❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

As seems to be my style, I will begin this column with an apology; I am sorry that this newsletter is being sent to you much after its intended publication date. The original intent was to have the newsletters published every six months. How about if I promise to distribute two newsletters in a calendar year? Thank you for your patience and understanding.

In addition to the work on the newsletter, I continue the process of entering the survey data. It is my goal to have the data entered and ready to analyze within a few months. Drs. Lynn and Levy are reviewing the content of the survey to assist us in determining areas that would yield good results from the perspective of the medical community. We fervently believe that the survey work offers us an important tool for learning about TM and for educating physicians, other health care providers and ourselves.

As is noted elsewhere in this newsletter, our membership is growing quite rapidly. We have more than quadrupled our numbers in a year and a half. If the published incidence of TM, as 1 in 1.3 million, is in the ballpark, there are thousands of people in the United States who have this diagnosis. Every decade there would be approximately 2,500 people who are diagnosed with TM. The Association has been in existence for under five years, and people are just beginning to find us. And we are being found by people from all over the world, thanks to the really wonderful work that is performed by Jim Lubin. Our web site is being visited by thousands of people from every state in the United States and from countries all over the world. Our membership looks like the United Nations.

Our membership is a community. We are a community represented by a tremendous diversity of cultures and languages. We are men and women and boys and girls. We are of many different races and ethnicities. We come from every walk of life, from every economic class, and from every religious heritage. We are a community because we share a common interest and concern that has become an integral part of all of our lives. It is a common interest that no one else understands quite like we do; that no one else appreciates quite like we do. None of us willingly selected membership in the community, and all would gladly turn in their membership card if given the option. But our membership is a community. A community with a shared history of experiences. A community with a shared language ... girdling effect, AFOs, L'Hermittes Sign, spasticity, Tegratol ... I don't often use this language outside of this community. It is a community with a shared concern, and a shared desire to educate ourselves and each other, to support each other, to encourage each other.

We are a community so long as we are communicating with each other. Communication is the life-blood of our TM community; communication is how we are held together. And that is the reason the newsletter, the TMIC, the directory and the conferences serve such vital functions for our Association. These are our vehicles for communication in our community. I read every message that is posted on the TMIC. I have observed that part of our community grow and flourish over the past two years. The community expands and contracts and expands. New members appear...frightened, confused. Support, encouragement and information begin to flow immediately ... from Jan, Barbara, Gunny, Phil, Maureen, Sharon, Netta, Nora, Jo Ellen .... Bob has at least five or ten new pieces of medical research posted every week. Someone asks for a definition of a medical term; Jim offers a few links to medical sites where you can spend a month reading about that term. The communication goes on day and night, every day... and it goes on between members of a real community.

Deanne and I are contacted by people all the time who are looking for information about doctors, hospitals, and social services. We do not have this information, because it has to be dealt with on the local level. We send everyone a membership directory and we encourage everyone to develop and nurture their local TM community. We are motivated to hold a conference for the Association next summer, because we recognize what

that contact means for the development and cohesiveness of our community. We saw what happened, emotionally and socially and psychologically, when a group of people were brought together, for even a short period of time, who share something that no one else in the world shares. Pauline, Maureen, Heather, Paula, Drema, Gunny, Phil, Debbie, Deanne and I will never be the same. The personal meetings accelerate and intensify those bonds in the community.

The newsletter is an important part of our community. And that is why I opened my letter with the apology. I recognize how important this vehicle for communication is for our community, and it is a great concern to me when it is not offered as often as it should be to our members. The communication is vital to our community's existence. Please take every opportunity to engage in this communication. Send me your contributions to the newsletter. If you have a computer, get involved in the TMIC. Use your directory to find other people with TM in your community; get in touch with them and start a local support group -- formal or informal. Volunteer to be a TMA State Representative, or find your State Representative, some time in the near future, and volunteer to help them. Come to the TMA conference next summer. These are all ways to communicate and to foster a more vital TM community.

I have taken the opportunity to add editorial comments in several of the articles. I have identified these comments by putting them in italics. The purpose is to provide context or to offer additional information. If you asked Pauline, she would tell you it comes from my inability not to have the last word -- even in the newsletter! We hope you have had a good, safe and healthy summer. Take good care of yourselves and each other.

From the President
Deanne Gilmur

Sandy
Welcome TMA Members,

For those of you who are new to The Transverse Myelitis Association and our newsletter, a recap of our history may be useful. In 1991 my daughter, then 18 months old, was diagnosed with Transverse Myelitis and like so many others among us, our family experienced many changes and losses without much information and support. In 1994, I sought to find others with the diagnosis through the assistance of NORD (National Organization of Rare Disorders) and to develop some kind of support organization. Through this process, I met Sandy Siegel (our newsletter editor & VP, and so much more), who also encountered this uncommon condition when Pauline was diagnosed with TM four years ago. Pauline and Sandy had received my initial letter and questionnaire; the survey was designed to solicit information from people regarding the services they would like to receive from an association. Gratefully, Sandy contacted me to offer his assistance after which we began the tedious process of becoming a 501(c) (3) non-profit organization, locating a wonderful board of directors, developing a professional initial contact packet, designing a brochure, and directly responding to questions and concerns from people with TM and their family members via the telephone and e-mail. Our web site and TMIC (Transverse Myelitis Internet Club) were developed and are maintained by Jim Lubin, the TMA's Internet and Web Site Director. While there remains a tremendous amount of work to be done, the Association has accomplished many of the goals we had set for ourselves at our inception.

More recently, our Association took another huge step when several TMA members and the Board of Directors met in Columbus, Ohio at a joint conference with the FOP Association and representatives of NORD. While our numbers at the conference were small, the impact of meeting and spending time with others with TM (and their families) was one of the most moving experiences imaginable. The informational resources shared, the life-long friendships made, and the growing ability to cope and even laugh at our circumstances made this a memorable time. It was also a time during which we worked, worked and worked. We planned future TMA goals, brainstormed about funding approaches, reviewed organization by-laws, and met with professionals from other advocacy groups, as well as health care providers. The Board also met with Dr. Joanne Lynn during the conference. Dr. Lynn, a neurologist at The Ohio State University, has assisted the Association in many important ways. At the meeting, she offered the Board significant direction for designing approaches to communicate with and establish working relationships with the medical and health care community. The conference offered us a tremendous learning opportunity, and we are most grateful to The International FOP Association, NORD, and particularly to Sharon Neumann and Dr. Charles Levy, who made this conference possible and who invited the TMA to attend. With our Board of Directors located all over the United States, our planning and organizing communications are all of the long-distance variety. The ability to have two full days of face-to-face meetings offered the Board an invaluable opportunity to make progress on our Association's development.

One of the more exciting results of the conference was the Board's decision to plan a TMA conference in mid-August

of 1999 in Tacoma/Seattle, Washington. We observed and experienced the benefits those with TM and FOP derived from their participation in the conference and wanted to make this opportunity available to all of the members in our Association. I am convinced that each of you who attend will find your life positively changed and enriched by the resources shared, information learned, and so importantly, the friendships and support you will gain. We hope that you will be able to join us in Washington next summer. The time, energy and expense of putting together a conference are considerable. The Association will pursue this endeavor only if our membership communicates that you are interested in having us do so. We would require more than 30 individuals or their families to **commit** to attending the conference for us to continue this process. Please let us know if you plan to attend the TMA conference by filling out and returning the form we have included in this newsletter. In addition, the Board is trying to locate funding to assist with the expenses of putting on such a conference. Without major funding support, the Association will not be able to finance the conference. If anyone is aware of potential sources or ideas for funding (i.e., grants, donations, sponsorships), please contact me or Sandy.

More specifics regarding the conference will be forthcoming. We would bring in professionals to make presentations on a variety of subjects, such as pain management, orthotics, and physical therapy. We also need your input to know what topics you would like to have addressed at the conference. You can provide us with this information on the form. Additionally, Paula Lazzeri has posted a message on the TMIC asking that members provide her with ideas about presentation topics. You can send your topics of interest to Paula through the TMIC.

Earlier this year, I received a call from a gentleman whose 21 year old brother had just been diagnosed with TM. He was having difficulty with the diagnosis and with staying positive. I remembered a family that I had spoken to months earlier who lived in the same area. I knew that Kerry and Joan Defilippo would be supportive and would be willing to go the extra mile to help this young man. I called them, explained the situation, and the Defilippo's went immediately to see him. Their visit, support and encouragement were a tremendous help to him. I believe that this personal contact can make a huge difference to any person/family going through the initial diagnosis and adjustments to TM. Hence, this and other similar experiences have helped me to recognize the value of having TMA State Representatives. The idea is that individuals would serve as the state contacts to the Board, would make contact with those diagnosed in their state, and would provide support in any feasible way. There are other important functions which could be performed by the State Representatives. The article in this newsletter that describes the work that Pam Ramsey is performing in Virginia offers additional information about the possible services that may be offered on the state level. If any of you are interested and would like to volunteer, please contact the Association. You may do so by using the form provided in the newsletter. With all of the countries we have members from in the Association, we would also like to have a TMA National Representative for each of the countries. Many of you have indicated an interest in volunteering for work in the Association; we hope that these new and important positions will provide you with that opportunity. The rewards associated with this activity are immeasurable.

The Association continues its effort to look for funding. This is particularly important with our membership rapidly growing and a conference being planned in the near future. Please be aware that funding is critical. Should you know of any potential resources or support for the TMA, please contact Paula Lazzeri, our treasurer, or myself and I will send you any information, such as our tax ID number, that would facilitate the contributions. I also wish to take this opportunity to thank the Claddagh Foundation which recently donated $5,000 to The Transverse Myelitis Association. What a generous and thoughtful gift! This foundation is one supported by friends and family members of Mary Kate Callahan, a child with the TM diagnosis. The Foundation is attempting to impact spinal cord related conditions. Their efforts have helped us meet our publication and mailing costs during the past months. Again, a huge thank you from the Association and all of its members!

My best to all of you. And thank you for your many efforts for the TMA and for the support that you provide to each other. The directory is an effective tool for seeking others for mutual support. Please use it.

Until the next newsletter, take care of yourselves and, if you can, please plan to attend the August 1999 TMA Conference!

Sincerely,
Deanne Gilmur
President/Founder

Introduction

The Process Of Adaptation To Effects Of Severe Injury And Illness

James A. Arnett and Denise S. Rabold

We are please to present the first installment in a series of articles written by James A. Arnett, Ph.D. and Denise S. Rabold, Ph.D. Drs. Arnett and Rabold are faculty members in the Division of Rehabilitation Psychology, Department of Physical Medicine and Rehabilitation at The Ohio State University. Rehabilitation Psychology is a specialty of psychology that serves individuals with disabilities as they adjust, adapt, and progress toward healthy and satisfying lifestyles. Psychologists working in rehabilitation use education, remediation, counseling, and advocacy to minimize effects of impairments due to disabling medical conditions and promote wellness through optimal psychological and social functioning. Dr. Arnett has a broad base of experience with a range of disabling conditions, and specializes in evaluation of mental performance and adjustment issues associated with impaired brain function. Dr. Rabold is licensed as both a psychologist and speech-language pathologist. She specializes in counseling and cognitive remediation for work, school, and community re-entry after acquired brain injury.

We are very pleased to have this opportunity to present our ideas about the process of adaptation to the effects of injury and illness. After some preliminary discussion, we realized this project involved many important issues, and adequate treatment would probably require more than one article. The process of adjusting to, and living with, a disabling illness is complex, and to treat it fairly will require giving attention to many issues and concerns. Because every person is unique, it is impossible to discuss the adaptation process without attending to the problem of individual differences. Analysis becomes even more complicated when we consider that each unique individual also lives in a unique environment, and has -- within a range -- unique effects of a disease. In considering these problems, we elected to begin our presentation with a general discussion of human behavior, as applied to illness, impairment, and adjustment. We will then present ideas about the adaptation process, and move to more specific factors and problems related to impairments and adaptation. We plan to deal with specific topics including community and work re-entry, relationships, sexuality, and issues of psychological distress. Finally, although we intend to address specific problems related to Transverse Myelitis, we recognize that many of the ideas presented here probably have utility for a broader range of disabling injury and illness. We welcome your questions, suggestions, and comments, as we prepare future articles.

Part 1 Human Behavior And Reaction To Severe Injury And Illness

The process of adaptation to severe injury and illness is complex and highly individualized. Any attempt to understand this process must start with an examination of the basics of human behavior. Questions about how humans adapt to severe injury and illness are really part of a larger question about what causes human behavior. Before attempting a study of the process of adaptation, we must take a more general look at human behavior.

Questions about human behavior and human nature, or about what makes us do the things we do, have occupied the minds of great thinkers throughout history. The fact that so much has been written on this subject, and there are so many different theories, should lead us to believe there are no simple answers. There is a variety of explanations for behavioral and psychological problems; however, in studying the process of adaptation to disabling illness, most theories fall short, because they do not account for all factors affecting behavior. Most theories of behavior and personality are either incomplete or they do not offer adequate explanation for all of the great variety of human behavior we see around us. Probably the biggest problem most theories of human behavior have is that they are limited only to the psyche or psychological makeup of the individual. While this is important, the internal psychological makeup of an individual is only one part or one factor that goes into the determination of behavior.

A better approach to understanding human behavior is described by Trieschmann* who suggests that human behavior is the result of three interacting factors. These factors are best described as an organic factor, a person and personality factor, and an environmental factor. Trieschmann describes behavior as including health and rehabilitation adjustment; and she deals mostly with adjustment and adaptation in rehabilitation. The behavior that we see in others, and the way we ourselves behave can be viewed as a result of an interaction of these three factors. Put another way, we do what we do because of: 1) what we are physically capable of doing, 2) our personality and our unique way of looking at the world, and 3) the environment in which we find ourselves.

For the purpose of this article, we will

define personality as a unique complex set of attitudes, expectations, beliefs, coping strategies, decision rules, and behavioral style. This may sound complicated, but these are really some of the personal qualities that make each of us unique individuals. We expect these personal and personality qualities to be relatively stable over time, including before and after onset of a major illness.

In studying the reaction to severe injury and illness, it is useful to consider Treishmann's view of human behavior. We know, for example, that individuals react in different ways to severe injury or an illness such as Transverse Myelitis (TM). We know that individuals are unique before the onset of the illness, so it should not be surprising that reactions to illness and the process of adaptation are also unique. We know that each individual finds their own way to adapt to the changes brought on by illness and injury. Any attempt to describe a detailed, step-by-step process of adaptation fails because it does not allow for unique qualities of the disease, individual personal differences, and unique environmental factors. It is impossible to study the process of adaptation without dealing with the differences in degree of injury, unique personal factors, and the variety of environments (life situations) among persons who are struggling with adaptation.

We will now take a closer look at the three factors of behavior, as they might apply to adaptation to TM or illness involving significant limitations of function.

First consider the organic, or physiological, factor. This factor includes all that an individual is capable of doing based on organic function. Organic function would be determined by level of spinal cord lesion, with resulting impairment of muscle function. It includes muscle strength. It includes the basic senses plus coordination, sense of balance, and tactile sense. The organic factor includes how the body reacts to stress. It includes how much sleep one needs in order to feel good. Note that medication affects body chemistry, and in a sense, changes what the physical body is capable of doing. Within the physical body -- without regard to personality issues -- the effects of illness and injury vary greatly. TM has a great variety of effects depending on size and location of damage. TM can affect different amounts of both gray and white matter of the spinal cord in one or more adjacent thoracic segments. The degree and severity of the injury determines functional capability of the body, and this physical capability affects the process of adaptation. The question, “what will I do?” is usually followed closely by “what can I do?”

Next, consider the personality factor. This factor includes all the things that make us unique as individuals. We may be shy or outgoing, quick or slow to make decisions, even and steady or up and down. We may be liberal or conservative, or we may be someone who doesn't want to be considered as either. When making a decision, we may look for all the facts, make lists, and try to think logically, or we may prefer to use our intuition or feelings. We may take risks or we may prefer not to. We may attack a problem directly or we may prefer to avoid a direct attack. We differ from one another in a great many ways. Of course, we differ in how we react to change and loss. What is the individual's reaction to a serious syndrome like TM? How one reacts to such a problem depends on many personal qualities. Consider the reactions to loss of physical ability by two different people, one who greatly enjoys physical activities and the outdoors, and one who does not. Limited mobility could easily represent a greater problem for one person than for another. Note also that education and work experience often play a part in adaptation to illness, again because of the different physical demands of various jobs. How one adapts to uncertainty, uncertain prognosis, and course of disease is especially important with TM because so much about the syndrome is unclear.

Finally, let us examine the affect of environmental factors on behavior and adjustment. Obviously, the family is an environmental factor that plays a major role in adjustment. Imagine the affects on behavior of a family that is caring, reassuring, and supportive and a family that is withdrawn and tentative in their support. Likewise, imagine the affects on behavior caused by a sympathetic and an unsympathetic employer. Consider also the possible affects on an individual of health care agencies, hospital environments, hospital staff, and work environments. Consider the differences between physically accessible buildings and those that are not, or only minimally accessible. The reactions of friends, spouses, family members, health care workers, and coworkers are all part of the environmental effect.

In summary, there are many ways of adapting to the effects of a severe injury or illness. It is impossible to describe a standard process of adaptation because humans do not all act the same in response to a specific injury or illness. Human behavior is complex, and any attempt to describe the process of adaptation must account for the great variety of behavior and experience. Human behavior is best described as a complex interaction of physiology (what the physical body can do), environment (the physical

environment and the support of others), and person and personality (the kind of person I am, including the ways I solve problems and manage my needs). Each individual will find their own way of adapting to the effects of illness. Although there is no one sure way to go about it, the process of adaptation to disability does involve certain standard tasks, a review of which will make up our next article.

*Reference: Trieschmann, R.B. (1988) Spinal Cord Injuries, Psychological, Social, and Vocational Rehabilitation, 2nd ed. New York: Demos Publications.

Joanne Lynn, MD is an Assistant Professor of Neurology at The Ohio State University. She is currently on the staff of The Ohio State University Multiple Sclerosis Center and has special interests in clinical research on the treatment of MS. Dr. Lynn serves on the Medical Advisory Board of The Transverse Myelitis Association.

Member Questions and Answers from Dr. Lynn

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

1. ***How do people cope with leg and foot spasms, especially at night? The neurologist told me to stretch well before I go to bed and try to keep legs from touching each other in bed. I've also learned to keep them as warm as possible. These things don't work well. Any suggestions.***

Normally there is a balance between relaxation and excitation of muscles and this is controlled by the nervous system. When there is injury to the spinal cord from myelitis, there is often a loss of this balance, with an increase in muscle tone known as spasticity. This may cause cramps and spasms or, when very severe, a lasting stiffness causing inability to put a joint through a normal range of motion. Passive stretching is an effective way to decrease spasticity for many people and also helps to maintain normal range of motion for joints despite weakness. A person can learn a regimen of passive stretching from a physical therapist or can consult books. People with multiple sclerosis also have problems with spasticity and one helpful description of stretching is offered in Shapiro R. Syptom, Management in Multiple Sclerosis, 2nd ed., 1994, New York: Demos Publications.

However, sometimes stretching just doesn't do the trick by itself. There are several medications to try. Lioresal (baclofen) is a very common antispasticity drug which can help with cramps and spasms. Lioresal works on nerves in the spinal cord that control muscle tone. The amount needed or tolerated differs from individual to individual. Some people develop sedation, nausea, or worsening of weakness from this medication. It is common to start with a low dose such as a half or whole 10 mg tablet at night and then gradually increase the dose. There are other medications which can also help with spasms and cramps and these include: flexeril, tizanidine, clonazepam and valium. Use of any of these medications should be supervised by a physician. Often neurologists and physiatrists who see many patients with spinal cord injury are more comfortable prescribing these medications than other types of physicians.

2. ***What is cyclosporine? Why is it used? What are the benefits and risks?***

Cyclosporine is an immunosuppressive chemical produced by the fungus Tolypocladium inflatum. It suppresses the immune system by blocking the ability of T helper cells to produce molecules important to the production of inflammation and tissue damage. T helper cells are one type of white blood cells that may abnormally attack human tissues in autoimmune disease.

Cyclosporine has been used to suppress the immune system in organ transplantation to prevent or lessen rejection. It has also been used to treat several autoimmune diseases that attack the human nervous system and there is significant experience in myasthenia gravis and inflammatory muscle diseases (dermatomyositis and polymyositis). Cyclosporine has shown some benefit in animal models of multiple sclerosis but results have been discouraging in clinical trials in multiple sclerosis.

There are many potential complications from treatment with cyclosporine as there are with any agent that is used to suppress the immune system on a chronic basis. This is not meant to be an exhaustive list but gives the most common complications. Chronic suppression of the immune system carries an increased risk for common infections and for opportunistic

infections, which are infections that generally do not occur in healthy people but may occur in people whose immune systems are not functioning normally. Hypertension (high blood pressure) is the most common side effect and is usually reversible when the drug is discontinued. Cyclosporine may also cause dysfunction of the kidneys by causing constriction of the arterioles (small arteries) in the kidneys. There is less risk of this when a dose of less than 5 mg/kg/day is used. There is also a risk of cancers with use of cyclosporine. This risk is 3.0 to 4.9 times higher than the risk of the general population. Most often these are lymphoproliferative cancers (e.g., lymphoma, leukemia) or skin cancer. Cyclosporine can also have toxic effects on the brain, especially the cerebellum. Other side effects include liver inflammation/injury, gallstones, decreased appetite, imbalances of body potassium and magnesium, and abnormal sensations (e.g., burning or tingling) in various parts of the body.

When a person is being treated with cyclosporine, he or she should be followed closely by the physician, with frequent checks of blood pressure, blood tests to check blood counts, renal function, and routine chemistries, as well as screening examinations to check for skin and lymph node cancer.

3) ***Have you heard of intravenous cytoxan treatment for Transverse Myelitis associated with lupus?***

Systemic lupus erythematosis (SLE) is a chronic autoimmune disease that affects many organs and may vary greatly in severity and which organs are affected from person to person. Some people with SLE have rashes, arthritis, mouth ulcers, or problems with kidneys, lungs, or blood cells. Involvement of the central nervous system (brain and spinal cord) is also common in SLE. Transverse Myelitis may occur in SLE and often this may be severe, recurrent or progressive. Because of this, aggressive immunosuppression is recommended by some researchers.

Prednisone is the traditional treatment for the various problems associated with SLE. However, chronic prednisone use is often associated with significant side effects, such as osteoporosis and catarracts. In addition, at times the myelitis associated with SLE may be so aggressive that it does not respond to prednisone alone. One regimen that has been recommended is the use of corticosteroids in combination with cyclophosphamide. One approach is to give monthly intravenous doses of cyclophosphamide along with corticosteroids for some period of time (six to twelve months) followed by oral prednisone with or without oral cyclophosphamide.

Cyclophosphamide is a form of nitrogen mustard and damages the DNA in rapidly dividing cells which include white blood cells. Moderate doses are used for immunosuppression in autoimmune diseases. Toxicities include, but are not limited to, bleeding from the bladder wall, bladder cancer (risk dependent on cumulative dose), low blood counts, nausea, vomiting, hair loss, infertility.

Several references regarding the use of cyclophosphamide for treatment of myelopathy associated with SLE:

1) McCune WJ, et. al. "Clinical and Immunologic Effects of Monthly Administration of intravenous cyclophosphamide in severe systemic lupus erythematosis," New England Journal Medicine. 1988, 318:1423-31.

2) Barile L and Lavalle. "Transverse Myelitis in systemic lupus erythematosis: the effect of IV pulse methylprednisolone and cyclophosphamide," Journal of Rheumatology. 1992, 19:370-2.

3) Bevra Hannahs Hahn. "Management of Systemic Lupus Erythematosis," in Kelley WN, Harris Jr ED, Ruddy S, and Sledge CB. Textbook of Rheumatology, Volume 2, Fifth Edition. W.B. Saunders Co., Philadelphia 1997 (a major comprehensive rheumatology text).

Deanne Gilmur Honored at FOP/TMA Conference

Deanne Gilmur was recognized during the awards banquet of the FOP/TMA Conference on May 9, 1998. The award was presented by Paula Lazzeri, representing the TMA Board of Directors, and on behalf of the membership of the TMA. The certificate of appreciation recognizes Deanne:

- For her commitment to educate, advocate for and serve those with Transverse Myelitis;
- For her unselfish ability to grow beyond her own difficult experiences to help others;
- For her leadership to found The Transverse Myelitis Association;
- For her creative energy to organize and direct the TMA's development;
- For her compassion to give comfort and support to those in need; and
- For her spirit, intellect, good humor,

In Their Own Words: Pain Management

Not all people who have Transverse Myelitis experience nerve pain, but for those who do, this becomes one of the most difficult aspects of having this condition. In this issue of The Transverse Myelitis Association Newsletter, the issue of pain management will be addressed through the following articles submitted by our members for the In Their Own Words column. In preparing their articles, the members were asked to consider the following issues: 1) Provide a brief description of your history with TM; how long you have had TM, the initial symptoms, your current condition and where your injury is located. 2) Describe when in the course of having TM you began to experience pain. 3) Describe where you feel pain and try to describe the sensations that you feel. If you experience different sensations in different parts of your body, please identify those. 4) Describe your history with medications to treat the pain. Describe the medications that have been successful for you and those which have not, including the combinations and dosages. 5) What, besides the medications,has been successful in decreasing your pain? 6) Are there certain activities or positions that cause you to experience more pain? 7) Describe the explanation you received from your doctor as to the cause of your pain. 8) If your pain has stopped, please describe how long after you have had TM that this occurred, and describe any circumstances surrounding this event. 9) Anything else that would help a person with pain from TM better cope with their situation. We are most grateful for our members' willingness to share this information in the newsletter.

Anonymous
female, age 60

friendship, generosity, kindness, insight and courage.

We are all very grateful for the opportunities that Deanne has create for us and are very proud of her accomplishments. Thank you, Deanne.

I have a sensation in my right foot that I call tingling, but it is sometimes really more like a hideous electric shock. During the day, I get annoying tingling. I wriggle the foot, and if privacy permits, stamp it. It is when I put my feet up to relax or try to sleep that it is just plain murder. Also, when having an MRI, it is impossible for me to keep the leg from twitching.

I was diagnosed with TM about 8 years ago and was hospitalized and given IV cortisone. The doctors told me, after an MRI, that the lesion was in the cervical area and that I am 80% recovered. I can walk about a half block at a time, but the weakest link in my mobility probably is not the TM because I also have a fractured femur from a fall after having had my hip replaced. The surgeons don't want to touch it probably because of my other medical problems (osteoporosis and lupus). My balance never was too good, but now it is so bad that I have to hold on to something or look for a ramp to go down one step and that, I believe, is a result of TM. For about 2 years before the diagnosis, I was troubled with the tingling but could walk and just accepted it, assuming it was poor circulation. It was diagnosed when I sought medical help one day because the foot went numb and that's when I was hospitalized. I am female, age 60.

That was by way of background. Back to pain and pain management. I have tried Baclofen, Nortryptiline, Klonopin and Flexeril, as well as all kinds of anti-inflammatory medications, both prescription and over-the-counter. None of these helped. No matter how sleepy the medications made me, I went to bed and soon realized that my right foot was in a frog-like position with the sole resting against the left foot in some kind of effort to damp the vibration and knew it was going to be a long night. Darvocet usually does take the edge off so I can get some sleep. I'm very careful only to take it at night and only then when really necessary and I, frankly, live in dread of being told that I have to go back to that much agony because of fear of addiction.

Jessie Danninger

I developed Transverse Myelitis in April, 1993 at the age of 19. Within 24 hours of onset, I was almost totally paralyzed from the neck down. The lesion occurred at C-4 and therefore it was my hands and arms that were most seriously affected. I had severe pain during onset, but that disappeared within a day. I spent the next month in the hospital and rehabilitation center learning to walk and take care of myself. By the time I left the rehabilitation center, I could walk, but I was weak and my hands were both very paralyzed. In the four and a half years since, I have become much stronger and my hand function has been greatly improved through tendon transfer surgery. I currently work forty hours a week, but I am easily fatigued.

One of the most difficult aspects of recovery was dealing with the intense pain that developed about 6 weeks after onset. By then I had returned home and was spending a lot of time doing therapy, so I thought the pain in my hands (the most severely paralyzed area for me) was just due to overuse. I tried to cut back a little on my hand therapy to rest them, but the pain continued to get worse. It gradually spread up my arms to my wrists, elbows and shoulders. Within a month of the pain beginning, it was at its worst. The pain is difficult to describe. It was not muscular pain but deeper, like in the tendons and bones -- a little like what I imagine tennis-elbow feeling like. It was most intense in my joints and it was constant. I tried slings to rest my arms, but that didn't help. My parents bought a mini whirlpool machine for the bathtub which helped a little, but only while I was in the tub. I would wrap a heating pad around my arms very tightly and would turn it on "HIGH". This helped some, but I burned myself a couple times this way. Nothing helped very much and the pain was beginning to be intolerable. Eventually, it was so intense and constant that it became incapacitating. I could do nothing all day except lie around holding my arms and trying to make the pain go away. I would sleep as much as possible because that was the only time I felt relief. My doctor suggested that the pain may be from "incorrect sensory transmission due to damaged nerves" and he prescribed ibuprofen and Tylenol, but the effects were hardly noticeable.

In August, after about two months of severe pain, I saw a neurologist at the Mayo Clinic in Rochester, Minnesota. He prescribed Amitriptylene. This was a miracle drug for me. After just one dose, my pain began to subside. Sixty mg a day kept the pain away and I was able to return to school that fall. Unfortunately, this medicine made me very sleepy and I usually slept about 10-12 hours a day. However, the relief I got from that horrible pain was well worth it. While on this medication, I normally felt no pain, but if I would get stressed out or not get enough sleep, I would begin to feel that aching in my shoulders, elbows and hands. Whenever I forgot to take a dose, I would realize that the pain was just beneath the surface.

In May of 1995, two years after I was struck by Transverse Myelitis, I was scheduled to have the tendon transfer surgery on my right hand. In order to prepare for the surgery, I had to stop taking all medication. I intended to do this gradually. I usually would take six 10 mg pills of Amitriptylene a day, and I planned to try to take fewer -- I planned to just take them when the pain became unbearable. I decided to start this a month before surgery so that by the time the surgery date rolled around, I would have weaned myself off the pills completely. But the day that I began this process, I never took a single pill. I didn't need any the next day either. When I stopped taking the medication, I realized that the pain had vanished completely. By that time, I had been on 60 mg of Amitriptylene a day for almost two years and at some point for some reason, the pain had disappeared. I went ahead with that surgery as well as a second and the pain never returned. I have not been on any pain killer for over two and a half years and I have no pain. Occasionally, I'll get a twinge of mild pain, similar to the kind I had four years ago, but only when I'm very stressed or very tired. I always need at least eight hours of sleep a night. To relieve it, I take a nap or find a way to unstress myself (such as get a massage). Sitting in one position for a long time also tends to induce the pain, but it is easily relieved by changing position or moving around. I

Jo Ellen Finkelstein

wish I could say more about exactly when or why my pain went away. It's difficult for me to understand why, especially since the pain was so excruciating initially. All I can say is that I struggled with the pain for a while, I found relief with Amitriptylene, I prayed a lot and one day my pain was gone.
I began my journey with TM on October 6,1996. I was returning from a weekend at a Science Fiction Convention, and noticed on the way back that my back and hips hurt. When we stopped for gas and a soda (and bathroom break), I almost fell and my boyfriend noticed that I was walking funny. When we got home, I laid down thinking I had overdone it during the weekend. I took some aspirin and tried to take a nap. When I tried to get up, I couldn't move my legs. I think I really lost it then; I know I was screaming and crying from pain and fear. We had no idea what was happening.

In the ER they did X-rays, cat scans, and a spinal tap. Later, I had a mylogram and they tried to do an MRI, but I'm so claustrophobic that they had to get me out almost immediately. I was in the hospital for the entire month, physical and occupational therapy twice a day. By this time, I was at least standing up over my walker and had walked down the parallel bars with assistance. My doctor thought I needed two to three more weeks of therapy, but the insurance company said to send me home. I was home for a week and seemed to be doing fairly well when I had intense back pain again one night. Back to the ER where they checked me for a ***kidney stone***! Guess what? They didn't find one! So, they sent

me back home in an ambulance even though I couldn't move my legs again. And this time I wasn't breathing well. By the next morning, I hadn't urinated in over twelve hours, still couldn't move my legs, and was having more problems breathing. Back to the ER. This time they gave me some IV Valium and gave me an MRI. Hello -- guess what they saw? A very clear spot on my spinal cord! I guess that it wasn't psychosomatic paralysis after all! They found the lesion on my spine at about T-10. The first diagnosis was Spinal Infarct, but they later changed that to Acute Transverse Myelitis. I had never heard of that, even though I had gone to nursing school and was in the nursing field. I went down to the medical library to see what I could find out. There wasn't much there and what I did find wasn't exactly encouraging. I left in tears.

I simply couldn't understand why all of these things had happened to me. Six months before the myelitis hit, I had lost my husband of 17 months to pancreatic cancer. I had just started to pull my life back together, and I had a new job lined up. I didn't work after Bruce was diagnosed, because we knew we didn't have a lifetime to spend with each other. Some new friends, a new love interest -- I hadn't been looking, but we met and clicked immediately. Life seemed to be looking brighter after a long black tunnel. So why me, and why this? Maybe, as my mother says, there is a reason for everything that happens -- if so, I wish to heck I had a clue!!!!

I was in the hospital this time for a month and a half, getting out just in time for Christmas. Home for a few weeks at which time we realized that I had a decubitus on my right hip. We thought that it was a stage two decub, but when I started running a fever and had drainage from it, I went back to the hospital. As they debrided it, they discovered that it went all the way to the bone and had tunnels branching off it. Well, this is a lovely place to spend New Years! A month and a half later, they were preparing to send me home as I seemed to be healing nicely. I asked them to do a CT to check that there was nothing else going wrong. The infection was in the bone. I was home for a week and had to go back to have the bone scraped and a muscle flap done. They finally sent me home again (for a week), but the surgeon had missed some tissue that had died just before they sent me home, so back I went. Two weeks later, I was back home and coping with trying to get my life going again. Meanwhile, Dragon (my significant other) had been neglecting his health and managed to have a heart attack right after I came home. He had to have a triple bypass which meant he couldn't help me take care of myself for a least six weeks. My mom (77 years young) couldn't stay with me to take care of me for all that time and her house isn't accessible at all. None of my sisters or my brother could help (out of state and coping with their lives), so the insurance company shipped me off to a rehab facility connected with my hospital. I was the only one under fifty! I threw my version of a temper tantrum (less kicking my heels on the floor) and then got over it and made the best of it. I actually managed to cheer up some of the patients and became sort of a cheerleader in therapy.

My pain began with the onset of the TM. I had pain in my back from the beginning that was controlled with shots of Demerol in the hospital. After a while, they changed me to Darvocet PRN (as needed). Eventually, I stopped taking this too. That is, when the numbness in my feet started bothering me. It was constant and felt like my feet had fallen asleep with the "pins and needles" feeling always there. Eventually, it also included a "burning" sensation as though I had set my feet too close to the fireplace. I was also having problems with muscle spasms in my legs. The spasms would travel up my legs to my back and around my diaphragm. They were so hard and so frequent that my back and ribs hurt constantly from the muscles tensing up.

After speaking to Dr. Fischer (my physiatrist), he started me on Baclofen (10 mg., four times daily) which relieved the spasms almost immediately. The pain in my back and ribs went away. It also helped with bladder spasms. I still have some spasms, but not nearly the way they were before.

After seeing several postings on the tmic list about relieving the pains and burning in the feet with Neurontin, I approached my doctor with a request to try it. So far, he has me on a low dose which I feel has helped slightly. We will probably have to adjust the dose to be more efficient.

I have found that if I find something to distract myself, I can usually ignore the pain for a while. But it is always there, just moved to the back of my awareness. If I am asleep, it usually doesn't bother me unless it is really bad and wakes me up. There were times when I was in the hospital that it was pretty bad. I had a tendency to sleep a lot, partly to ignore the pain and partly because of depression. The worst times for the pain in my legs is when I have water build-up in my system. When I have edema in my feet and legs, it is extremely painful and I tend to go back to bed so that I can elevate my feet and legs.

The only real explanation that my doctors have been able to give me for the pain is that it is probably related to

nerve damage from the lesion on my spine. So, there isn't much to do for it except possibly biofeedback and pain medications, which I prefer not to use unless absolutely necessary. In the meantime, I continue to use distraction and occasionally aspirin to control it.

Having worked with people with constant pain before this struck me (I did private duty nursing with the majority of my patients being terminal cancer patients), I was aware of many ways of coping with pain. I never thought that I would be the one having to use them!

Currently, I am working on going back to rehab and will be fitted with braces to try to stand and take a few steps. I have been home now for a record breaking three months and have been working on getting a new life going. I have an appointment to meet with vocational rehab people. I got on a list to find an accessible house through the local housing authority that I can buy. Just this weekend (Labor Day), I worked at the Jerry Lewis telethon, as I did last year, and hope to continue working for them every year.

I hope I will be among those who make significant recovery. I'm working on standing with my therapist. But I'm not letting life pass me by. I will admit that there have been times when I wanted to die (too chicken to do anything, though), so they still have me going to a psychiatrist once a month and it helps. I have also had to cope with my late husband's ex-wife -- to stay in touch with my step-son -- and Bruce's mother. Of all the things Bruce left behind, I wish he had taken them! Having my computer here has been a great outlet for me. When I get down, I can write in a journal I keep, or I get into the paintbox area and create something that gives a

Sheila Fitzell

visual expression of how I feel. I've even used it to create pictures representing the ex-wife and the mother-in-law and after I think about what I drew, ***I delete them***!!!!

I was diagnosed with TM in August of 1996. Prior to that time, I had recurring pains in the joints of my legs and hands. I was also very lethargic. I started to have difficulty with my balance when walking and I became incontinent. I couldn't seem to lift my right foot and I started to drag it. Then I couldn't stand up. This all happened in less than a week. I was hospitalized and given tests and then steroids. It appeared I was improving and started physical therapy. I then moved to the rehab floor. A few days later, blood tests revealed that my potassium level was extremely low, and my electrolytes were out of whack. After this I became paralyzed and though I was given more steroids, they didn't work. I spent a total of two months in the hospital. My injury is located in the C7, and T4, T5 sections.

I began experiencing pain about 3-4 weeks after entering the hospital. Sitting in a wheelchair was very uncomfortable. My feet felt as if they had weights on them that were dragging them down. This hurt terribly and I was given Tylenol. However, the only time I got relief was when I was sleeping. Eventually, I had burning sensations from the tops of my legs to my feet and this whole area was hypersensitive. The least nudge could send me into orbit, and I could not bear the slightest weight on my legs. I still have mild tingling in my hands, and occasionally experience twitches in my upper back and face. The tendonitis I had in my wrists and hands has diminished. At present, I have burning sensations in my ankles and feet, and my feet are still hypersensitive.

My doctor prescribed Elavil to help calm the nerve endings, however, I experienced unpleasant side effects and stopped taking the Elavil. I occasionally take Tylenol to take the edge off of the pain.

In the past 18 months the degree of pain has varied, and I firmly believe the barometric pressure plays a role in this. It doesn't seem to matter whether I sit on the couch with my feet on the floor or with my legs up on the couch. The discomfort and pain is there. So, this is what I have found to help me. First, I am angry because I'm hurting, so I decide that I can't feel any worse and start to do some exercises. I do stretches, toe raises, knee bends, etc., and walk around the house several times. Sometimes I use the stationary bicycle. My feet tend to sweat now, and then they become cold and hurt, so I change my socks and sneakers, but first I powder my feet and rub them a little. This does help for a while and I usually do this 3-4 times a day. The other thing that works for me is WARMTH! Sometimes after I do the above, I put my legs and feet up on the couch and wrap a fleece blanket around them. Being warm is really soothing. When the sun does appear and streams through my window, I sit or stand in it's rays. It feels so good. I wonder if I was a cat in a former life! Additionally, I find having your mind involved with something is very helpful, such as telephoning a friend and listening to their problems, read a book, write letters. Of course, depending upon your degree of independence, get out of the house, get someone to go for a walk with you. Go out to lunch, take an elderly

friend to church or to the grocery store, bake a cake. Normally, I am unable to sit for more than an hour without getting up and walking a little. However, recently I sat for three hours watching a movie, Titanic, and because my mind was occupied, I did not notice any pain or discomfort in my legs or feet; just a little stiff when I got up!

Let's face it, we may have to live with this pain for the rest of our lives...so let's live!! I do not remember ever receiving an explanation as to the cause of pain.

Pauline Habib

I'll be interested in reading about other peoples' ways of dealing with the pain. I hope this is of help to someone.

Sincerely,
Sheila Fitzell

I have had TM almost four years now. I first started to experience lower back pain about two months before my injury. Then, in July 1994, I caught the flu. As I was trying to get my clothes on after a shower, I bent down too far. I felt an excruciating pain in my lower back and fell to the floor. I was paralyzed from the waist down and diagnosed a week later with lesions at T-12.

I remember that my pain first started in my feet. My feet were swollen for quite awhile after I was hospitalized, and I attributed my pain to the swelling. After I started physical therapy, I began having pain from the waist down. I thought that it was because I was spending too much time in my wheelchair. The pain felt like I had a very bad sunburn. The pain became so bad that I would lay down between PT sessions. I found that laying on my side with a pillow between by legs (I didn't like the sensation of my skin touching) and the bed elevated seemed to ease the pain. Finally, the pain was so intense that I complained to the nurses and doctors.

I currently take 200 mg. of Tegritol during the day and 75 mg. of Amitryptiline at night. The Amitryptiline helps me sleep by making me very drowsy, it helps with my bladder urgency, and it may also be helping to alleviate some pain. Before I started taking the Amitryptiline, I would have to go to the bathroom about 5 times a night. I experience a dull burning sensation during a typical day. I would not be able to take the Amitryptiline during the day because it really makes me drowsy.

I always wake up in the morning with little or no pain. I usually feel little or no pain when I shower and when I am in the pool. Laying horizontally always eases my pain as does elevating my feet and sitting on my hip. Sitting for any length of time causes me much pain.

From what I understand, the nerve coverings were damaged. So, the message that is received from the brain is that there is some damage and thus there should be pain.

I was on Dilantin for a short time. It was not effective in relieving my pain. My neurologist put me on Tegritol. I was on 800 mg. of Tegritol during the day and 75 mg. of Amitryptiline at night for about three years. We started out with a low dosage of Tegritol and gradually worked up to 800 mg. About every four months, I have to have my blood taken to check the levels of Tegritol.

I decided that I wanted to see if I could reduce the amount of Tegritol I was taking everyday. I wanted to reduce the medication, because twice when I got the flu, I overdosed on the Tegritol. I was told that this happened because my body underwent a drastic change due to having the flu. As a result of the high levels, both times, the doctors cut back my dosage and gradually increased the amount again after I recovered from the sickness.

With direction from my neurologist, I have gone from taking four 200 mg. tablets to one 200 mg. tablet a day. I have remained at the one pill a day now for about two months. I can feel the increase in pain, but I am able to cope with the pain at this level. I am wanting to be completely off of the Tegritol. I am hoping that I will have more energy because of not taking Tegritol. I wake up tired and go through my day very tired.

I do not really understand how this pain I experience through most of my day really works. I know that I have not had any visible improvement in my condition for about two years. So, how is it that I am able to reduce my pain medication? I think that I am able to better manage it for myself. Before I got TM, I never understood how people "lived" with pain everyday. Well, medications help to get the pain to a place that's manageable and you just deal with it.

I am a kindergarten teacher. I absolutely love my job! When I am with my kids, I do not experience any pain. Because I am so focused on the children, I do not feel tired or feel pain. Keeping busy and doing things I love to do has helped me tremendously to take the focus off of how I am feeling.

The TMA does not endorse any of the

In Their Own Words

In each issue of the newsletter, we will bring you a column which 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.

Deborah Capuano
Wakefield MA

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.

My name is Deborah Capuano. I am 48 years old. I have two sons, Andrew, 26 and David, 24, who both live out on their own. I am divorced and live alone. My story sounds somewhat like Kerry DeFilippo's of Chicago.

I was away on vacation in March of 1997 in Aruba. I noticed while walking on the beach that my feet felt funny -- tingling. I thought maybe something bit me. Later, I went horseback riding in the mountains. Nothing like what you see on television when they show someone galloping on the beach. We went over a mountain to get to a beach and I was scared to death I would fall off the horse -- or that the horse would fall off of the mountain with me on it.

Because of my fear, I pressed my feet hard into the stirrups, numbing my feet some more. The rest of my vacation (a few days), I was bothered while walking. When I returned home, I was numb from the waist down. My feet felt like blocks of ice and sitting was very uncomfortable as the numbness seemed to intensify. Before the full onset, which did not take long, I noted at night, while falling to sleep, I would have the shakes inside to the point where the bed felt like it was vibrating.

I saw my primary doctor, Andrew Lim, who ran some blood test and sent me to a neurologist, Dr. Paul Chervin, who ran many tests; four MRI's, including brain (I wanted the brain scan to hang over my desk at work for proof -- as I'm blond, you can imagine the jokes as I went for a brain scan)! I also had blood tests and a spinal tap.

End result -- Dr. Chervin told me that I had Transverse Myelitis. I never heard of this and to boot, there were no answers as to why I had TM. I went to Dr. Chervin thinking I had harmed myself while horseback riding or maybe I had swallowed something evil when I snorkeled, as I believed that I had swallowed the whole ocean. Not so. I took prednisone, 60 mg. for one month. Nothing. That was it for me. It has to run its course.

I was always active and now I can't even drive myself to work, because I can't feel the pedals. I feel like I walk like a robot, but after reading other stories, I praise the Lord that I do walk. I feel like I have a pair of panty hose from hell on and I can never get them off. I have the hot burning feelings in my back and my neck sometimes feels weak. I have control of my bowels and bladder. I drink a lot of water and I do go to the bathroom a lot. I have a sensation or a pressure when I need to use my bowels, but I do not feel the sensation when all passes.

I've continued to work. My co-worker and friend, Ellen Bergeron, has picked me up and dropped me off to work. I am a medical biller and sit a lot, but -- or should I say butt -- I get up a lot and stretch and change position. The beginning of this was harder to deal with and I wanted to stay home and I had to sometimes. Going to work made me stay somewhat normal. With support from family and friends, I tried to keep a normal schedule. At the end of the day, I couldn't wait to go home and go to bed. Always tired.

Also, and I have not read about this, I told the doctor that I had this sensation when I dropped my head (chin to chest). I have a shooting vibration that goes from my neck and straight down both legs and my feet. It occurs more when I am exhausted. But I almost like it, because it is a feeling and beyond that, I had none. This is called Lhermittes sign?

I am in my eighth month. The hard numbness has gone, but the tightness remains within, as under my skin. I can feel touch now, but it is almost annoying. I am back to driving; actually, I drove in the fourth month as my feet had what I call a release, but an asleep-like feeling, tingles.

And so it goes. I'm told I will get well. I know I'm in for some pain as this leaves. I have to say that although I've been lucky about the pain, I have been bothered with achy knees. I was told mostly women are effected in their joints with this? I know I have used my body differently through this.

Can't wait for a good night's sleep; rolling over is a wake up job to flip your strange legs.

My sisters, Susan and Doty, helped me find you on the internet. I do not have a computer. But I was so excited to hear of this support association with Transverse Myelitis. I felt like I was the only one in the world with this. Not that I'd wish this on anyone, but you feel power in numbers and maybe our goals will be reached when we all help each other.

This is what I have done. Once a week, I went to my friend's, Donna Beal's, who is a message therapist. She has helped me immensely with positive thinking -- she is very holistic and we even went to a healing session together -- very powerful. She has been very generous, as this is her business.

I have read Spontaneous Healing, by Andrew Weil, M.D. -- a powerful book that can help give hope. I really loved this book. I listen to music. I've gotten into healthier eating and take herbs -- Astragalus, Vitamin C, Flax Seed Oil -- to help my immune system. In Dr. Andrew Weil's book, he makes a comment, Illness can be a gift. Well, that's one to think about. You have no choice but to slow down and take a good hard look at your life.

I've always liked to write (surprised :)?) -- mostly poems and some songs. I never did anything with this. But the positive thing out of my Transverse Myelitis is that I got one of my poems published! Talk about slowing down and taking time.

I continue to heal. I pray all the time and thank G-d for people who care, like Deanne Gilmur who founded this Association for people like us. G-d bless us all and especially the Association officers.

Debbie Ziler
Akron, Ohio

I received a letter from Debbie Ziler in November, 1997. Debbie was diagnosed with Transverse Myelitis in August, 1986. She has provided us with a letter that she had sent to Ann Landers about her experience with TM to offer support to another person who had been given the diagnosis. I have included both of her letters in the column.

November 13, 1997

I just received the October Newsletter which prompted me to complete the survey I copied from the Web. I've also included a medical history prepared in 1988 for the Cleveland Clinic, and a letter I wrote back in June of '88. Publish it if you think it would be of help to anyone. The onset of my illness dates back to August of 86. I am one of the longer-term survivors you are looking to hear more from.

Not that I wanted a reminder, but I wish I had kept a diary of events during my illness so I would have detailed information of what actually took place which might have been helpful to others. It was just so overwhelming at that time that I never got around to it. I've answered the survey questions to the best of my recollection, but I'm sure I've forgotten some things. It was not a time in my life that I wanted to etch in stone.

My recovery was fairly quick. Within 6 months I was back to work (on a part-time basis at first, working back to a full 40-hour week eventually). I am left with a neurogenic bladder, (I am now able to void some on my own, but not always and never complete; I use intermittent catheterization), abnormal temperature and skin sensation from the chest down remain, and periodic lower back pain still persists with tingling in my legs. I've learned to live with the low energy level and interrupted sleep pattern due to the neurogenic bladder.

What you're doing is a wonderful thing. I first found out about the Association through the Web. With mixed emotions, I read everything I could -- sometimes not wanting to see what I was reading, but still forging on. Knowledge is still better than being in the dark. Thanks for all your efforts.

Sincerely,
Debbie Ziler

June 9, 1988

Dear Ann:
This letter is written to the gentleman diagnosed as having Transverse Myelitis. His wife wrote to you asking for direction.

I am a 34-year old woman who in August of 1986 was diagnosed as having Transverse Myelitis. I was temporarily paralyzed from the chest down. The illness also shut down bowel and bladder function. I have still not fully recovered normal bladder function. However, after 2-1/2 months in the hospital, 6 months off work and many hours of therapy, I am back to full-time work.

The main reason for my writing this letter is to relay to this gentleman to **not give up on himself**. A week into my illness, one of the young neurosurgeons in attendance told me I would have a 50-50 chance of ever getting out of bed again. I thought that was an awful thing to tell

someone and I refused to believe him. I tried to set goals for myself from that day on. They told me I'd be ready to be transferred to a rehab hospital in two weeks -- I told them I was ready to go 1 day short of two weeks -- that was my first victory -- I felt in control (as much as you possibly can be in this situation).

There are certain side effects of this illness that just can't be hurried through. Neurological damage takes time to heal. But don't give up on yourself no matter what the doctors have told you. The mind is a very powerful thing if you'll let it work for you and not against you. I've read cases where people have rid their bodies of tumors without invasive surgery -- just by thinking them away. Scan the literature and read as many success stories as you can. Believe in the inner power of healing.

No doctors cured me. I cured myself. They were only there to administer sleeping pills so I would get a good night's rest -- and prescribe antidepressants for depression -- to check vital signs -- and to collect their fee. Maybe I'm being a little too harsh -- but this illness is so new to the medical profession that they really don't know what to look for. They tried to grow cultures of the virus to isolate what type it was, but had no success. After five spinals, I'd had it! I was the first case my family physician had ever seen!

This is a very hard illness to deal with -- especially when it afflicts someone healthy and full of life. For me, family was my salvation. I'm not out of the woods yet; I've been left with nerve damage from the chest down -- the result of this being a loss of normal sensation in these areas; it does not alter my life in any way other than cutting and bruising myself and not knowing it until the marks show up. On the plus side, mosquitoes are no longer a nuisance -- I can't feel the bites, thus no scratching. **I cannot state strongly enough the need for a positive attitude** -- I know it's hard, but I truly believe it hastened my recovery.

I won't deny that it's been a long hard road back to recovery. I don't think, knowing what I know now, that I'd be able to do it again -- but I did it! If there is anything else I can say or do to give you hope, please do not hesitate to contact me. Best wishes to you,

Terri Miller
Brandon MS

Debbie Ziler

Mind Over Matter!!

Dear Sandy:

I wrote to you back in September when I was first diagnosed with Transverse Myelitis. Today, 4 1/2 months later, I am definitely not that same person inside or out. Please share this letter with the rest of the troops so they can understand that there is hope for this "condition."

At the time, I wasn't sure of my fate. My area of lesion was at l5-s1, I work for an orthopedic surgeon, so when I started having problems, we immediately thought herniated disc. He sent me home for bed rest and a medrol dose pack. He didn't want to do any surgery on me, so his brother, being a neurosurgeon, he decided it would be best that he take a look at me. His brother was out of town, so I laid at home with bed rest for almost one week before I was seen again. It had started with one foot tingling, then progressing to the knee, then the numbness started. By the time the brother got back into town, both legs were numb, I had incredible pain down both legs, bowel was involved and I had what they call saddle anesthesia. Everywhere you would sit on a saddle I was numb.

I saw the brother and he immediately saw my symptoms and sent me to the hospital, thinking that this was some sort of neurologic problem and not a disc. This was a teaching institution, so he thought I would be in the best place. This was a Monday night. By Tuesday night, I had my first MRI of the brain. This showed nothing. Then my MRI of the spine. There it was, a lesion at l5-s1. I couldn't believe that this little area was causing all this problem. They immediately did a spinal tap to send off for multiple sclerosis, and started me on a five day course of solumedrol 1000 mg. Daily. This seemed to help some.

After my course of steroids, I was sent home. I was to be under the care of a physician that was out of town. I was to see her in two and one half weeks. The physicians sending me home didn't prescribe any physical therapy. They sent me home on a medrol dose pack and pain medication because I still had severe pain.

I laid in bed for two weeks and continued to regress. Finally, my physician saw me only to inform me that the physicians in the hospital forgot to draw blood to go with my spinal fluid for my MS test, so the lab just threw my fluid away. Finally, after a re-tap, this came back with no suspicion for MS. My doctor started treating me for my Transverse Myelitis. The most important factor that she did for me was physical therapy three days a week. She also replaced my pain medication with a medicine called Neurontin, which helped my pain tremendously! She also started me on Metrotrexate once

a week, three pills, twelve hours apart. This made me very ill. Finally, she told me of a drug called Zofran to help with this. You take it one hour before chemo and it would help with the sickness. It worked. I didn't even know I was taking the chemo. This was an experimental thing she was doing, but reports showed it worked. It was to stop the progression of the lesion.

Within a month and a half of diagnosis, I was off my walker, to a cane, at work for four hours a day and feeling like I could go back full time! I guess I wasn't convincing enough, so I worked that much harder!! Within two weeks, I was off my cane, and working full time. I worked very had to get my strength back! This is very important. You can build muscles and walk even if you don't feel your legs or feet! It can be done.

The physical therapist that I had was wonderful. She worked on upper body strength, lower body strength, balance and propriaception; all this was completely gone, except for the upper body strength. It seemed like that was all I had. Once I started getting my strength back, there was no stopping me! All the rest seemed to follow with time.

The last of December, the 29th to be exact, my daughter's first birthday, I had a repeat MRI. The chemo worked, my lesion was gone!!! Nothing there except some scar tissue which was to be expected. Now it is February 2, 1998 and I still have some numbness in my feet, a small amount up the lateral aspect of my legs and a small amount of "saddle anesthesia," but I feel that I am continuing to progress.

I realize that I am probably a story that most people don't hear about; not as bad as others. But that is why I am writing. There is hope to beat this thing!

I would love to give any inspiration I can to any patients newly diagnosed or to those who have had it for years! You can't let this thing get you down. The moment you think it is, you just work that much harder to make sure it doesn't! I have a wonderful husband that worked hard for me during this time. He took care of my family so I could take care of myself. I had a lot of support from my mother and father, sister and brother, and the church that I grew up in 30 years ago sent out prayers everywhere. They took up collections for me while I was out of work. I had a lot of love!!!!! This, too, is important.

If I can be of any help to anyone out there, please let me know! This is very important to me to let people know that this thing doesn't have to be as bad as you might think. Thanks for letting me share!

Sincerely,
Terri Miller, 37, and looking forward to a life filled with hope and happiness!

Paul Sullivan
Phelps, Kentucky

Hey, Sandy, this is my story. But first of all, thanks so much for all you have done so bummys like me can understand this TM a little better.

On February 25 of 1990, I was called out from my home by a young sister who had a friend in school that was thinking about killing himself. So, an elder called me up and asked if I would care to check things out, because the boy and I had about the same upbringing. So, off I went at 2:00 AM to find the boy and try to help. When I found him, I talked him into going to drink some coffee and talk at a nearby restaurant. So, we did and I got through to him a little. Got him talked into coming home with me to lift weights and check a few things out in the good book, the Bible, to help him see that he was not alone.

When I got in my truck, I saw I was low on gas, so I stopped to fill up and get a pop or two. While I was paying for my gas, a robber came from nowhere and stabbed me in the back between T7 and T8. Boy, did it hurt. It left me with my right leg stiff. It would not work. He had hit my spine with the tip of the knife. And I was down for some while. Also, got staff infection from it. Had to take antibiotics for six weeks to kill it out. But through hard work, I mean hard, I have lifted weights for 30 years now, and no workout was as hard as me getting my toe to start working. But I did. And one thing after another came back until I just about got it all back. Except for the dorsalflex. I had toe drop.

But after a while, I got so spastic, there were times that the attacks would last up close to two hours and the pain got to where I could not stand it. There were so many times I would pray to die to get some relief. Then one day, my doctor in Cincinnati, Ohio said, let's put a battery in your back to stop them spasms. So, I said, anything. And, you know, it worked -- it worked good to the point to where I was out running in the yard with my boys. I was so happy. But after about three or four months, scar tissue grew and it stopped working and I was right back in the same mess I was in before. So much pain, and the tremors got even worse. So, the doctor said, let me put a pump in ya' and put Baclofen in it. But I had a reaction to it, so he put Morphine in it. And it worked. But the side effects were bad to the bone. Each time I went for a refill, I would

vomit for a week, at least. But I could walk without pain. Before, each time I would use my dorsalflex or hamstring, it was like hitting my funnybone in my elbow. I just could not do it. It just hurt too much. But I have got to say the Morphine they put in, it stopped all that.

But after about a year or less, I started getting dizzy to the point where I went and saw three different doctors. But they all said that nothing was wrong. But after about a month of getting weaker and weaker, I got up one night to go to the bathroom only to fall to the ground. I was having a heart attack from the Morphine. It caused my blood pressure to drop to 90 over 40 or less. So, they kept me in the hospital in ICU for three days, then flew me to Lexington, Kentucky where they done a heart catheteritization. At the same time, they changed the Morphine. They said they thought I had got a bad batch.

Everything went OK until the next morning when I woke up. I had never vomited so hard and long, and my right leg was numb from the foot to the knee. I told the doctor something was wrong, but he said it was just a side effect to the new Morphine. So, he checked me out of the hospital. But I knew something was wrong, so I went only across the street and checked into a hotel. I went to bed. Never have I been so tired. So, my wife tried two more different times to get the doctor to see me only to turn me down saying it's only a side effect of the new medication. So, as the day went on, so did the numbness until it got in the other leg and up to my waist in both legs. Now I am a complete, and I do believe it all came from the Morphine. What do you think? After I checked back in the hospital the next day, they cut off the pump and filled it with water. And you know, I have not been dizzy since.

So, if any out there gets a pump, please watch out for dizziness and weakness. If it comes, be sure to get it checked out. And if any of the symptoms come on you like me, make the doctor see ya'. Don't let him say, it's just another side effect. Well, I guess this hill-billy has said enough. If I can be of any help, let me know.

Your hill-billy friend,
Paul Sullivan

Thanks for the reply to my first E-mail. Actually, my daughter from Cambridge is helping me during this recovery . I guess the hardest part is the severity of this relapse. I have had over 7 grams of Solumedrol in the past two weeks and am continuing on Dekadron for a short while. I am basically confined to home, moving from the bed to the port-o-potty, to the wheel chair, and now the walker. I am very lucky to have a lap pool and I did get in it the other day. Tomorrow I will water walk again -- no lap swimming yet. My TM experiences are very similar to many of the stories I have read. I have been diagnosed for 15 1/2 years. I was relapse free for over 8 years. I feel certain that many of my ten relapses were caused by ignorance of the medical community. For example, I was given a tetanus shot four months after my initial attack. Within seven days, I had great weakness in my legs. Some time after that I was given solocaine for the removal of warts on my hands. Again, I relapsed. Then one of my sons came down with mono and I relapsed again. My recovery after these relapses varied in degree. However, I was able to get back to a fairly normal life. I played tennis again; I began golfing more seriously. I walked without a limp unless very tired. Fast forward to the fall of l997. Seven weeks before my son's wedding, I relapsed following an acupuncture treatment to relieve the band of pain in my chest. Within ten minutes of the treatment, my right leg was feeling strange sensations. I have no clue what happened to cause this relapse. I am seeing an excellent doctor at Southwest Medical School here in Dallas. We certainly share many characteristics with MS patients. My brain scan is clear; I have no oligloconal bands in my spinal tap. My lesion, at about T-4, is always the same -- no multiple lesions. I will keep you informed of any new things this doctor wants to try. Please share this letter if you feel it would be helpful. Thanks for your encouraging words.

Elaine Henrion

My name is Sheila Fitzell and on 3 January 96, after 18 years of Federal service, I retired from Westover ARB, MA. My husband, Mike, had retired the previous year and had been waiting for me to reach 62. Prior to TM, my health had been good. I have always been physically active doing step aerobics, walking, dancing, and had plenty of energy to play with our grandchildren who live nearby. We have a total of nine delightful grandchildren. In February of 96, to celebrate our retirement, Mike and I went on a lovely vacation to Hawaii and climbed up Diamond Head (no small feat). In May, 96 we drove to Florida, stopping on the way to visit friends and relatives in Virginia, North Carolina, and Georgia. We had arranged to meet our son, his wife and their four children for a week at Disneyland. The following is what happened.

Sheila Fitzell
South Hadley MA

On 3 June, 96 at Disney World in Florida, I received whiplash on the Thunder Mountain ride. My symptoms were a severe headache, pain at the back of the neck, burning sensation on either side of my hips, extreme pain between the shoulder blades when walking, skin super sensitive to the slightest touch (felt like sunburn). The doctor prescribed muscle relaxant tablets and activator and muscle therapy was prescribed by a chiropractor. The symptoms became worse to include double vision upon waking up and with lower back pain traveling down my buttocks and upper legs. We drove home from Florida to Massachusetts on 24 June 96.

On 26 June 96, I went to my primary care physician about the lower back pain. He ordered a CAT SCAN of my lumbar region. The results were normal! Over the next few weeks, I returned to my doctor with the following complaints: headaches, mainly confined to the top of my head. I felt as if someone was pulling my hair out. I also felt sharp pains in the bones of my face. I had joint pains in my hands (fingers, thumbs, etc.) and elbows. The onset was sudden and the pain would last a day or two and would switch from one extremity to the other. I woke up one morning and was unable to move my right ankle in either direction without extreme pain. As the day wore on, I was unable to bear any weight on that foot without severe pain. I was treated with anti-inflammatory pills and I was better three or four days later.

Because of the continued head pains and tingling sensations down my arms and hands, my doctor referred me to a neurologist who noted diminished reflex responses in my legs. On 31 July 96 he ordered an MRI. I returned to him a week later for the results. The MRI appeared normal. I told the neurologist that I was having some difficulty with my balance when walking. Also, when I was standing at the vanity in the bathroom, I found myself swaying towards the mirror. The neurologist ordered a Sensory Evoked Potentials of the extremities. Unfortunately, I was unable to get an appointment until a month later. At this point, I was extremely fatigued all the time and then on 9 August 96 I became incontinent. I couldn't understand what was happening to me. I had always had plenty of energy and the bladder of a camel! On Sunday, 11 August 96, I had difficulty in walking, my legs felt weak and I began to drag my right foot which felt like pins and needles. On 12 August 96 the foot dragging was more pronounced. I tried to reach my neurologist, but he was out of town, so I contacted my PC physician. He ordered a CAT SCAN. On 14 August 96 I woke up and went to get out of bed to stand and promptly collapsed. My legs were unable to bear my weight. I could not walk without great assistance. I was scared. My right foot is no use at all. I was admitted to Holyoke Hospital and neurological tests were performed. Steroids and bed rest are ordered and then MRI's followed. The diagnosis was Transverse Myelitis. My doctor explained that it was caused by a virus attacking the myelin sheath, etc. I drove myself crazy thinking about where I might have picked up this virus. I really felt helpless as there was no one to talk to about this. Within a few days, I was able to use the walker and with help, go to the bathroom. After about a week, I started physical therapy and seemed to be improving. My spirits were good. Ten days after being admitted, I was transferred to the rehab unit within the hospital. Then I started having PT twice a day. At this point, I was using the walker. A few days later, I became extremely weak, and my muscles fatigued easily and once again, my legs gave way. I was unable to use the walker and needed help to get to the commode. A blood test indicated that my potassium level was extremely low, my electrolytes were out of whack! What a mess. I could barely lift a spoonful of apple sauce. I felt nauseated all the time. I believe that it was probably anxiety. With high doses of potassium, I quickly improved, however, I never got back to where I was in my progression in PT and my energy level was low. Other setbacks included loss of trunk control, I now was unable to sit up without help. Paralysis of the legs, and now the sensation of a tight band around my ribs. I was terrified. Of course, no one said the word paralysis. I referred to it as numbness and when this vice-like grip of my rib cage came, I knew fear! I wondered if the "numbness" was going to continue. I truly was scared. I wasn't in control. A painful rotator cuff and extreme pain in my left wrist and lower arm made me miserable. Pain in the fingers of both hands and also thumb joints. I had several tests for arthritis, and all came back OK. One day I woke up and the front portion of my tongue was numb. There was some spasticity in my legs. The tingling in my hands was worse when I bent my head. My appetite was poor, probably because I felt constantly nervous. My hands and arms felt weak, and my sense of touch was different. Things just didn't feel right. My right hand trembled some. No one was saying anything and I thought, is this what the rest of my life is going to be like? I could not cry while I was in the hospital and I felt like I had to put on a cheerful face for everyone. With my British background, I had to pull-up-my-socks-and-get-on-with-it, so to speak. My girlfriend, Peggy, would either come to see me every day or call me. She would bring me little treats like

ice cream sundaes or Italian pastries. Mike would often come during dinner time and one night Peggy and her husband brought pizza and wine (non-alcoholic) and even wine glasses. As much as I appreciated all these little treats, I was not able to enjoy them because of the state of my anxiety. My world, as I knew it, had come crumbling down. I was terribly dependent upon others for my needs. This is a very humbling experience!

7 October 96 I was discharged from the hospital and came home in a wheelchair unable to move even a toe! I was unable to stand or sit up without assistance. I was unable to turn myself in bed. Unable to use the commode without assistance. Our home was a town house with the washer and dryer located in the basement and the full bathrooms and bedrooms upstairs. The dining room was open to the living room. Prior to my coming home, Mike had had to build a 28 foot ramp as there were four steep steps leading into the condo. Another smaller ramp was built to cover three steps leading down into the living room. This made it possible for me to be wheeled down for a change of scenery. Because I could not use the stairs, Mike had removed the dining room furniture and borrowed a single bed. The dining room thus became my bedroom/bathroom for the next two and a half months. What a delightful surprise I had when I was first wheeled into the dining room and saw the pretty flowered sheets and a coverlet on the bed. It looked lovely after the sterile hospital room of the last two months. Mike had gone shopping for these things knowing how much I liked pretty things. I doubly appreciated this act as Mike absolutely hates shopping.

At this time, my legs were hypersensitive and I could not bear the slightest weight on my legs. If my legs or feet came into contact with something cold, I felt a burning sensation. If someone bumped them even slightly when I was in my wheelchair or bed, it would send terrible sensations up my feet and legs. The burning sensation in my legs was constant but bearable, and yet there were times that my feet and legs felt like blocks of ice and were very painful. If my legs were near anything that was metal, they seemed to attract the cold (and still do); all and all, extremely unpleasant feelings. When I first came home, I was evaluated by the physical therapist and tested 0-trace for muscle strength. I started to have PT twice a week and then once a week. After the first two weeks home, I began to see small improvements which has continued. My physical therapist, Karen, was a wonderful, caring and supportive person. Our first attempt to go out in the car to a local store was horrendous. Mike got me into the wheelchair *and then* into my winter jacket (mistake #1); off we went down the ramp to the car. He then hoisted me up out of the chair, because at this point I was no help to myself, and turned me around so that I could flop into the car. We had to be careful that I didn't bash my head against the door frame. Anyway, after repeating this procedure three more times, we were safely back at home and thoroughly exhausted and thinking that we'd not be trying this again too soon! However, the next time Karen came, we asked her how we could make it easier for Mike and me to go out. The SLIDE BOARD!! I had been doing exercises for my trunk control and once sitting up, I could stay that way. I was able to use the slide board to get from the bed to the chair and eventually into the half-bath room. What a treat that was in terms of a little independence!!

Before I came home from the hospital, my girlfriend, June, who at the time lived in North Carolina, offered to come and help us. What an ANGEL! I don't know how Mike and I would have survived without her. June was appalled when she first saw me as I had lost quite a bit of weight and looked pathetic. She later told me that she had felt overwhelmed at my condition. June has great organizational skills and she literally rolled up her sleeves and went to work! It took several days for her to organize my bedroom so that everything that was needed was on hand. She bought one of those wire vegetable carts on wheels and we filled that with supplies. June tried to coax me to eat by making favorite and tempting meals and many deserts. At first, my heart was not in eating as I felt anxious all the time, and my tongue was still quite numb; food did not taste right. She was always cheerful and kept looking for ways to make me feel better about myself. She would put her warm hands on my feet and push against them, and move my legs and help me with the trunk control therapy. Little by little each week, we saw some tiny improvement. June would have made a terrific physical therapist or First Sergeant!! Each time Karen came, June would make suggestions of what she thought we could do to improve our situation. Karen was very open to these suggestions and had plenty of her own. Mike built me a four foot parallel bar. My first attempt to use it left me totally exhausted. Karen had wheeled me over to it and on the count of three, I would try to pull myself up and try to make a step. I couldn't believe how incredibly weak I was. And, of course, the next day my wrists and/or shoulders were painful. It didn't take much for my tendons to become inflamed. Mike got me some hand and wrist protectors to wear (like for those who have carpel tunnel syndrome) in the hopes that it would help. I just needed to

remember not to press with my hands. However, when your legs are weak, you tend to use your hands and arms for support. Just doing five repetitions of any given exercise tired me out. However, Karen, June and my friend, Peggy, gave me such encouragement and hope that I began to believe I might walk again.

After six weeks of caring for me and helping Mike, June returned to North Carolina. I was devastated. Mike was upset, too. She was my lifeline. How were we going to manage. Well, my friend had prepared us. We had lists of menus, and the right kinds of foods, etc. taped to the refrigerator. However, June had also talked to me about how Mike was going to need all the help I could give him as he was worn out from worry and concern. Over the years our roles had been clearly defined with me being the care-giver and nurturer and Mike providing for our family's welfare and generally taking care of us. Mike is a caring, loving person who wants to fix any problems. This TM had him at wits end, and now he had to be care-giver, cook, do the laundry, shopping, pay the bills, fight with the insurance company, etc. He did yeoman's duty! I know I'm blessed to have him in my life. Before June left, we contacted friends who each agreed to come in once a week for an hour to do my leg therapy. This was when I still needed help moving. There were eight ladies (I call them Angels). I did therapy twice a day. Sometimes I could barely get through as I was easily fatigued. It was good to see other people and hear their stories and Mike felt comfortable leaving me to run errands while the "Angels" were here. So we both benefited. They are wonderful ladies; three of them worked full time and still came. How could I not get better with such love. I was determined to pull my weight and pushed myself to do as much as possible to help Mike. However, when the muscles fatigued, there was nothing I could do but rest.

Mike and I settled into a new rhythm, and like others before us in situations such as ours, you learn ways to cope. I would wheel myself into the kitchen and park next to the sink remembering to put the brakes on. Then pulling myself up, I would be able to start to make the meal or do dishes. I could also fold clothes. For our self worth, I think it's important to be able to contribute. At this point, of course, I was still in the leg braces and that allowed me to move along side the cabinets as I could hold onto the counter top for security. There were times when we both "lost it," his from the overburden and mine from frustration. As I started to progress, I told Karen that I had a goal. I needed to be able to master the stairs in order to sleep in my own bed with my husband of forty-three years by Christmas. My grandchildren, who live a few miles away, had told their father that it just wouldn't be the same if Nana and Pa didn't come for Christmas. So, I had another reason for wanting to master the stairs and not wanting to let my darlings down. I prayed for the strength and stamina to be able to climb the steps into their house. We succeeded and enjoyed Christmas day with them.

7 January 97. The insurance would no longer pay for the VNA therapist to come to the house. So, I must go out to a rehab center. I'm anxious about this and wish I didn't have to change. Karen has been so good for me and I've done so well with her. Additionally, I'm worried that I won't have enough energy left by the time I reach the place. The rehab is located inside the local YMCA and in order to reach it, I will need to use the wheelchair to conserve my energy. Once inside, I will use a walker. My fears and concerns were allayed when I met Donna, my new therapist. I was re-tested and my muscle strength was 3+ to -4. Donna gave me new exercises to do including therabands and ankle weights. After my first session there, I used a public bathroom by myself for the first time ... another little bit of independence!

1 February 97. Today, I started to use a walking cane.

18 February 97. I went to Brigham and Women's Hospital in Boston for a third opinion and to rule out the possibility of MS. After the neurologist had reviewed my medical records and performed some of his own tests, he gave us the answer we hoped for. I did not have MS, but TM. Thank,
G-d. What a relief. During those first few months at home, my emotions were like a roller coaster. We had put our townhouse up for sale and it was nerve wracking. However, we did sell it and closed on 27 May. Three days later, we moved into our new condo which was all on one floor and certainly makes life easier for us both. It has taken the past six months for me to feel like this is home, because at first, there wasn't much I could do. However, as I've gained more energy and stamina, I have been able to put my own touches to the place. It will feel more like home once I have some family gatherings here.

Of all the things I missed the most, it was not being able to participate with my grandchildren. This left such an ache in me. However, this summer I was able to go to some of their baseball games and then in the fall, of course, all three played soccer. They have been for a sleep-over and we've been together for holidays, so things are getting back to normal. I continue to progress and have much more stamina now and only use a cane in

unknown territory. I still have some burning sensations in my right foot and the foot often feels like it's asleep. The cold air really makes my legs very uncomfortable, a stinging sensation. So, like Linus, I always have a small blanket with me. However, I'm not complaining. I thank
G-d every time I stand in the shower, kneel, walk around the kitchen and cook, and walk down the street!

This past 18 months, there have been many prayers said for my recovery; some by people I don't even know. I believe those prayers along with the physical therapy and the caring support of my family and friends has helped me to get where I am today.

A few months ago, I found out about the TMA. Sandy Siegel very graciously gave me time and information and the names of fellow victims of TM in my area. It has been wonderful talking with these people. They have been very kind and understanding and shared their experiences with me.

I started this story with events leading up to my diagnosis of TM. At first my doctor thought the whiplash I suffered at Disney World was a contributing factor, however, my neurologist said no. I don't care; I just want to get well!

Katie Gilmur: An Inspiration To Us All

Deanne Gilmur

Katie was one of those babies that couldn't move fast enough or early enough. She walked independently at 8 1/2 months old. When she was 10 months old, I walked into the kitchen where she had been playing with pots and pans to find her standing on the kitchen counter climbing onto the top of the refrigerator! She was so precocious and physically athletic. It was this athleticism that was needed after her TM diagnosis.

Some months after her first birthday, she was playing with several other toddlers in our home. She tripped twice. I thought it must be the new salt-water sandals - her first. A couple of hours later, while shopping, she collapsed. I put her on her feet and she "melted" again. I tried again. This time instinct told me whatever was happening was a major CNS problem. At the pediatrician's office, she was checked and then we were sent home to watch. At 3:00 a.m. the next morning she hadn't urinated and could not stand. In the morning she received a MRI and was hospitalized for a week. It was a hellish time. The world had changed in just a few hours. It felt like all of our dreams and hopes for Katie were gone. We didn't know what her future would be and at that point, even if she would have a future. And this diagnosis - Transverse Myelitis? What did that mean?

Over the next 7 years, we learned what it means. It means Katie is partially paralyzed from the T9 level down. It means she spent much of her pre-school years in physical therapy; it means she wears braces that are often uncomfortable for her. It means she has difficulty walking safely or playing active games. It means she gets foot sores that hurt and are difficult to heal; it means struggling with incontinence and bladder infections and so much more.

But it also means that she is developing into a wonderfully intelligent and lovely girl that seems unwilling to let anything stand in her way. She has enormous drive and determination. She has also developed skills that under other circumstances may not have been developed.

To help improve Katie's coordination and muscle tone, we started her taking horseback riding lessons through a local therapeutic horse back riding program when she was 2 1/2 years old. My oldest daughter, Britany, had been a serious show rider and had volunteered in the same therapeutic riding program when she was younger. I knew from this experience that Katie could gain balance and stability, and would have great fun - all while learning to ride. For the next 2 1/2 years we regularly attended the riding classes. Katie developed as a rider and clearly had a natural "seat," the term horsepeople use for the correct position in the saddle. Eventually, my husband became a board member for the therapeutic riding program and helped organize the annual auction. It was at this event that our future horse was being auctioned and my husband did the bidding! We were urged by a friend to bid on Joy's Pride, a then 14 year old half Arabian/ half Saddlebred mare. We purchased "Pride" whose easy gait makes it easier for Katie to ride. From that point on, this wonderfully talented and kind mare and Katie became a team. She now competes regularly in English hunter classes and very successfully.

She recently won the High Point English Award at February's Tacoma Unit Winter Series Show. To see 9 year old Katie aboard her 15.1 hand horse, Joy's Pride, she looks tiny and fragile. But inside that tiny package is the heart and determination of a champion. Katie's acceptance of her

disability and her enthusiasm for riding is an inspiration to anyone who meets her. Her award came after competing in just 5 other shows.

What's important about her success is that she, like all kids with TM, needed to find some recreational outlet, a sport she could compete well in. To be able to successfully ride and show her horse has become a very important part of her life. There are many activities and sports our kids can do even with decreased abilities to ambulate. For her, horseback riding is something she can compete in with anyone. You cannot see her disability when she is in the saddle. She's now beginning to take her horse over jumps. She reports that she loves the feeling of flying over obstacles. I can see the joy on her face when she and her horse are galloping. She's found a way to run! Katie may not have become such a talented rider if she had not gotten TM.

Please, don't misunderstand. I grieve daily for her losses and know there are plenty of difficult times ahead. Being different isn't easy. I don't romanticize this adversity. I don't believe she got this because we could handle it. Sometimes, maybe often, I don't handle it. Instead, I'm tired and angry and afraid for her. But she's tough and strong and unafraid. She is surviving TM very nicely. In fact, she's thriving in spite of it with a little help from her horse.

Membership Directory for Children with Transverse Myelitis

Katie's story represents one among a growing number of children in our Association who have been diagnosed with TM. The Association recognizes that children have special needs that are different in many ways from those experienced by adults with TM. In order to better serve our membership, the Association needs to learn more about our members; the first survey was the beginning of that process. A frequent request made of the Association comes from parents who are seeking out other parents who have children with TM. Often, parents are also looking for other children who are of similar age and who have similar experiences as their own child so that they might correspond with each other. We would like to facilitate this network for parents of children with TM. We will publish a separate directory that lists the same information that is found in our Association's membership directory, only with the addition of the names and ages of the children who have TM. We will only distribute this directory to parents who have a child with TM and who provide the information for inclusion in the directory. The information can be reported to the Association on the form that is included in this newsletter. SJS

Breaking news... Deanne Gilmur throws away all of her yellow legal pads and purchases computer.

Deanne can now be reached through e-mail at:

dgilmurtma@aol.com

Local Support for Persons with TM: Transverse Myelitis Support Group in Norfolk, Virginia

Pam Ramsay

Hello, my name is Pam Ramsay, President of our local Transverse Myelitis Support Group in Norfolk, Virginia. My son was diagnosed with Acute TM March 16, 1990. He began having flu-like symptoms which became progressively worse over a two-week period, having headaches, fever, numbness and weakness in lower extremities. Upon arriving at our local hospital, my son was in a coma. He remained in the coma for five days. When he regained consciousness, he had a memory loss of about two years. In his mind, he was four years old. He was affected at the T-5 to T-6 level. He was paralyzed and in stable but critical condition. The virus was still attacking his nervous system with a 50/50 chance of surviving. He started therapy and was on the road to recovery.

My son was transferred to the Richmond Crippled Children's Hospital where he was to undergo extensive rehabilitation. During the first month of rehab, he showed signs of his toes moving. We were told that it was muscle spasms. He was progressing daily and was having more movement in his feet and legs. By the end of the two month stay, he was able to walk with KAFO and forearm crutches. The next hurdle he endured was his bladder not functioning properly. He had a bladder augmentation. The surgery was successful, but he started at ground zero with rehabilitation. He has entered Sub-Acute Rehabilitation twice because of severe weakness. Today he is up and ready to challenge the world.

My motivation for starting this support group is to help others going through what we went through. We want to make a difference helping others ease their pain. It took me eight years to start this support group. I was too angry and was trying to put the blame on someone for what my

son went through and for what he is going through on a daily basis. Our goal through this support group is AWARENESS.

We welcome any suggestions and encourage people to contact the TMA. We encourage everyone who has TM to fill out the survey and return it to Sandy. We need doctors to know more about this syndrome, what it does, and the effects it has on people.

Pam Ramsay
Transverse Myelitis Support Group
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The Association was very pleased when Pam contacted us about starting a local TM support group in her community. Pam was very clear that she wanted to be there for people who were going through the difficult experiences that she, her family and her son endured with TM. We were excited about Pam's interest, because we desperately need for people to find each other and assist each other on the local level. That is the primary purpose for the distribution of the membership directory and its organization by state and country. There is a great deal the TMA can do to support and assist our members. But there is a great deal that you can do for each other, and perhaps more efficiently and effectively. The most frequently requested information we get from our members concerns a referral to a neurologist who specializes in TM. Our answer is that no one specializes in TM at this time. We encourage people to contact the persons with TM who live in their area and to share information and experiences about the neurologists they are using. It has to be of some benefit for both the physician and for the persons with TM to be seeing a doctor who has broader experiences with the condition. If people from a community are able to share this information with each other, they may be able to enrich the experiences of a neurologist who can, in turn, employ these experiences to help his or her patients more knowledgeably and effectively.

There is also a great benefit to be gained through the sharing of information and experiences at the community level. Each local and state government has a unique set of agencies, with unique rules and procedures. There is a great opportunity available for everyone when you share this information with each other. Most of you have had to find this information for yourselves, including everything from social service agencies and the services they make available, good rehabilitation hospitals or clinics, physiatrists and other medical specialists, good sources of adaptive equipment, references to physical and occupational therapists, to information about accessibility issues and employment opportunities. There are people in your communities who have had to educate themselves in most of these areas. You can learn from each other and greatly assist others who must learn it for the first time. You are all the most valuable resources for each other.

It requires someone to come forward and to make a commitment to organize the group. As I have learned in the past four years in the TMA, it is an enormous commitment and responsibility. But there is an enormous reward for the efforts. The first time you talk to a person who has been newly diagnosed with TM, and are able to share all of the information you have about TM, about the TMIC and the TMA, about the services and assistance available in your community -- and when you experience their relief that they are not alone, and their gratitude for your being there for them, you will never question the value of your commitment to your support group.

We are very excited for Pam and wish her well in her efforts with the Transverse Myelitis Support Group of Norfolk, Virginia. If you live near Norfolk, please contact Pam to get involved in the Group. If you are interested in starting a support group in your community, please contact the TMA and we will assist you in any way we can. We also encourage you to volunteer to be one of the TMA State or Country Representatives. We urge you to get involved. SJS

We Don't Want to Lose You

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

I am Deborah Capen, the Secretary of The Transverse Myelitis Association. My personal experience with TM has shown me that there is a lot of frustration associated with it, along with new physical disabilities that one must learn to cope.

I am 46 years old with no past health

Deborah Capen, Secretary of The Transverse Myelitis Association

problems. My children are all grown, so now the immediate family consists of just my husband and myself. I maintain three businesses in two states which demands a very active lifestyle and includes a lot of traveling. On December 30, 1996, we were flying from California to Miami. While on our first layover at the Minneapolis airport, I began having terrible cramping pain in the backs of my legs. Over a period of 1 1/2 hours, I went from painful walking to not being able to take a step forward, to not being able to stand up. I became paralyzed from the waist down.

I had been involved in a single-car rollover accident on December 15, with no obvious injuries at the time. So when I was taken to the first hospital, that was mentioned to medical personnel as a possible cause of the sudden paralysis. Based upon a quick examination, it was determined that my paralysis was not accident-related, but neurological. The doctors admitted that they were not experienced enough in neurological problems, so I was taken by ambulance to the Neurological Trauma Center in downtown Minneapolis. I was admitted immediately with an initial diagnosis of possible Gullian-Barre Syndrome. Tests performed on me included MRI's, spinal tap, electrical impulse tests on my legs, blood tests, and more blood tests. Along with aggressive testing, I was started on IV steroid treatments. After a few days, the new diagnosis was Transverse Myelitis, with a lesion at the L-2 level. My body's response to the steroid treatments was almost immediate. The first morning after the steroids, I could just barely wiggle the big toe on my right foot. At that time, it seemed like such a major accomplishment. Each day there was a bit more improvement. By day four, I was started in rehabilitation and physical therapy. That was the first time I could stand with a walker.

My daughters had flown in from Detroit to stay with me at the hospital. They are all involved in the medical field, so the hospital was very accommodating. When I took my first step, they all applauded. I have had positive support from all of my family from the very beginning. I believe that has been a major factor in my healing process.

Although the doctors were able to diagnose the Transverse Myelitis, they were not able to tell me why I got it. Each doctor has had a different opinion as to how long I would live with the problems associated with TM.

I was released from the hospital 8 days later to fly back home to California. I left with a walker, a week's supply of pain pills, a booklet on how to self-catheterize, and many, many questions.

Through close friends and a lot of research, I was referred to an excellent neurologist. He is very experienced in spinal cord illnesses, and has worked with me to find the perfect balance of medications and treatments. Through the Internet, I discovered the Transverse Myelitis Internet Club, an excellent support group for TM "victims" that was started by Jim Lubin. Ultimately, my search led me to The Transverse Myelitis Association.

I have learned that there are so many different "theories" concerning the cause and prognosis of TM. In speaking to many of you, I have realized that there is so little known about spinal cord illnesses, and that a lot of doctors are "groping in the dark," when treating TM patients.

It has been a year since I was diagnosed. In the first two months, I noticed almost daily improvement. Then my progress slowed, and I had to note my improvement on a monthly basis. I have gone from walking with the aid of a walker, to walking with a cane. I now only need the cane on days that are a little stressful, or when I am pushing myself too hard. My doctor told me that my worst enemies are "stress and fatigue." There are days that I can walk with hardly a limp; then sometimes I can barely keep balance to walk at all.

I am back to traveling in business, however, the physical activity is still somewhat limited. My energies are now geared toward staying in the office, and "delegating" the work that I cannot physically handle. There have been bad, painful periods, and with the help of my husband and friends, I have gotten through the bad times.

There are so many people in the world that are being diagnosed with Transverse Myelitis, and I know how they feel. They have never heard of this rare disorder, want to know "Why Me?," and for some of them, there may be little improvement in their new disabilities.

The Transverse Myelitis Association has been formed to help those of us with TM gain a bit more knowledge of our disorder; to know that we are not alone. I hope that my administrative skills will be of benefit to the TMA - that together as a team we can accomplish the goals that have been set.

If anybody would like to contact me, I

would be very happy to talk to you. I can be reached on the Internet via e-mail at <dcapen@ivic.net>. You can also write or call me at the numbers listed on the back of this newsletter.

Debbie has brought a wonderful energy and enthusiasm to her work as Secretary of the Association. She is driven in her tasks by her compassion and the insights she has acquired through her own experiences with TM. Debbie has brought her business skills, experience and expertise to the planning and operation of our Association. We are really pleased to have Debbie as the Secretary of The Transverse Myelitis Association. We greatly appreciate her efforts to make us a more efficient and responsive organization. SJS

October 25, 1979. I was 12 years old and at a Halloween party. I had a bad back ache and decided to go to bed early. When I woke up in the morning, the back ache was still there so my friend's Mom took me home. Once home my Mom tried a heating pad on my back. But once again the

Paula Lazzeri, Treasurer of The Transverse Myelitis Association

ache just wouldn't go away. So my Mom and Dad took me to the emergency room. They checked me over, X-rayed me and sent me home with the diagnosis of a pinched nerve.

By the time I got home, my balance was getting pretty bad. As I walked through my house, my knees would buckle and I barely had enough strength to get up. Feeling very weak, I laid down in front of the TV with my siblings. While there I fell asleep. I felt this wave of paralysis go from my feet to my neck. When I awoke, my mother was telling me to go to bed. I laid there and said "I can't Momma, I can't move". This was early evening about 7:00 PM.

The doctors were shocked to see me again in the emergency room paralyzed from my neck down. I could move my arms a little. I was effected at the C6-7 level. I was put through all the tests. About a month post onset, I was diagnosed with Transverse Myelitis and moved to a Children's Hospital where I underwent intensive physical and occupational therapy. After 4 months of Children's Hospital, I was released to go home. I was able to regain most of the use of my hands. The fine motor skills are still tough. They have since moved the level of my paralysis to T-1. I can feel everything from T-1 down but pain and temperature. My legs feel numb and tingly. I use a wheelchair 100% of my day.

I was never given steroids. I don't know if they were giving them that long ago. I'm now 31. It hasn't stopped me much. My family has always been very encouraging and supportive. I made it through college, have worked as a tax accountant for the past 9 years, am married now for 11 years, and have a 5 year old son. Unfortunately, I've also had cysts, a collapsed lung, 3 full spinal fusions, broken tailbone, broken femur, many bladder infections, and skin breakdowns. Quite the busy life.

Thanks,
Paula
*It only takes knowing Paula for about five minutes before you fall in love with her. She is a truly remarkable person. That she has recounted her story for you in about 400 words speaks volumes about her. Paula is definitely a **doer**. She has had very difficult experiences and has had some serious losses. But she also has a really great life! She is surrounded by a wonderful family, has a college education and a career, and is a full participant in life! We are all enriched from knowing and working with her; the Association regularly benefits from her contributions. We are very proud of all of Paula's accomplishments and are grateful for the job she performs for The Transverse Myelitis Association. SJS*

Once again, the generosity of caring people has multiplied the balance of our account. As of June, 1998 The Transverse Myelitis Association has an account balance of over $6000.00. Thanks to the Claddagh Foundation for the $5,000.00 donation earlier this year. This is one small step toward our ultimate goals and we're getting

TMA 1997 Financial Report

Paula Lazzeri, Treasurer

excited knowing the future will be even greater.

Our membership of 180 people is now more than 925 and growing. The ability to make the world aware of our organization through the Internet and our newsletter publication has been of tremendous value, as we all know. I'm sure it's of no surprise to you how many people are ignorant of this disease, including physicians, nurses and medical research people. Our newsletter now goes out to an incredibly large reading audience. As you saw in the last Treasurer's report, Sandy, our editor, and Deanne, our president, had been paying for all of the printing, postage and telephone costs of the Association through 1997. It's time for the rest of us to sit up and do our part!

It may help to know where your

donations go when you send in your check or money order. A percentage will go toward defraying the costs of printing, the postage to mail all communications, the phone calls necessary and all work regarding the Association. Now hear this great news! Plans are on the table for a future conference to be held in Tacoma/ Seattle. We will be working to raise funds to see that plan through. Remember, the TMA is a not-for-profit organization and your contributions are all tax deductible.

We are exploring many avenues for fund raising, such as researching government grants, corporation golf tournaments, car washes, garage sales, and appeals to philanthropic sources dedicated to needs such as ours. We welcome any and all ideas that will help our Association along these lines. You know where to reach us.

If you are interested in making a tax-deductible contribution to the TMA, please make your check to The Transverse Myelitis Association and mail it to: Paula Lazzeri, Treasurer, The Transverse Myelitis Association, 10105 167th Place NE, Redmond, WA, 98052. We greatly appreciate your generosity! As a review of the past year, I have included the TMA 1997 Annual Financial Report below. The expenses identified in this report were covered by Deanne and Sandy. There was an operating net loss, because none of the donations were used in 1997 to cover expenses. Given the small account, it was decided that the Association should carry a balance.

The Transverse Myelitis Association 1997 Annual Report

As you know, The Transverse Myelitis Association is supported by your tax-deductible contributions. Contributions to the organization are greatly appreciated as they are needed to continue TMA's current level of service and activities, and to enable TMA to increase the scope of services

Revenues:	
Donations	1162.16
Total Revenues	1162.16
Expenses:	
Internet Access	199.32
Mileage	4.80
Parking	2.00
Phone	739.27
Postage	633.04
Printing	1800.54
Supplies	91.10
Total Expenses	3470.07
Net Income/ (Loss)	**(2307.91)**

Contributions to The Transverse Myelitis Association Through the United Way

Dick Gilmur

and activities that it provides. There are many ways to financially support the activities of the Association. In addition to sending your contributions directly to the TMA, the United Way program may provide you with a practical alternative method for contributing.

In each of our communities, United Way conducts annual fundraising drives. The United Way program allows participants to identify specific 501(c)(3) organizations to receive their contribution. In some areas this is called the "Donor Voice" program, in others it is called "Specific Care." Your area may even have a different name for this aspect of United Way giving. You can designate The Transverse Myelitis Association as the recipient of your United Way contribution by following these instructions. All you have to do is write the name, address and phone number of our organization (see below) in the appropriate place on your United Way pledge form. Please encourage your friends, relatives and co-workers to consider designating the TMA as well.

The Transverse Myelitis Association received funding as part of United Way's 1997 fundraising campaign. Consequently, the TMA is already identified through United Way of Pierce County, Washington as an organization that can receive United Way funding when you designate the TMA as the recipient of your contribution.

The TMA depends on community support. The TMA community is expansive as it includes each of you, your City or Town, your medical community, your educational institutions, your libraries, and your friends and relatives. Contributions are essential to the continued success and growth of the Association and its programs and services. The Association tries to serve each of you to the best of our ability and to the extent of our finances. Together we can continue the TMA's success story. Please consider supporting the TMA.

All direct contributions to The Transverse Myelitis Association can be sent to Paula Lazzeri, Treasurer (*see Treasurer's Financial Report for Paula's address*). United Way contributions require the corporate address to be used. When you fill out the United Way form you must include the following information

with the TMA designation:

The Transverse Myelitis Association
3548 Tahoma Place West
University Place, WA 98466
(253)565-8156

The TMA began to administer surveys to our members in January, 1997. Our membership at that time was approximately 180 people. Today, we have over 925 members in the Association. The survey represents an attempt to collect, analyze and publish information about Transverse Myelitis, including

The TMA Survey Research: It's Not Too Late to Make Your Valuable Contribution

Sandy Siegel

such issues as the onset of the condition, the treatment of symptoms, and the demographic characteristics of people who are diagnosed with TM. Physicians cannot begin to understand TM without your willingness to share with them information about yourself and your experiences. The TMA has access to more people with TM than any doctor, health care institution or research organization; we are the best source of information on the Transverse Myelitis condition. The more information we are able to report to physicians, the better they will understand TM. With better understanding comes better treatment; we are all the beneficiaries of this information and experience. Given the diversity of experiences that are represented by our members, it is imperative that everyone participate in completing the survey.

If you have not completed and returned the survey, you may get a copy of it by writing to or calling Deanne Gilmur. The survey is also available on our web site. You can download a copy or you can fill it out on-line and send it electronically in your e-mail or internet software. If you have the survey, but have not yet completed it, please take this opportunity to help us help you! Please take the time to complete and return it.

Please follow these instructions when responding to the survey. Most of the survey questions are open-ended. We have provided only minimal space on the questionnaire for your responses. For some of these questions, you are going to need additional paper to provide us with your answers. We urge you to use additional paper and to provide us with as thorough answers to each of the questions as possible. When you use additional paper, please number each of the responses so that they can be properly matched with the appropriate question.

Please answer the questions to the best of your ability. If you have difficulty remembering dates, the specific sequence of events and their durations, medications or any other specific information requested in the survey, please discuss these issues with your families and with your doctors. Attempt to reconstruct events as best as you can. It is important that we collect accurate information. If you are providing us with approximations or with your best recollections, that is fine. Just indicate the level of accuracy of the information in association with the information you provide us. For example, if you are not certain of the exact amount of time you experienced flu symptoms before you contracted TM, please indicate that your answer is an estimation.

If you have difficulty writing or typing, please ask someone to assist you in completing the survey. So long as the responses are properly numbered, you may use whatever paper you would like to complete the survey. Also, if it is easier for you to complete and send the information electronically, please feel free to type your responses and e-mail them to the Association. Please send them to srulyosef@aol.com.

We greatly appreciate your willingness to provide us with this very personal information. We will publish the results of the survey analysis in future newsletters. If you have any questions or concerns about the survey, please feel free to contact Sandy Siegel or Deanne Gilmur. Please send the responses to:

Sandy Siegel
The Transverse Myelitis Association
1787 Sutter Parkway
Powell, Ohio 43065

TMA Internet Update

Jim Lubin

In February, 1998 the TMA obtained the Internet domain address **myelitis.org** and changed to a new web server host. With the new domain address, it has made it easier for people to find us online. The new server host has also given us more storage, 50Mb of storage. The original web site was on a sub-account on AOL. With the additional storage, I was able to move the TMIC web pages and message archives off of my private internet account to the TMA account at **myelitis.org**. This has also enabled us to have pictures of members online so we can "meet" each other. Here is a summary of the new web pages:

TMA Home Page: ***http://www.myelitis.org***
TMIC Home Page: ***http://www.myelitis.org/tmic***
TMIC Message Archive: ***http://www.myelitis.org/tmic/archive***
Members' photos: ***http://www.myelitis.org/tmic/members***

New e-mail addresses:
Debbie Capen: ***dcapen@myelitis.org***
Jim Lubin: ***jlubin@myelitis.org***
Paula Lazzeri: ***plazzeri@myelitis.org***
Sandy Siegel: ***ssiegel@myelitis.org***

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

The Transverse Myelitis Association

Sanford J. Siegel
1787 Sutter Parkway
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The Transverse Myelitis Association announces a conference and fund raiser in Seattle in August, 1999