.D.
Assistant Professor, Neurology
Director, Johns Hopkins Transverse Myelopathy Center
Johns Hopkins Hospital
600 North Wolfe Street
Pathology 627C
Baltimore, MD 21287

Charles E. Levy, M.D.
Assistant Professor, Orthopaedics and Rehabilitation
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North Florida/South Georgia Veterans Health Service
University of Florida
1601 SW Archer Road
Gainesville, FL 32608

D. Joanne Lynn, M.D.
Associate Professor, Neurology
Multiple Sclerosis Center
The Ohio State University Medical Center
453 Means Hall
1654 Upham Drive
Columbus, OH 43210

Leslie Morrison, M.D.
Associate Professor, Pediatric Neurology
University Health Sciences Center
2211 Lomas Boulevard NE
Albuquerque, NM 87131

Frank S. Pidcock, M.D.
Associate Director of Rehabilitation
Assistant Professor of Physical Medicine and Rehabilitation and Pediatrics
Kennedy Krieger Institute
Johns Hopkins University School of Medicine
707 North Broadway
Baltimore MD 21205

Officers and Board of Directors of The Transverse Myelitis Association

Sanford J. Siegel
President
1787 Sutter Parkway
Powell OH 43065-8806
(614)766-1806
ssiegel@myelitis.org

Stephen J. Miller
Vice President
1717 State Route 72 South
Jamestown OH 45335
(937)453-9832
smiller@myelitis.org

Paula Lazzeri
Treasurer
10105 167th Place NE
Redmond WA 98052
(206)883-7914
plazzeri@myelitis.org

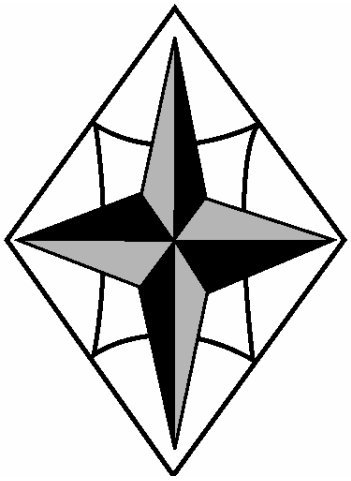
Deborah Capen
Secretary
PO Box 2084
Hemet CA 92546
(909)658-2689
dcapen@myelitis.org

Jim Lubin
Information Technology Director
jlubin@myelitis.org

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

The Transverse Myelitis Association

Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065-8806



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