❖Transverse Myelitis Association❖

Volume 1 Issue 1 January 1997

We are pleased and proud to bring you the inaugural issue of the Transverse Meylitis Association Newsletter

A Letter from Deanne Gilmur, President of the Transverse Myelitis Association

My best to all readers interested in the TMA. As you undoubtedly recognize, this is the associations first newsletter. How frequently newsletters are written and distributed are as yet uncertain; much will depend on your input and our editors patience. Our editor is Sandy Siegel, who has become a partner in the development of this organization. Together we hope that this newsletter will provide a sense of support and cohesiveness, ideas for coping mechanisms, and information regarding resources and related research. At this point I am building the database of members and a clearing house of articles and information. I have a long ways to go to perfect this first phase of the association's development.

With your support and approval, I have drafted the following short and long term goals for the Transverse Myelitis Association:

Short Term:

1) To continue to build a database of members for mutual networking and support.
2) To continue to locate relevant articles and information for distribution to members.
3) To develop and circulate a newsletter at least twice annually for the purpose of communication and information sharing.
4) To complete the process of legal non-profit organization status.
5) To develop a professional TMA brochure.

> ***It has been such a privilege to talk to so many of you; I have been moved by the courage and effort that you have expressed.***

Long Term:

1) To gather statistics from our membership for eventual research purposes.
2) To investigate the potential of interaction with larger related organizations.
3) To investigate and fund appropriate research.
4) To maximize opportunities for interactions and gatherings amongst members.

As formal as the above may sound, the overall goal is to establish a sound organization that offers people support, answers, and hope that we're all in need of when confronted with this diagnosis. Please contact me if you have suggestions or input regarding the goals. It has been such a privilege to talk to so many of you; I have been moved by the courage and effort that you have expressed. It is my greatest hope that this Association will assist in the healing of both those with the diagnosis as well as family members.

Sincerely,

Deanne Gilmur has moved; please note the change of address:

3548 Tacoma Place West
University Place, WA 98466

Deanne's phone number remains:

From the editor

By Sanford J. Siegel

On July 29, 1994 Pauline fell to the floor with an excruciating pain in her lower back. We rushed her to a hospital and within a week she was diagnosed with acute transverse myelitis. As most of you are so aware, what followed were months and months of tests, therapy and questions. So many questions and so few answers. The doctors, nurses and therapists offered answers that were, at best, ambiguous and difficult to understand. When seeking answers as to cause, we were offered only theories, and then only with some reluctance. And as to any future potential risks, various probability statistics were recited -- and recited without much reassurance or conviction. What has remained is so much confusion about cause, about relationships to the auto-immune disorders, about treatment, therapies and medications, and about future quality of life and health risks. These were very lonely and frustrating times. Neither of us knew anyone with transverse myelitis nor had even heard of transverse myelitis.

Pauline has been THE very special person in my life for nine years. Pauline is a kindergarten teacher and I am a cultural anthropologist. She is a truly remarkable person who has taught me much about life and is now teaching fifty kindergartners every year the meaning of disABILITY. We live in Columbus, Ohio.

We began to search for answers about transverse myelitis. That search brought us to Deanne Gilmur from Tacoma, Washington. Deanne's daughter was diagnosed with transverse myelitis when she was eighteen months old. Deanne started the Transverse Myelitis Association in 1994. We were put in touch with Deanne through the National Organization of Rare Disorders. When I reached Deanne, I offered to assist her and TMA in any way I could. It is through that offer that Deanne asked me to be the editor of your TMA Newsletter.

We are very pleased to bring you the first publication of the TMA Newsletter. We hope that you find it informative and useful in your own search for answers. At the very least, we hope that it helps you to understand that you are not alone. We need to be there for each other -- and we will be.

We want to hear from you. If you have any comments about the newsletter, including information that you would like to have covered in future issues, please let us know. If you would like to submit an article for future publications, or are interested in writing an article for the ***IN THEIR OWN WORDS*** column, we would greatly appreciate your contributions. Please send all of your correspondence regarding the newsletter to the address I have provided below. You may also send me material over the internet.

Over the past year, Deanne conducted the first mailing to people who had made contact with her through a reference from NORD. We were sent various medical articles regarding transverse myelitis, as well as a directory of individuals who had been in contact with Deanne. She has also mailed a survey to solicit perspectives on what the TMA should be for its members -- what services should be offered and what activities should be pursued. She has been in personal contact with many of us. Deanne's efforts at initiating the TMA, disseminating information about transverse myelitis and encouraging and structuring a social network for offering emotional support have been outstanding. As we publish our first newsletter of the Transverse Myelitis Association, I wanted to take the opportunity to thank Deanne for her leadership, her kindness and generosity, and her perseverance -- we are all the benefactors of her hard work and dedication to the Association. Thank you, Deanne.

Sanford "Sandy" J. Siegel

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Jim Lubin: An Inspiration and a Wealth of Information on the

My name is Jim Lubin. I was diagnosed with acute transverse myelitis in 1989. I woke up the morning of May 17th with a sore neck on my right side. I thought I had just slept wrong, took a couple of Tylenol and went to work. About an hour later, I started feeling dizzy and the pain in my right shoulder increased. I lost feeling in my legs and couldn't stand. I started loosing my breath just as the paramedics got there. That is the last thing I remember until I woke up in ICU; I couldn't move and couldn't speak. To make a long story short, I had a MRI several weeks later which showed a lesion at the C1/C2 level.

I'm still paralyzed from the neck down and completely dependent on a ventilator to breathe. I can now feel everything except my right arm and have less feeling on my whole right side.

Jim posted this message on August 18, 1996 on the Transverse Myelitis Internet Club (TMIC). Jim started the club to provide a forum for people with transverse myelitis and their families and friends to exchange information, offer emotional support and share perspectives on their experiences. For those of us who have access to the Internet and have been searching for information on transverse myelitis, Jim has become an inspiration and a source of a great deal of valuable information about transverse myelitis and about disability.

In addition to the TMIC, Jim has developed and maintains an Internet site he has named the disABILITY Information and Resources page. He has constructed the site with numerous links to disability topics all over the Internet. The site has compiled links to such topics as disability-related products and services, spinal cord injury resources, government and legislative information, social security information, legal information on disability issues, medical related newsletters and publications, medical newsgroups, disabilities organizations, disability resources relating to recreation, travel, sports training and athletic competition, university-based disability information, and information pertaining to the Americans with Disabilities Act. Jim has also compiled links to information about transverse myelitis. The disABILITY Information and Resources page includes the equivalent of five pages of links which literally transport an information seeker all over the Internet.

Jim's experience and expertise with computers and software are quite obvious and impressive from ***what*** he has accomplished on the Internet. What is less obvious and more remarkable is ***how*** Jim performs these tasks.

Jim's computer activities and his work on the Internet were the subject of a journal article in a health publication. Anne Federwisch, OTR, wrote an article about Jim in *Nursing & Allied Healthweek* entitled, "Computer becomes therapy, link to world for patient." (URL **http://www.healthweek.com**, article posted 11-6-95). The following excerpt from Ms. Federwisch's article explains how Jim is able to use his computer:

From August 1989 through January 1990 Lubin was in rehabilitation at the University of Washington Medical Center in Seattle. "Rehabilitation was kind of boring most of the time because I was a C2 quad -- I couldn't do much," he said.

Lubin said therapy grew more interesting once he gained access to a computer. His regular occupational therapist called in Denis Anson, MS, OTR, a computer access specialist and lecturer in the division of occupational therapy in the University of Washington's department of rehabilitation medicine, to determine the best way for Lubin to use the computer.

Anson taught Lubin how to use Morse code with a sip-and-puff interface. Lubin gently inhales and exhales (sips and puffs) into an air switch connected to a computer. An adaptive device translates each sip into a dot in Morse code and each puff into a dash. The dots and dashes are translated into commands and letters on the computer screen.

Lubin mastered Morse code and the sip-and-puff technique in less than a month. A special valve (a Passy Muir tracheostomy speaking valve) lets air go into his trach but blocks it from going out allowing him to speak and to sip and puff while on the respirator. "That way I have to exhale through my mouth and/or nose. Also I can hold my breath this way," Lubin said.

Lubin said that only a little air is needed to activate the sip-and-puff switches. "It's more just moving my tongue to change the pressure in my mouth. I just do very fast sips and puffs. I keep exhaling through my nose while I am typing."

Lubin now uses the sip-and-puff technique at home on his computer to access the Internet. Using an adaptive device called Adap2U, made by AdapTek Interface in Mercer Island, Wash., Lubin sips and puffs into an air switch to type into the computer.

Using the technique Lubin now can type 17 words a minute.

There is a photograph of Jim and his adaptive device and computer on his homepage (**http://www.eskimo.com/~jlubin**). You may access Jim's disABILITY Information and Resources at **http://www.eskimo.com/~jlubin/disabled/**. If you are interested in joining the Transverse myelitis Internet Club, send a message to "**tmic-list-request@eskimo.com**" with the subject "subscribe." You will be placed on the list and will receive all of the messages that are posted by any member of the group. Once you have subscribed, you may introduce yourself to the group by posting your own message. This can be accomplished by sending a message to: "**tmic-list@eskimo.com**". Jim has established an archive for all of the messages that have been sent in the TMIC. This may be accessed at **http://www.eskimo.com/~jlubin/disabled/tmic**. The archive allows you to search the material by date, subject or author. Regardless of when you join the tmic, you can catch up on all of the exchanges that have taken place since the tmic's initiation, as well as share all of the valuable information that has been posted by the participants. It is a unique and valuable way to learn from people who have shared many of your own experiences.

Jim has graciously offered to assist the Transverse Myelitis Association by establishing a presence on the Internet. We are in the process of preparing materials that Jim will develop into a homepage on American On-Line. This site will be available to anyone with access to the Internet. Jim will be maintaining the site for TMA. We will provide you with an address or URL for this site when it is available. We will provide this information to you in the next newsletter, and through the tmic. The TMA homepage will assist us in reaching more people with transverse myelitis, and their families and loved ones. We are very excited and grateful to have Jim's considerable talents be made available to TMA.

Jim lives in Bothell, Washington. If you would like to send Jim e-mail, he can be reached at: **jlubin@eskimo.com**.

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 also our hope that the stories will help us all realize that we are not alone.

Betty Rovenstine

Witchita, Kansas

My name is Betty Rovenstine and I live in Wichita, Kansas. My transverse myelitis came about on September 27, 1989. It started around 8:30 AM with numbness in my feet and legs. By the time we arrived at the Minor Emergency Center I was unable to stand. I went in an ambulance to the hospital where I had many tests -- MRI, Cat Scan, etc. - and was diagnosed as having transverse myelitis, which is inflammation of the spinal cord going across, opposed to up and down. I am still on pain medication, Darvacet - 100 for back pain. I believe other than the pain, the thing that bothers me the most is the paralysis in my legs, feet, and all my lower body, and the leg nerves because of the myelin (nerve cushion) being stripped from the nerves. I have a prescription which helps somewhat, but not entirely.

The prescription medicine is generic Elavil (Amitriptyline). I can only take it at bedtime because of the side effect of drowsiness. I was in the hospital five weeks with therapy twice daily, but I still couldn't stand on my feet until I began out-patient therapy. My therapist then taught me to stand alone and to walk again. She stood me between the parallel bars and guided my feet with hers as she sat on a stool and rolled backwards, keeping my feet apart since they wanted to hug one another. I can walk with my walker to and from the car with my husband just behind me, or I would probably fall. I was warned by the therapist not to try it alone.

My bladder and bowels do not function on their own. We catheterize four times a day, the last one done at 10:45 so it lasts all night. We must wait until a B.M. works on down and help eliminate it, which is painful but necessary.

I had forty-six chiropractic treatments, but it did not help. It only aggravated the condition. I have normal use of my arms and hands for which I am grateful.

I cook, wash dishes, dust, and anything I can do, but my husband vacuums, grocery shops, does the laundry and all the everyday things I am unable to do. He also gardens, plants flowers and does all the outside work on this half acre. We're grateful also that this all waited until he retired from Boeing Aircraft, after forty-one years. I am seventy-two and he seventy-seven. I thank G-d for him every day. In 1979 he had a heart attack and one year later he had surgery with five by-passes and has had regular and good check-ups since the surgery sixteen years later; and I feel that I am a very lucky lady to still have him.

I didn't realize before I heard from NORD, the National Organization

You can reach TMA on the internet. You can send us information, submit stories and articles for the newsletter, contribute your articles for the ***In Their Own Words*** column, and refer new members to TMA by using the the Internet.

srulyosef@AOL.com

of Rare Disorders, that TM was so widespread. I live in my wheelchair and am up in it all morning and until our noon meal at 1:30 or 2:00 PM and by then I am more than ready to go to bed for the remainder of the day and evening until bedtime. I hope my article will be of help to someone who is unfortunate enough to endure TM.

Betty Rovenstine

Dale Green
Paisley, Oregon

My name is Dale Green. I am 58 years old and I have transverse myelitis. It all started on the night of October 10, 1994. My left arm started to go numb. Then by the next morning I couldn't move from my chest down. I could shrug my shoulders and turn my head is all. I had feeling in the left side of my body, but not the right.

I spent seven days in C.C.U. in Bend, Oregon then another two weeks there. By the time I left Bend I could move my right hand some and lift my right arm a little. I could move my left hand some and my toes.

After Bend I got moved to rehab in Eugene, Oregon. There I got so I could stand in a standing frame and do some bridging. I also got to where I could feed myself. I got an electric wheel chair with a tilt. I spent six weeks there then I went to a nursing home in Redmond, Oregon where I spent the next seven months getting therapy. I went back to Bend Rehab for three weeks for more therapy before I moved back home.

I have been home now for almost one year. The pain I deal with is neck, bladder, and butt pain because the chair I have now does not tilt so I tend to sit too long. I take pain pills. I live six miles from a hot mineral pool so I tried getting in it to exercise. I really enjoyed it.

The part of my spine that was effected was up in my neck. In Eugene one doctor said he could try to help by doing surgery to repair the nerves, but two other doctors said that they wouldn't recommend it.

Dale Green

A Work In Progress...
By Deanne Gilmur and Sandy Siegel

It has been a very busy and gratifying year working to establish the Transverse Myelitis Association. There is so much work to be done. There are a number of on-going activities that we wanted to describe for you.

One of our most important activities is to formally file for non-profit status with the IRS. We have some decisions to make regarding our formal organization. It is important to keep in mind that we are not formally recognized as a not-for-profit agency. For this reason, we ask that you not make contributions to TMA. When we have completed this process, we will inform our membership of our status and describe our formal organization.

We are in the process of developing a membership directory for TMA. One of our major goals is to create a network where we can find information and support from others who share our experiences. The directory will serve as one means for our movement in that direction. The directory may also help us find people in our own and neighboring communities where we can begin to initiate more local support networks. We will also include e-mail addresses in the directory. The directory will help us to keep track of our membership. We ask that you keep us informed of any changes in your addresses or telephone numbers. Our hope is to have the directory published and distributed early in 1997.

We are also developing a process for the systematic collection of information about our members. Perhaps one of the most frustrating aspects of transverse myelitis is the scarcity of information about transverse myelitis and the people who have it. Given the very small incidence of transverse myelitis, there is little research, if any, being performed on tm. We believe that one of the important functions of TMA can be the collection and dissemination of information about tm. We are going to begin collecting demographic, medical and experiential information in a survey that is included in this newsletter. Be assured that this information will never be released in association with your name. We will protect the anonymity of our members. Our goal is to provide information to assist our members and to offer information to the medical community that will ultimately help our members in understanding and coping with transverse myelitis. As we begin to compile and analyze the database, we will share this information with you in our newsletter. This process will serve to provide all of us with a broader and deeper understanding of our own circumstances.

Another important activity of TMA

is the preparation of a bibliography and library of transverse myelitis research publications. We have begun the compilation of journal articles. A mailing was prepared earlier in the year that contained some of these articles. In your own research, you are going to find additional research articles and publications. We would appreciate any information you can share with us to expand our bibliography. We will prepare a bibliography in the near future that will be mailed to each of you for your explorations about tm. We will continually update the bibliography with our own searches, and with the material that all of you share with us.

A final immediate activity is the preparation of a brochure that we can use to describe the Transverse Myelitis Association. We will send copies of this publication to NORD for the purpose of referring transverse myelitis patients to our organization. If you found us through some other means besides NORD and the Transverse Myelitis Internet Club/Jim Lubin's DisABILITY Information and Resources, we would be very interested in that information. Additionally, if there are others who should receive a copy of our brochure for the purpose of referral, please let us know.

We want to fashion the goals and activities of TMA to serve the needs of our members. We will continue to survey our members to seek your opinions. Please help us to help you. If you are searching for specific information on a subject, let us know, and we will communicate your need for that information; there are others in our membership who may be able to help you. If there are particular activities you would be interested in TMA engaging in or sponsoring, please make your opinions known to us. We are helping to provide the materials for this work in progress. Its design is up to you.

Jim Farreri: *We Have a Very Understanding Attorney*

The Transverse Myelitis Association is in its infancy. There is much work to be done to ensure that the goals and activities of the TMA meet the needs and desires of our members. There are also many important decisions to be made about how we will be structured and how we will function as an organization. Two important activities concern becoming a corporation and an IRS filing to become a not-for-profit organization. It became obvious to us that we were going to need to establish a long-term relationship with an attorney who would be able to assist us with these processes, and would be able to provide us with legal advice in the future.

Our search for an attorney has occupied some considerable time and energy over the past six months. While the TMA possesses lofty goals, our financial situation is much closer to earth. Our search included bar associations and university law clinics. And we were not meeting with much success. In October, we posted a message in the Transverse Myelitis Internet Club asking for the assistance of an attorney. We received a response from a gentleman who was a participant in the TMIC. After the exchange of a few e-mails, Jim Fareri volunteered to assist the Transverse Myelitis Association by providing us with any legal advice and assistance we might require.

Jim possesses a very intimate understanding of the mission and goals of the Transverse Myelitis Association. Jim Fareri has transverse myelitis. I asked Jim to provide us with some information about himself and about his experience with transverse myelitis.

I was born in Pittsburgh, Pennsylvania on July 7, 1957. I went to college at Pitt (78) and law school at Rutgers (81). I have been at the same firm since graduation and will have practiced law for fifteen years as of October 29th. I am admitted to practice in Pennsylvania and New Jersey. I primarily do litigation, especially plaintiff's personal injury and employment discrimination cases. I am married and have two beautiful daughters ages eight and six. I am currently the President of a board of directors of a Pennsylvania not-for-profit corporation, Developmental Educational Services, Inc., which provides educational, vocational, and support services to developmentally disabled children and adults. I am treasurer of my local fire company.

> ***When I discussed the practice of law at Good Shepherd with one of the nurses he told me something I'll never forget: "you don't make legal arguments with your legs." Sometimes in life the obvious is a revelation.***

Last summer was when I got acute transverse myelitis. I was in good health all of my life. On a Friday afternoon, as I was preparing to go on vacation, I suddenly discovered I could not urinate. After three trips *to the emergency room, and the beginning of paralysis in my legs, I was diagnosed with Gullin Buarre and rushed to Thomas Jefferson Hospital in Philadelphia. By the time I got there I was paralyzed from my sternum down and close to needing a respirator. The doctors there diagnosed acute transverse myelitis and gave me acute IV doses of Solumedrol. The paralysis stopped rising. I didn't need a respirator, and was alive, so actually I was pretty happy.*

After a week on the neuro ward, I was sent to rehabilitation. I transferred to Good Shepherd Rehabilitation Hospital in Allentown, Pennsylvania which is to rehab hospitals what Michael Jordan is to basketball. I was discharged in late August in my Quickie wheelchair, unable to walk, but with slight movement and feeling in my legs. As an outpatient, they taught me how to walk again, from braces and the parallel bars, to braces and a walker, then just the walker, crutches, a single crutch then nothing by the first of the year. I stopped therapy, all treatment and medicines around March. I have not fully recovered. My legs are weak, numb, sometimes painful, and I cannot run or walk far, or play my favorite activity of golf. I get tired easily. Worst of all, my bowel and bladder are still screwed up; to use the doc's lingo, "neurogenic."

Like a lot of us, these unhappy events followed a flu-like viral illness a week before initial onset. I work full-time like I did before, but with more difficulty. When I discussed the practice of law at Good Shepherd with one of the nurses he told me something I'll never forget: "you don't make legal arguments with your legs." Sometimes in life the obvious is a revelation.

As with so many others with transverse myelitis, Jim has met the physical and emotional challenges of his illness to return to work and to continue to make valuable contributions to those around him in his community. We greatly appreciate Jim's willingness to volunteer his time and effort in furthering the goals and activities of TMA. We are both very pleased and proud to have Jim Fareri as our Transverse Myelitis Association legal counsel.

Instructions For Completing the Enclosed Survey

Most of the survey questions are open-ended. We have provided only minimal space on the questionnaire for your responses due to our space limitations. For most 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 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 transverse myelitis, please indicate that your answer is an approximation.

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 us electronically. You may send them to **srulyosef@AOL.com**.

We would like to begin the analysis of the survey results as quickly as possible. We are planning on both a content and statistical analysis of the data and information. Data coding, data entry, and data and information analysis are time intensive tasks. Please try to return the surveys to us by **March 1st**. The surveys should be mailed to:

Transverse Myelitis Association
c/o Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065

In the process of reviewing and filling out the answers to the survey, you may think of additional issues or information that we have not covered in this first questionnaire. When you return your responses, please provide us with any questions or issues you would like to see included in future surveys. You may also wish to discuss this survey with your doctors. If they have additional issues or information that they would find useful, please include those areas, as well. If your doctor is interested in reviewing the results of the research, please communicate his/her interest to us. Please provide us with their name and address and we will include them in our dissemination of the results.

We greatly appreciate your willingness to provide us with this very personal information. We believe that this information will ultimately help doctors better understand transverse myelitis and the people who have contracted this illness. We believe that this information will ultimately help our members.

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.

Thanks for helping with the postage...

As you can well imagine, the Transverse Myelitis Association mailings have become a significant expense. We are asking that you assist us by providing the postage to return the surveys. In most cases, the survey responses will weigh more than one ounce; the postage will be more than a 32 cent first class stamp. Please be sure that the proper postage is on the return, so that your survey is delivered. We greatly appreciate your willingness to assume this cost.

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