



THE TRANSVERSE MYELITIS ASSOCIATION

Advocating for those with rare neuroimmunologic disorders

GENERAL MEMBERSHIP MEETING MINUTES

A meeting of the general membership of the Transverse Myelitis Association was held on Sunday, August 15, 1999, at the Doubletree Guest Suites Hotel in Seattle, Washington.

Officers present at the meeting: Deanne Gilmur, Sandy Siegel, Paula Lazzeri, and Deborah Capen.
Officers absent: Jim Lubin.

Approximately 45 members were in attendance.

The meeting was brought to order by the President, Deanne Gilmur at approximately 9:00 a.m.

Review and Summary of Accomplishments to Date:

- In November 1996, the TMA became incorporated as a non-profit organization in the State of Washington.

- In 1997, the Medical Advisory Board was created. TMA's first Medical Advisory Board members included Dr. Charles Levy and Dr. Joanne Lynn.
- The initial Information Packet for new members and interested persons was developed. Changes are made from time to time to improve and expand the packet.
- The TMA Membership Directory was created, which Sandy Siegel has worked very hard to put together, manage and update. The directory is distributed to new members and new editions are provided to all TMA members.
- TMA initiated its newsletter with distribution as close to 2 times annually as is humanly possible. The TMA newsletter is a very difficult task managed by Sandy Siegel. TMA has talked about making the newsletter a quarterly publication, but it is not possible at this point in time.
- The Website was put together by Jim Lubin, and he is continually changing the site to make it grow and respond to TMA's needs. It has been a wonderful means to educate people and keep members informed of updates, such as having the Symposium Program posted.
- In September 1997, the TMA registered as a nonprofit organization – receiving 501(c)(3) IRS status. This allows TMA to solicit donations as a tax-exempt charitable organization.
- TMA has worked hard to increase interactions and relationships with the medical community, public health institutions like the National Institute of Health, and other nonprofits. Preparation for the Symposium prompted many contacts with numerous medical professionals and organizations. The foundation for building stronger ties has been laid with various agencies and provider groups. Also, TMA's relationships with The Myelin Project and the Johns Hopkins Transverse Myelopathy Center are expected to continue to grow in the future.
- In March of 1999, [the New York State Legislature passed a Resolution naming June 6, 1999 as Transverse Myelitis Day](#). TMA member, Pam Schechter, spearheaded the effort and organized a day full of TM awareness and support activities and educational exchanges. Ian Hawkins in Australia, who has created a very active support group for TM, was instrumental in promoting a [National TM Awareness Day](#) as well. This will be an annual event, planned for May of next year.
- The First International Symposium and all the interactions and planning that led up to it consumed most of 1999 for many of the Board members. The extensive preparations during the last few months made this event and all of its activities possible.
- TMA's current membership is approximately 1,700 in 34 countries. Dr. Kerr is estimating that there are approximately 33,000 people in the United States with TM.

Review of 1998-1999 Goals and Summary of Meeting Discussion

- *1999 Symposium.* During the past year, TMA Board members have been focusing on the 1999 Symposium as a primary goal.
- *Disseminate Educational Information and Resources About TM and Issues Related to this Condition.* One of the chief things TMA is trying to accomplish is to make sure that more individuals with TM, as well as family members and providers, know as much as possible about this condition. TMA is constantly trying to find the best information available to pass along to our membership. This is an “ongoing” goal.
- *Facilitate Support and Networking Opportunities for Persons with TM, their Families, and Providers.* TMA has accomplished this “ongoing” goal via such mechanisms as the Initial Information Packet, Website, Membership Directory, newsletters, phone and e-mail contacts, and the 1999 Symposium. State and National representatives and their responsibilities and duties are components of an idea being developed which should increase TMA’s ability to provide support to individuals with TM and their families.
- *Increase Awareness of TM, its Impact and the Need for Additional Research.* TMA has been working on this goal through its discussions with other organizations like the National Multiple Sclerosis Society at a local level. Other opportunities have been New York’s TM Awareness Day. TM awareness and support systems are also growing through the Transverse Myelitis Internet Club. Public Relation efforts conducted as part of the planning and advertising of the 1999 Symposium has also helped spread the word about TMA and TM.
- *Develop Partnership Opportunities Between TMA and the Medical Community/Providers.* This has been ongoing, and the culmination of this process during 1999 has been our contact with Dr. Kerr, and the development of the Johns Hopkins Transverse Myelopathy Center at Johns Hopkins Hospital in Baltimore Maryland.
- *Expand the Medical Advisory Board.* This is also an ongoing goal. TMA is happy to report that Dr. James Bowen, Assistant Professor of Neurology and the Director of Neurology Services for the Multiple Sclerosis Center at the University of Washington in Seattle, Washington, and Dr. Douglas Kerr, Assistant Professor of Neurology and Co-Director of the Transverse Myelopathy Center at Johns Hopkins in Baltimore, Maryland have both accepted the request to become members of TMA’s Medical Advisory Board. These two additions to the Medical Advisory Board have given TMA good representation from across the United States.

Summary of Discussions on General Future Plans and Directions

Membership Changes. TMA Board of Directors (Board) have discussed how best to maintain, grow and develop the Association with the recognition that one of the ultimate goals is to become an organization that can impact cure research. Ideas about whether TMA should become a fee based membership organization to help ensure adequate resources for growth and expansion into other interest areas were discussed, as were other ways to encourage financial support. The Board asked to hear opinions and ideas from the membership.

Suggestions from the audience included asking for donations in the newsletter. Another suggestion was to offer incentives in exchange for donations, i.e. for \$20, you receive a T-shirt, for a higher amount, receive cassette tapes of the lectures. In this way, TMA could “entice” some members to pay, but wouldn’t exclude those who could not pay.

Dr. Levy expressed the opinion that membership fees were not a good idea as they would tend to limit access. He indicated that a good idea would be to set specific economic goals, then publish a specific amount in the newsletter from time to time along with a bar graph to show how far we are from that goal.

A suggestion was offered from the audience to offer free membership upon initial contact for the first year, then ask for a “nominal” fee of perhaps \$20 to contribute toward the “operating budget”.

Regarding TMA’s operating needs, which are considerable, it was discussed that TMA could report what the prior six months’ expenses were, and project what the next six months’ would be in the newsletter, and that this could be a method to inform the membership of operating budget needs. As TMA is getting approximately 50 new members each month, the cost of calling new members/ contacts; and sending out the Initial Information Packet, Membership Directory, and newsletters would be estimated and included in the projection. The costs associated with contacts who request the Initial Information Packet, but do not wish to become a member would also need to be included.

(A sample of the comments from the audience – “I am the mother of a four-year-old daughter with transverse myelitis. There are two things I would like to discuss. I think that we as the Association are a family. Both the family members AND the patients with TM are part of that family, and we need, as the Association to take care of the family, and I see that as “free”, and I think that SHOULD be free. But also, where do you get the money to take care of the family? You need to go OUTSIDE the family to get the support and the money to take care of the family. And the other part that I see is research. I see all these wonderful people, and I want them out of their chairs. I want to see their quality of life and treatment, and everyday living improved. So that is the research component, and I am banking on

that, as the mother of a daughter with TM. I want to raise those funds. I almost see those as two different components – take care of the family, then raise the money to find a cure, and to find treatments. Those are huge jobs, and when I see the state representatives, I think that they can go to each state and accomplish two goals by telling everybody what transverse myelitis is all about, and while you are talking about it, you are getting money. Examples are the Juvenile Diabetes walk, and the MS Walk. Why can't we have a TM Walk in every state, why can't we have a TM Awareness Day across the United States and outside of the US to increase awareness and ask for funds? I have walked up and down our street; I tell people that "I have a daughter who is 4 years old and here is what happened". People whip out their wallets, they whip out their checkbooks. I didn't get too many "no's" from people, and I think when we get into the fundraising, I think when we bring it home, there are a lot of great people out there, a lot of great businesses. So when you talk about how it is affecting the community, you are absolutely right, when it only affects two or three people, they are not as motivated. But I think that if you are the person in that state, if you reach out to your family and businesses, you bring it home, and it IS affecting your family. It is an overwhelming thing, you think "what if I find a cure tomorrow, I want everybody to be okay". I want to thank you for kicking off this off, because it is wonderful and we are behind you 100%. But how do you get all these great people together? The motivation is there, now we need the money!")

Another suggestion was to include a self-addressed envelope with the newsletter, to make it easier to mail in a contribution.

A member from the audience offered a suggestion that the Association should define what it costs to run membership services on an annual basis. Then for the research portion use a different fundraising campaign, also to offer that if any one person had a better financial situation, to possibly pay more than \$10 to offset some members who cannot afford to pay. The people that can afford to pay more for membership could probably use the "tax break" from contributing more.

Outcome: The Board decided that it would take all of the suggestions into consideration. It was resolved at this point in time that TMA will not begin asking for membership fees, but pursue methods to encourage donations from the membership and other interested parties.

State and National Volunteer Representatives. The Board indicated that a meeting following the General Membership Meeting would discuss this topic in more detail. The Board explained that TMA has envisioned having State and National volunteer representatives for some time and that in some states and countries some forms of this is already happening. It was explained that the idea of having representatives came about when a family that TMA had been in contact with in Illinois went to the hospital and supported another family with a member who was newly diagnosed with TM. They were having a very difficult time, and the family that already had experience with both TM and the Association provided the most significant support that the other family received during

the early stages of TM. So, it just seems that having representatives would be a very kind, helpful and supportive thing for TMA to set up.

Outcome: The Board concluded the general description of this topic by stating that additional discussion would occur during the State and National Volunteer Representative meeting. It was also mentioned that if someone wants to be a representative in any one of the states or countries, to contact TMA.

Establish Partnerships with Medical Providers and Treatment/Research Centers and with Organizations Dedicated to Promoting Research and Cures for Demyelinating Diseases. The Board commented that most of the meeting attendees were aware of what TMA has been doing in this area based upon the professionals that were invited to be presenters at the 1999 Symposium and due to previous comments about the conversations and contacts made during the planning and advertising of the Symposium.

Outcome: The Board indicated that efforts in this area will continue and that there will be an ongoing dialogue with many of the contacts made to date.

Develop Partnerships that Support Increased Volunteerism (i.e., Hal's Angels). The Board discussed that, while opportunities in this regard are always important to strive for, this specific topic came primarily out of the contact with the Hal Ketchum organization. As was discussed at the Saturday night banquet, members of Hal Ketchum's fan club have been looking for ways to help support TMA and increase TM awareness. They have started a group called Hal's Angels and will be coordinating with TMA on ways to help accomplish some of these goals.

Outcome: One Board member mentioned that it is a really interesting thing when people who are outside the immediate TM family come in and want to help. TMA will be looking to the Hal's Angels group to show us whether this is a workable plan. It certainly should be, and TMA is looking forward to seeing how this develops. (NOTE: Since the Symposium, some changes have been made in Hal Ketchum's organization and Hal's Angels are not presently active.)

Evaluate Potential Benefits of TMA Becoming a Member Organization of NORD (National Organization of Rare Disorders). TMA has considered ways to increase our involvement and association with other important nonprofits. One of the things that has been talked about from time to time is the idea of becoming an affiliate group of NORD. The Board was interested in hearing from the membership as to whether they felt this was a direction to move towards or not. Discussions centered around determining what the pros and cons of this might be and what the costs and obligations were. Based on what either the Board or attendees knew about this topic, it was felt that a plus is that NORD has a lot of orphan diseases coming together through them to support legislation, and that legislation could focus on new medications, or other topics pertinent to

TM patient's needs. It was also discussed that there are some funding requirements associated with becoming an affiliate and that TMA is not ready to entertain this financially yet.

TMA is currently registered with NORD. NORD has TMA's information, and that is how a lot of members have found us, and that will remain in place.

A question was asked of the audience for a show of hands to see how many people found the TMA through NORD. Five people in the audience responded, which was a significant number, since the total number in attendance was about 45 individuals.

Outcome: The Board decided that this is a topic that needs additional investigation, discussion and consideration. As there is no urgency on this topic, it was determined that this could be further evaluated as time permits.

Future Conferences (Consider Including CME's to Broaden Medical Provider/Community Participation). As the announcement had been made at the Saturday night banquet that the TMA and the Johns Hopkins Transverse Myelopathy Center had agreed to co-sponsor the next symposium in about two years (2001) in Baltimore, the membership spent time enjoying what certainly appears to be the continuation of the success of the 1999 Symposium. The Board expressed that it believes this is an ideal opportunity to continue the growth of TMA and the fact that it would be held on the other side of the United States would offer an opportunity to attend to many members who were unable to come to Seattle. It also seems to be a logical decision because of the work that Dr. Kerr has been doing and the Transverse Myelopathy Center. The Board hopes that by adding CME's additional medical providers and community providers will be encouraged to attend. The TMA will ensure the event meets the needs of our membership and that the personal, family social contact that everyone experienced during the 1999 event will continue.

Dr. Kerr said that he had observed the interaction that was going on among all of us, and he recognized that this really was of such primary value for us. He stated that he is envisioning the conference having a lot of medical researchers presenting, which is extremely important. But he is also envisioning the conference continuing what is such an important experience for all of us to have in coming together, in sharing our experiences, feelings and thoughts about the things that have affected us so personally.

Outcome: The Board will work directly with Dr. Kerr and Johns Hopkins on planning and conducting the 2001 Second International Symposium on Transverse Myelitis.

Identification of 1999-2000 Goals and Summary of Discussions

Continue to Expand Medical Advisory Board. TMA has done very well as part of the 1999 Symposium in adding two very important members. TMA now has four Medical Advisory Board members. TMA will continue to look for additional members, however, the Board believes that the existing Medical Advisory Board members should and would want to have people that they interact well with and have some commonalties with in terms of TM.

Outcome: The Board will seek input from the existing Medical Advisory Board members as to potential Medical Advisory Board candidates.

Develop Partnerships with Other Medical Providers and Treatment/Research Centers/Organizations. The Board indicated that this topic had already been discussed and that it is obvious what a significant relationship TMA will be having with the Transverse Myelopathy Center. In addition to the future and the 2001 Symposium, this partnership has resulted in more immediate benefits such as the linking of TMA's Website to the Website for the Transverse Myelopathy Center.

The Board also discussed other relationships that are being developed and will hopefully continue to develop. Henry Grantges of The Myelin Project, who was very kind to have stayed during this meeting, made the following comment about the summit meeting being planned.

Mr. Grantges – “One of the things that we are looking at is having meetings of the leadership of some of the organizations that are related to myelin disorders. There are a couple of organizations that deal with myelin disorders in children located in New York state, who have expressed an interest in organizing that meeting which would be in Washington, D.C. We could talk about common issues as far as organization, research and common issues as far as legislative and regulatory issues. This is one of the things that we are trying to put together right now, and we hope that it will be a good opportunity to build these alliances so that, while each organization has its own focus and its own purpose - essentially people that share the same disorder – they will be able to give each other support and encouragement. It is also a good thing to be able to build bridges between organizations and work towards these common goals, which will help all of us.”

Outcome: The Board will continue to develop partnerships to the benefit of TMA and its members. TMA will include the focus of cure research in its ongoing efforts and partnerships.

Develop Representative Activities in at Least 6 States and 4 Countries. The Board indicated that this may sound like a lot, but many people are already interested in doing these types of activities. It was stated that examples of such activities would be discussed in the State and National Volunteer Representatives meeting.

Outcome: The Board concluded this topic by stating that additional discussion would occur during the State and National Volunteer Representative meeting.

· Update and Expand Educational Materials/Initial Information Packet. TMA is always looking to upgrade and include the best possible materials. The Board hopes that anytime a person finds something they feel should be added to the initial packet, that they will bring it to the Board's attention. By the time most people find TMA, they are at least a couple of weeks into their whole process, and have already had the "rug pulled out". It would be nice to have TMA's materials and support a little bit sooner. What needs to happen is that more providers need to have the TMA brochures with the Association's contact numbers or the Internet address.

One of the things that TMA has to offer as an organization is to be able to provide the Membership Directory to the membership. With that directory individuals can find other people who live in their area who have TM and have been through these experiences, and who have experience with the local rehab facilities and with local OT's, PT's and Neurologists.

It was discussed how some people have requested not to be included in the directory at all or that their phone number not be published. It was indicated that if any member sees that their name OR number has been published, and they wish it to be removed, they should contact Sandy Siegel. Sandy talked about the fact that everyone understands the privacy issue and individual preferences on this topic. Sandy went on to state that the other side of this topic, of course, is that if a TMA member wants to offer their experience and relationship to other people in their community when they get TM, they need to be included in the directory so they are accessible to others. Sandy stressed that there is tremendous value in having a directory that provides complete contact information so TMA members can reach others to establish local supports and promote information sharing that could never be matched on the national or international level. Sandy finished his comments on this topic by stating that there is a balance that has to be achieved in the directory and by the membership, and that hopefully there will always be people willing to share their experiences with others by being included in the directory.

Outcome: The Board will continue to update and expand TMA materials as appropriate.

· Develop Enhancements to Website and Information Exchange via Website. This is an ongoing project, which is done constantly, and will continue to be a long-term goal.

Outcome: The Board will continue to support updates and upgrades to the Website to facilitate information exchange.

Summary of Closing Comments

· The Board informed the attendees that tapes will be sold of the Symposium. Paula Lazzeri's brother was the technology person who was taking the videos, and he is going to be editing those and

putting them together for TMA. The cost of the tapes will be determined once this is completed. They should be minimally priced. Also, it was suggested that the tape could not only be useful as a personal memento and for those who could not come, but also for rehab clinics and providers that may need to know more of this information. So loaning them out would be a very good idea, if an individual purchases their own.

Sandy Siegel made the following closing comments: “I also want to take the opportunity to thank Dick, Deanne and Paula for really doing an absolutely yeoman’s job in putting this symposium together. The Board came together in a really serendipitous fashion. It has been an expression of interest in volunteering to do some work. What has been really wonderful about this, it is a really wonderful group of people. I have thoroughly enjoyed working with all of these folks. Dick and Deanne are really special people. They have a wonderful blend of talent, and we have experienced that this weekend in the quality of people they have brought here to bring these presentations, and who are interested in us, and the logistics that they have wound their way through which have been really complicated, especially with juggling family and jobs. I have been totally awestruck at the quality of everything that they have put together for this. I will never find words to say “Thank You.” And thank you for coming from all over the world to attend. What an awesome experience!”

Dick Gilmur, TMA Symposium Coordinator made the following final comments: “I would like to add what a pleasure it has been serving you for the last three days. I feel so personally connected to everybody. This was so momentous for us to be able to do this, to have all of you here and to have everybody benefit. Thank you so much.”

The meeting was adjourned at 10:45 a.m.

Deborah Nord Capen
Secretary

These Minutes were adopted by the Board of Directors on November 15, 1999 during an internet email meeting.