The Transverse Myelitis Association Newsletter

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From the Editor

Sandy Siegel

I hope that you are all doing well. I am thrilled to reintroduce the TMA Newsletter. I published something that looked like a newsletter in 1997. Since then, it grew and evolved into something more substantial. Hence, in the January publication (which was mailed in April), the TMA newsletter became the inaugural TMA Journal. Well, we are now back to something that looks like a newsletter. With the shorter format and with mailing help from the Ohio TM Support Group, we are hoping that we can use the TMA Newsletter to communicate more frequently with our members.

Leslie Cerio, Stephen Miller and Shannon O'Keefe made a visit to the Victory Junction Gang Camp in March. Our Kid's Camp Planning Team toured the facilities, learned about the programs and had meetings with the VJGC Directors and Staff. The planning efforts for the Young Adult Retreat Weekend in November 2006 and the Kids and Family Camp in August 2007 are moving forward. The 2006 Rare Neuroimmunologic Disorders Symposium is rapidly approaching. We have been working with Chitra Krishnan from the Johns Hopkins TM Center and Project RESTORE to plan and prepare for the symposium. The program agendas for both the science and clinical programs are exceptional. We hope that many of you will be able to make it to Baltimore this July.

Leslie Cerio, Pauline and I had a wonderful meeting with Art Mellor in April in Boston. We had an interesting, thoughtful and detailed discussion about the work of the Accelerated Cure Project and the important partnership between ACP and the TMA. Stephen has been working to grow our support groups around the world; and there are new groups developing all of the time. If there is no support group in your country, or in your state or in your city, we need for you to volunteer to get one going. We need for people in Brazil, Canada and India to help us organize your membership and to assist us with the TMA membership database and mailings!

Jim spends every single day doing the work of the TMA. He is constantly seeking more efficient ways for us to do our work, to improve the effectiveness of our web site and to improve our communications with our members. Jim recently improved our membership form so that we could collect more accurate information when people sign up for the TMA. We are in the process of having this form translated into many different languages (Thank you to Ursula, Ulrika, Mette, Roland, Abbas, Val, Marina and everyone else who is contributing to this important effort).

Debbie, Jim, Stephen, and Paula are in regular communications with our members. Particularly for people who are newly diagnosed, there are so many requests for information and a great need for emotional support. We spend many, many hours responding to emails, writing letters and talking to our members on the telephone. I receive at least twenty emails every week from people seeking information and support, and Pauline and I get at least two or three phone calls every evening.

There is someone around the world who is receiving a TM, ADEM, NMO, MS and ON diagnosis every single day. We are glad that these people and their families are finding us. The work can be emotionally draining, and it is stressful. People are often seeking guidance about issues that we are not at all in a position to provide. Some people live in places where medical care is either rudimentary or non-existent. Or there are people who do not have medical insurance and are, therefore, very limited in the medical care they are able to receive. We all do the best we can.

The work is also exhilarating. There is nothing more energizing than the opportunity to help someone through a most difficult time in their lives. The people I work with – the TMA officers, our support group leaders, the TMA medical advisory board, the physicians who we work with regularly and refer people to often from medical centers around the country and around the world, the parents who serve as a support network and the many volunteers who participate in fundraising – remind me every single day what goodness there is in the world.

And all of this work is being done by volunteers. What an extraordinary group of people! There are so many opportunities available to join this group of exceptional volunteers. You will read about some of these opportunities in this newsletter. You can make such a significant and positive difference in other people's lives. Please take this opportunity. The biggest and the most positive difference will happen for you!

Please take good care of yourselves and each other.

Longitudinally Extensive Transverse Myelitis: An Interview with Brian G. Weinshenker, M.D.

Professor of Neurology, Mayo Clinic College of Medicine
Rochester MN USA

The Mayo Clinic has been at the forefront of research in the neuroimmunologic disorders. Studies by the Mayo researchers are providing us with tremendous insights into the diagnoses of these rare disorders, their complex definitions and relationships, their causes, and their acute treatments and long-term management strategies. Mayo has recently published the results of three critical studies which report the discovery of an antibody blood test for neuromyelitis optica, and proof that this antibody binds to aquaporin 4, a protein involved in the movement of water through the "blood brain barrier." Most importantly to the transverse myelitis community, a positive result from this blood test indicates a significant risk of recurrence of long length transverse myelitis after a first attack of transverse myelitis. These three original articles will be reprinted in the next publication of the TMA Journal (January, 2007). Dr. Weinshenker will also provide us with an introductory article to these studies to help us more clearly understand the significance of these findings for the neuroimmunologic community.

The Transverse Myelitis Association recognizes the critical findings and recommendations emanating from the longitudinally extensive transverse myelitis study. Dr. Weinshenker graciously accepted our invitation for the following interview so that we could communicate these results and recommendations to our membership as quickly as possible. It is important that you carefully review this information and discuss the recommendations with your neurologist.

Dr. Weinshenker, what is the background behind your recent discovery about the risk of recurrence in transverse myelitis?

Dr. Weinshenker: We have known for a number of years that transverse myelitis is a syndrome and not a specific disease with a single cause. Broadly, once rare causes of transverse myelitis, such as blood vessel disorders and direct viral infections are excluded, most cases likely represent autoimmune conditions wherein the immune system attacks the spinal cord. However, even within this autoimmune group, the condition seems to be heterogeneous. Two major groups can be defined largely based on the size of the spinal cord lesion. Small lesions affecting the outer parts of the spinal cord tend to occur in patients with, or at risk to develop, multiple sclerosis; partial transverse myelitis may be the first indication of future multiple sclerosis. In contrast, patients who have the more severe forms of transverse myelitis have lesions in the spinal cord extending over the length of three or more vertebrae (longitudinally extensive transverse myelitis, LETM). Such patients seem to be at low risk for developing multiple sclerosis; many, probably the majority, will never experience another attack. However, approximately 20% are at risk for having recurrent attacks. Until the present time, we have known little about the specific cause of transverse myelitis in this group of patients and the nature of the autoimmune reaction. Furthermore, we have not been able to identify those patients who are at risk for a recurrent attack.

Neuromyelitis optica (NMO) is a condition defined by attacks of LETM, as well as attacks of optic neuritis which cause loss of vision. We know that some patients who experience LETM will later develop optic neuritis and be diagnosed with neuromyelitis optica. Recently, by studying the serum of patients with neuromyelitis optica, our group has identified a specific antibody marker that can be detected by a technique called immunofluorescence; we have called it NMO-IgG (NMO antibody). Mayo Medical Laboratories offers this test as a clinical test for NMO and related disorders. We have known for roughly the last three years that this test is positive in patients with NMO and also patients with recurrent LETM, but is negative in patients with MS or who have transverse myelitis attacks similar to those seen in multiple sclerosis.

What has your recent research in patients with LETM shown?

Dr. Weinshenker: After we discovered this marker in patients with recurrent LETM, we asked how often it would be positive in patients with a first attack of LETM and how well it would predict the risk of recurrence of optic neuritis. We studied 29 patients with a first attack of LETM whose serum was referred to the Mayo Clinic for testing NMO-IgG, the new antibody marker for NMO. Thirty-eight percent had a positive test. In follow-up over a period of one year, there was a major difference in the risk of developing recurrent LETM or optic neuritis between the group that had a positive test for NMO-IgG versus the group that had a negative test. None of 14 patients who had a negative test developed a relapse of myelitis or optic neuritis at one-year of follow-up, whereas 5 out of 9 patients with a positive test (44%) developed recurrent transverse myelitis and 1 out of 9 (11%) developed optic neuritis.

What are your recommendations based on your study?

Dr. Weinshenker: Based on our results, we recommend that all patients with LETM should be tested for NMO-IgG and that patients with a positive test receive treatments that are effective in reducing the risk of relapse of NMO. These agents would include immunosuppressive drugs, such as azathioprine (Imuran), prednisone, or mycophenolate mofetil (CellCept). Specific recommendations should be made by the treating neurologist. The optimum length of treatment is unclear. However, the risk of relapse likely persists for several years and we have arbitrarily recommended a period of five years of treatment after an episode of LETM in a patient who tests positive for the NMO-IgG antibody marker.

We understand that our study is the first to show this result, and confirmatory studies will be necessary. It is a relatively small study in terms of the number of patients studied. However, the differences in risk appear to be large and convincing despite these small numbers. We could not identify any bias in the length of follow-up that would negate the validity of our results. Accordingly, we suspect these results will be supported by further research.

Who should be tested?

Dr. Weinshenker: We recommend that any patient who has LETM within the past five years should be tested. The risk probably declines with time when clinical follow-up does not reveal any subsequent episodes. At this time, it is hard to justify testing patients who have been symptom-free for five years beyond the first event of LETM. However, the data on which this recommendation is based are scant and should be left up to the discretion of the treating neurologist given the information that I have outlined.

Are there other markers that predict the risk of attack?

Dr. Weinshenker: Investigators at Johns Hopkins University have also reported that an antibody marker, SSA, that is present in patients with Sjögren's syndrome is associated with risk of relapse in patients with LETM. In fact, patients with NMO and patients who are positive for NMO-IgG are frequently positive for other autoantibody markers including SSA. In our study, the NMO-IgG marker that we discovered was more sensitive than the SSA antibody. All patients who relapsed were positive for NMO-IgG, which was not the case for SSA. NMO-IgG is also a more specific test for NMO than SSA. Accordingly, we feel that NMO-IgG is the preferred test at the present time to predict a risk of recurrent attacks of LETM.

What other implications does your study have in regards to our understanding of transverse myelitis?

Dr. Weinshenker: This study suggests that patients with the most severe form of transverse myelitis, LETM, often have a first episode or limited form of NMO. It suggests that approximately 40% of patients with LETM may have a condition that is immunologically related to NMO and that research into the cause and treatment of NMO will also have a strong impact on the treatment of LETM.

For example, plasma exchange is known to be very effective in attacks of LETM and also in patients with LETM and optic neuritis attacks who have NMO. Recent research has shown that the antibody marker referred to above reacts with a protein in the brain called aquaporin 4. Although it remains to be proven that this antibody actually causes the damage in NMO, and is not just a blood test marker, there is reason to be optimistic that we have discovered the antibody that is actually the perpetrator of the immune-mediated damage in this condition. Discovery of a target for the immune system in this disorder is the first step in identifying a specific way to inhibit the immune system attack in this condition. Far more research is necessary, however, before we can be certain that NMO IgG is the actual perpetrator of the damage that occurs in NMO and not just a marker. Either way, it appears that NMO-IgG will be a very useful clinical test for predicting risk of relapse for patients with LETM.

Please Keep Your Membership Information Current

Please keep us informed of any changes to your mailing address, your phone number and your email address. To let us know about any changes, please fill out a change of information form on the TMA web site: http://www.myelitis.org/memberform.htm – just click on the box indicating that you are changing existing information. By doing something as simple as keeping your information accurate in our records, you are helping to save the TMA money; funds that can be used for research or to support symposia or the TMA Kid's Camp. Thank you!

Finding the Cause and Cure for TM, NMO, ADEM and ON: We need your help!

Leslie Cerio and Sandy Siegel

We are establishing a task force for the purpose of raising money to fund the Accelerated Cure Project; the repository, registry and medical centers, as well as the research and clinical trials which will be conducted by the medical centers in the consortium. We need for you to get involved! We are going to need for a large number of people to get involved in this important work.

If you have experience in a not-for-profit organization, please consider getting involved in this effort. If you have experience in fundraising activities or event organizing, please consider volunteering to work on our task force. If you have served in a development position for a not-for-profit, we need for you to serve with us. If you are one of the support group leaders in the United States, we need for you to be involved. Please contact me or Sandy to volunteer:

Even if you cannot serve on the task force, there is a role for you. Collectively, we can make a difference for ourselves and for each other.

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I recently read the articles by Sandy, Art Mellor and Dr. Benjamin Greenberg in the TMA Journal about the Accelerated Cure Project (ACP) and the TMA's comprehensive plans for establishing a consortium of medical centers for research, clinical trials and clinical care. As I live in Boston, I had been reading about ACP and have often thought about the incredible potential a program of this nature would have for TM research. My daughter, Maria, got TM when she was three years old. I have been regularly communicating with Sandy in my role on the TMA planning committee for the Kid's Camp in 2007. During a recent conversation, Sandy told me that he and Pauline would be coming to Boston in mid-April for a meeting with Art Mellor and he asked me to get involved with this work. Getting involved with the ACP was something I had considered even before Sandy had asked, so I was thrilled to receive his invitation.

On Saturday, April 15th, Art and his wife, Debbie, Sandy, Pauline and I met to talk about the ACP and the TMA. Art described the development, organization and operations of the repository, registry, and medical centers. We had a very open discussion and we had many questions. We shared ideas about research and we shared our visions, hopes and our recognition of the tremendous potential that emanates from the resource ACP is creating for this research. We also discussed the power that surrounds the sharing of the results of medical research and collaborative studies between medical centers. Finally, we talked about forging a relationship between ACP and the TMA that would benefit all people who have any of the neuroimmunologic disorders of the central nervous system.

We left the meeting with such a positive sense of what the future holds for us in the TMA community. We have gone for so many years with such a rudimentary understanding of TM and almost no research specifically focused on this disease. Aside from the work being done by the wonderful physicians at Johns Hopkins and Mayo Clinic, Transverse Myelitis, and most of the other rare neuroimmunologic disorders do not receive sufficient focus. Research efforts are severely under-funded and the number of research projects in this area remains far too small.

What we needed to do was quite obvious and how it needed to be accomplished was equally obvious. Without hesitation, I said to Sandy, "We need a task force to raise money in our community specifically for this project. I am willing to head up this effort; it just needs to be done."

The reality is that I just don't have the time to take this on. I have a family; we have three young daughters. One of our children has TM. I am an attorney and work for a not-for-profit in the health care arena in Boston. Raising money for this research would be a significant contribution of time and energy, and time and energy are at a premium for me and for my family. We know that this is how it is for most of you. But this is an opportunity that we just cannot miss, and so, I am going to make this work for me. I owe this to my daughter. We all owe this to the people we have come to care for so much in our community. As I have read and heard Sandy say so many times, "If we don't come forward to do this work for people with TM, ADEM, NMO and ON, no one will; it is us or it will not be done."

Art Mellor is establishing the infrastructure to accelerate research on these diseases. He is creating an information database from an extensive questionnaire that will be administered by the medical centers, as well as from patient medical records. He is creating a repository that will contain blood and DNA samples, and eventually will contain spinal fluid. He is also setting up a network of medical centers in the United States that will collect this information and samples. This medical center infrastructure will serve to accelerate the number of people being entered into the database and repository, as these are the centers across the country that attract the most patients with these disorders. This infrastructure also has the potential for forming

the basis of multi-centered studies and clinical trials. The potential of this organization and infrastructure is awesome; and this effort is happening now. Dr. Greenberg and Johns Hopkins are leading the registry and repository work. Three other centers are in the process of coming on line: Shepherd Center in Atlanta, UMass Memorial in Worcester, Massachusetts and University of Texas Southwestern in Dallas. Other medical centers will be added into the network as ACP and the TMA are able to raise the funds to support these centers. Ultimately, the plan is to develop an international network.

Art Mellor's organization is called Accelerated Cure Project for Multiple Sclerosis. Art heads up an organization that is dedicated to curing MS by determining the causes. Art has MS. He is an incredibly competent, highly motivated and visionary person, and his work is focused on MS. Our opportunity has arisen because he has come to understand and appreciate that in order to learn the causes of MS, he has to include the other neuroimmunologic disorders in his approach. None of these disorders is well enough understood to draw bright and certain classificatory lines around any of them. He is including all of these disorders in his project, because it is good science to do so. His organization, however, is not Accelerated Cure Project for all of the neuroimmunologic disorders of the central nervous system.

If we did nothing at all, we would benefit from the work of ACP and the network of medical centers. The raw materials would exist in this registry and repository for researchers to study TM, ADEM, NMO and ON. Researchers would look at all of these disorders, because they will need to do so, even if they are focused on figuring out MS. But it is not possible to say how far this work will go without our involvement. Johns Hopkins and Mayo Clinic will continue to focus research efforts on TM; but they will continue to do so with the very limited funding they have received for this purpose to date. Remember, Dr. Kaplin's recent award for the TM and depression/cognitive impairment study represents the first exclusively funded TM research ever supported by the National Institutes of Health, the largest source of medical research funding in the United States. Additionally, we would like to be able to encourage the performance of studies, such as Dr. Kaplin's, across a network of medical centers so that he and other researchers can learn the causes and associations more effectively and more quickly. Likewise, when clinical trials, such as Dr. Kerr's work with neuroprotection during a demyelinating attack, are being performed, we would like to take advantage of this medical center network to accelerate this work. Just think about how much more quickly this study could be conducted if patients during a demyelinating attack could be recruited from ten different medical centers across the country, as opposed to those people who come only to Johns Hopkins. If the TMA funds these research projects and clinical trials, we know that they will happen.

Art Mellor is entirely supportive of our interests and our cause. He understands and appreciates what we are trying to accomplish. If we are going to encourage and support TM, ADEM, NMO and ON research, and to the extent that it does not overlap with a direct MS benefit, we are likely going to have to fund this work ourselves. We know that some TM cases seem to be associated with MS; we know that many TM cases do not appear to be at all associated with MS. We are going to be able to accelerate the growth of medical centers to include centers that we know attract larger numbers of TM, ADEM, NMO and ON patients, if we are able to support the funding of these centers. And we are going to be able to create better clinical care for patients by promoting greater understanding among the physician community that studies these diseases.

Art is creating an invaluable raw material for research on the neuroimmunologic disorders. He knows that MS researchers will find their own funding resources to conduct studies from the registry and repository. There are extensive fundraising efforts across the United States for the purpose of raising money for MS research. This fundraising is done by numerous MS organizations and the many MS Centers that are associated with medical schools across the country. Art is focused on creating a tool for the researchers and he knows that they will have their own resources to use this invaluable tool to do their work, and help find the causes of MS.

What funding is going to be available for TM researchers to study the resources that are made available from the registry and repository? The Transverse Myelitis Association is going to need to raise this money. Beyond the efforts of Project RESTORE at Johns Hopkins, I am not aware of any other significant program focused on raising money for TM research. And Project RESTORE raises money for TM research at Johns Hopkins. If we are going to take advantage of the incredible opportunity from ACP and increase the number of medical centers involved in conducting TM research, the TMA will have to raise the money.

The potential base of support for Art's organization is about the half a million people in the United States who have Multiple Sclerosis. Our base of support is something less than 40,000 people. There are numerous MS organizations across the United States and around the world. The TMA currently has about 4600 members in the United States. MS research does not cost 100

times more to perform because their numbers are 100 times greater. TM research and MS research will bear the same costs. We are just going to need to be 100 times more effective in our fundraising efforts!

So, how are we going to increase the effectiveness of our fundraising; to turn this potential into a reality for all of us? We are going to start with setting up a task force so that we have more than six people available to do this critically important work. We are not going to set up a task force to have meetings; we are going to find volunteers to contact our members to ask for financial support for this work. Today, we have 4600 people and their families and friends who have to be willing to help. We need to be able to demonstrate to you that we have an efficient, well-organized and effective research program, and that your dollars will be well-spent and will produce significant results. We will not have to convince 4600 people and their families and friends that there is value in doing TM, ADEM, NMO and ON research.

We are going to ask everyone to get involved in this effort. We know that some of you can help this effort financially. We know that others of you are not in a position to do so. But even if you are not able to make a contribution, you have family and friends who would like to make a difference in your life, if they were given the opportunity. We are going to ask you to provide them with this opportunity.

We all have this incredible opportunity to make a difference. What can **you** do? You can donate your time and volunteer to work on the task force; you can make a donation to the TMA to fund the ACP project; and you can talk to your family and friends and ask them to make a donation to the TMA. We need you to make this happen, and it will not happen without you! Please call us and volunteer to serve on the task force; you can play a critical role in finding the causes and cures for TM, ADEM, NMO and ON.

Richard Charles Gilmur

It is with the deepest sadness for me to communicate to the TMA community that Dick Gilmur passed away on April 5, 2006 at the age of 52. Dick had courageously fought Mantle Cell Lymphoma since his diagnosis in November 2004. Dick will be missed by his wonderful wife, Deanne, his children, Katie, Charlie and Britany, his family and friends and everyone who knew him.

Dick and Deanne founded the TMA in 1994; their daughter, Katie, got TM when she was 18 months old. Dick was instrumental in formally establishing the Association, including our incorporation, our 501 (c)(3) status, and the development of our by-laws. Dick also played a primary role in organizing our first Symposium in 1999 in Seattle. Dick's passion for advocacy for the TM community was a direct reflection of his love for his family.

To recognize Dick's many important contributions to the TMA and to honor his memory, we are naming our endowment fund, The Richard Charles Gilmur Endowment Fund. This endowment fund was Dick's project; he initiated the fund and guided its development. This fund was established for the purpose of supporting TM research. All of the contributions that have come and will come to the TMA in Dick's memory will be placed into this fund for TM research.

Our thoughts and prayers are with Deanne, Britany, Katie, Charlie and his family. His memory should serve as a blessing for his family, and for all who knew Dick.

2006 International Rare Neuroimmunologic Disorders Symposium

The 2006 International Rare Neuroimmunologic Disorders Symposium will be held in Baltimore at the Sheraton Inner Harbor from July 19th to July 23rd. The symposium will include both a science and clinical program. The clinical workshop will bring together patients, caregivers, physicians, primary care doctors, family practitioners, ER physicians, neurologists and other allied health professionals. The goal of this workshop will be to provide up-to-date knowledge on the diagnosis and management of the neuroimmunologic diseases. This will also be a platform for patients and caregivers to interact with other patients and with physicians and learn about novel therapies and clinical trials. A reception will be held Wednesday evening, July 19th. The first science and clinical sessions will begin on Thursday morning, July 20th. The science program will end on Saturday, July 22nd. The clinical program will end on Sunday morning, July 23rd.

The program agendas for the science and clinical programs are posted on our web site and the Johns Hopkins Project RESTORE web site. We urge you to review the agendas carefully when deciding if you would like to attend. We are very proud of the program that is being co-sponsored by Project RESTORE and The Transverse Myelitis Association. The leading physicians and researchers in the neuroimmunologic disorders from around the world will be attending and presenting at the symposium. We know that the information you are provided with from the presentations will make you a more effective advocate for your medical care.

http://www.myelitis.org/rnds2006

In addition to the formal presentations, you will have the opportunity to talk to physicians and researchers during the breaks and at meals. The Sunday morning session will provide you with the opportunity to engage in a question and answer period and dialogue with some of the members of the TMA medical advisory board and other physicians and researchers who participate. Finally, the symposium represents a wonderful opportunity for you to meet other people with the neuroimmunologic disorders and their family members. Lifelong friendships are created at these gatherings. The symposia are a very emotional and empowering experience.

The discounted hotel rate for TMA members is $145 per night. Please make your reservations at the hotel directly by identifying yourself as a member of The Transverse Myelitis Association and be sure to specify for the Rare Neuroimmunologic Disorders Symposium (RNDS).

For assistance with Sheraton reservations, please dial 1-888-625-5144, if you are calling from the U.S. or Canada.

Registration materials will be mailed to all members of The Transverse Myelitis Association. You can also register online by using the TMA or Project RESTORE links:

http://www.myelitis.org/rnds2006

The symposium will offer a number of workshops, as well as a gait, orthosis and wheelchair clinic. You will be able to review the workshop sessions in the clinical program agenda on the web site. The goal of the workshops is to provide a more interactive session with the physicians for an opportunity to discuss management issues, to explore other therapies and to have questions answered.

The gait, orthosis and wheelchair clinic and workshop will be directed by Drs. Chuck Levy, Barbara deLateur, and Frank Pidcock. Orthotists, physical therapists, adaptive equipment and wheelchair companies will also participate in the clinic and workshop. This clinic will offer an opportunity for one-on-one interaction with our physical medicine and rehabilitation team. The goal of this evaluation is to provide the participant with specific information that they would be able to take to their physicians and orthotists for discussion and guidance. We would encourage you to attend this clinic regardless of whether you sign up for a personal evaluation. You will be able to observe how an evaluation is done, and gain some knowledge and insight as to what you might expect from this process.

To participate in these sessions we are asking you to sign up for the specific workshops and/or the gait, orthosis and wheelchair clinic at the time you fill out and submit your registration materials.

We are looking forward to seeing you in Baltimore!

Registration Fees for the Rare Neuroimmunologic Disorders Symposium

	3 days	2 days	1 day
Physicians	$475	$325	$175
Residents/Fellows/Allied Health	$325	$225	$125
Patients/Families	$250	$175	$100
Graduate Students	$175	$125	$75

Young Adult's Weekend Retreat: November 17-19, 2006

The Victory Junction Gang Camp in Randleman, North Carolina has invited young adults from The Transverse Myelitis Association to attend a Young Adult Retreat Weekend. The first ever biennial retreat weekend for young adults will take place on November 17-19, 2006. The retreat is for those with TM, ADEM, NMO, and ON between the ages of sixteen and twenty-five and their caregivers, spouses or companions. All of the facilities and venues at the camp are completely accessible; horseback riding, fishing, and even a rock climbing wall.

We have invited Dr. Douglas Kerr, Dr. Adam Kaplin and Chitra Krishnan from our Medical Advisory Board and the John's Hopkins Transverse Myelitis Center and Project RESTORE to attend the retreat. They will be there to participate in the activities, answer your questions, and present an information session about research in restorative therapies and short and long-term treatments and symptom management practices.

We know that young adults face special challenges in their lives; going to high school and college, dating, getting married and starting families, seeking employment and initiating careers. The retreat weekend will include a seminar on transitioning into adulthood and independence with a special guest speaker. Issues such as finding insurance and accessible housing, as well as social and relationship situations and concerns will be addressed in separate, age-appropriate sessions. The weekend will include programming and activities specifically for the sixteen to nineteen year olds and for those twenty and above. The emphasis will be for a weekend of fun and relaxation.

The weekend will provide a chance for you to meet with others who understand your experiences better than anyone. Having the opportunity to share your experiences with each other will be enriching and empowering. We know that you will come away from this retreat with lifelong friendships.

There is no cost to attend this weekend of fun and friendships; however, you will need to provide your own transportation. The Piedmont Triad Airport in Greensboro, North Carolina is approximately 20 miles away and airport pick-ups are available, also free of charge.

We know that there are many of you from this age group who live outside of the United States and know that you would greatly benefit from being able to spend a weekend together. I urge you to find a way to get to the retreat, even though it will only take place over a long weekend in November. Please be creative in how you think about this possibility. Consider combining the trip with some additional travel in the United States. I would also urge you to contact other members who will be attending and you might consider making arrangements to extend your time together in the States. We will set up a bulletin board system on our web site to facilitate your communications with each other.

If you are interested in attending, please let us know of your intentions. Spaces are limited and will be available on a first-come, first-serve basis. The application deadline is October 5th. To reserve your place and request a Victory Junction Gang Camp application, or if you have any questions, please contact Stephen Miller at smiller@myelitis.org or (937) 453-9832.

We will set up a Retreat Weekend page on the TMA web site, so please visit regularly to receive news and updates. We will be posting more information as the details are confirmed.

The Transverse Myelitis Association is partnering with the Victory Junction Gang Camp (VJGC) in Randleman, North Carolina, to hold a bi-annual summer camp for kids ages seven to fifteen and their families. The camp occasionally accepts those outside of this range, however, the activities and facilities are geared toward those ages. Exceptions are made on a case-by-case basis so do not let the camper's age deter you from submitting an application. Space is limited and applications will be taken on a first-come, first-serve basis with consideration for those children between the ages of seven to fifteen. If your child will be younger than seven in August 2007 and you would like to attend, please still let us know of your intention and please still submit an application. We also want to reiterate that VJGC will be holding this camp for our community every other year. If you are unable to attend in 2007, there will be future opportunities to participate. This is not a once in a lifetime offer.

The number of families we can serve on-site is limited to 32 families of up to eight immediate members per family. Additional accommodations will be provided off-site for later applicants and/or families who do not require on-site accommodations. Victory Junction Gang Camp is very extraordinary in its eagerness to serve our pediatric TM, ADEM, NMO, ON community, including families, regardless of geographic location or extent of disability. The camp is totally accessible, including the activities – fishing, tower climbing, horseback riding, mini-golf, swimming, arts and crafts, and much, much more, all in facilities and a setting that is truly phenomenal. Full accommodations for ventilator dependent kids are on site as are fully staffed medical facilities.

We have invited all of the members of The Transverse Myelitis Association Medical Advisory Board and their families. Dr. Douglas Kerr, has commited to being there with his family, and we know that other members of our Medical Advisory Board will be attending with their families, as well. The physicians will be making some presentations to parents on the latest research on the neuroimmunologic disorders and symptom management strategies, and they will be available during the week to respond to your questions. The focus of the camp experience, however, will be on a fun-filled week for the entire family.

There is no cost to attend the camp. VJGC is providing the meals, lodging, and all of the fun activities to the families in our community for free. You will, however, need to get yourselves there. The Piedmont Triad Airport in Greensboro, North Carolina is approximately 20 miles away and airport pick-ups can be arranged.

If you are interested in attending, we need to know. We are aware that confirming a date well over a year in advance may not be possible, but please let us know of your intentions. If you would come but simply cannot due to travel expenses, let us know that, too. We can't promise to arrange your travel, but we will do what we can to make it happen.

To reserve your place, to learn how to apply, or if you have any questions, please contact Stephen Miller at smiller@myelitis.org or (937) 453-9832. Please check out the Victory Junction website: www.victoryjunction.org to learn more about the camp. This is a special arrangement for our community, so please don't contact the camp directly. We will let you know when it

is time to fill out and submit your application. In the meantime, please call or write me and get on our waiting list.

We encourage you to continue to watch for more information on the TMA website.

http://www.myelitis.org/kidscamp

We will be posting news and updates as details are available.

Dana Reeve 1961-2006

It is with great sadness that the TMA community extends its sympathies to the Dana Reeve family and the wonderful people at the Christopher Reeve Paralysis Foundation. Dana Reeve served as an incredibly powerful and positive advocate for quality of life issues for people with paralysis. She will be remembered for her intelligence, sensitivity, grace, patience and for her devotion and loyalty to her family.

The TMA will always remember Dana for her support of our organization and our community. The first institutional grant awarded to the TMA was a CRPF Quality of Life Grant to support the 2004 Rare Neuroimmunologic Symposium. The CRPF also invited the TMA to serve on the paralysis task force, recognizing that those who have paralysis from the rare neuroimmunologic disorders, such as TM, ADEM, MS, and NMO have an important contribution to make to the understanding of health and quality of life issues that surround paralysis.

None of us knows how we will handle a personal tragedy. We can only conjecture about how we might respond, but we really don't know. Christopher and Dana Reeve experienced this horrific tragedy when Christopher Reeve suffered his accident. It would have been perfectly reasonable and understandable, if the Reeve family had circled their wagons and focused on Christopher's rehabilitation and health issues and the family's emotional issues. They did not circle their wagons. There was something special about their values and their characters that motivated them to think beyond themselves and to make their cause and concerns those of the paralysis community. They reached out to all of us and included all of us; those who experienced paralysis from injury or from diseases or disorders or from birth defects. These were truly extraordinary people. They will be missed; they will be remembered.

Dana's loss is a horrible loss for her family; her loss is a personal and tragic loss for the Christopher Reeve Paralysis Foundation. Our memories of Dana should serve as a blessing for all of us; and we should honor her memory by continuing to work for the highest quality of life for those in our community and the paralysis community.

TM Awareness Day in Virginia
Pamela New

The TM Support Group of Virginia has joined those of New York, Ohio, and Australia in establishing a TM Awareness Day. After two years of hard work, many proclamation drafts and through two different administrations, Governor Timothy Kaine of The Commonwealth of Virginia, declared June 6, 2006 to be TM Awareness Day in The Commonwealth!

We began this effort more than two years ago when Mark Warner was our Governor. We began with the New York and Australia proclamations to develop a good working document. We revised and updated the information from publications posted on the TMA web site. The VA Support Group provided wonderful feedback and encouragement for this work. This day is truly for all of us!

I was thrilled when I received notification from the Governor's Special Assistant announcing that our proclamation was passed by our General Assembly and then signed by the Governor. We are thrilled and proud of the latest TM Awareness Day for the TMA community.

The next major project of the TM Support Group in Virginia will be an effort to raise awareness about Transverse Myelitis in Virginia's medical community. We are going to focus our efforts on emergency room physicians and ER personnel. I am a nurse. Our program will be initiated at the hospital where I served as a nurse manager. The TM Support Group of Virginia begins the next journey!

UK TM Society
Lew Gray
lewgray@blueyonder.co.uk

The UK TM Society has completed our first year of existence. We had 76 new members during 2005. The new support group in Poole is up and running and held two meetings; and another new group is in the process of being established up in Berkshire. Margaret Shearer and the Scotland Group has been especially busy lately supporting new patients with TM, including three infants with devastating attacks. Dr. Douglas Kerr has been involved in these paediatric cases and we are grateful for his willingness to consult and for his support.

We are proud and grateful to have received over 50 donations from individual members plus two corporate donations. We have also received over £800 ($1360) in tax rebates on contributions direct from Her Majesty's Revenue and Customs, since we are now a UK registered charity! This has allowed us to take over all printing and distribution of TMA Journal and New Member Packs for all of Europe.

If any 'European' members would like to help us with the cost of this work, Jim Lubin has now set up a link from our webpage www.myelitis.org.uk (hit 'Make a Donation' button) to GiveNow, where you can donate in euros, dollars or pounds using a credit or debit card. We are hoping to work more closely with TM members in other European countries to make more information available in European languages. Local coordinators are urgently required in Italy, France, Spain, Netherlands and Portugal.

Our members are increasingly using modern communication. Over 100 members have chosen to receive the TMA Journal electronically which is saving us postage and labour costs. We also plan to experiment holding a support group meeting by telephone conference call, to avoid travel problems; have any other groups in the world already tried this, and did it work OK? We would love to hear from you and to learn about your experiences.

Sally Rodohan, our Chair, is organising our first dedicated fundraising event on 17th June in North London (Irish music night) - right in the middle of the World Cup! I am personally looking forward to meeting more TMers at the July Baltimore Symposium.

Northern California TM Support Group
Judy Melcher

I live in Lodi; in northern California Wine Country. I own a medical business. I have been a durable medical equipment provider for the last 13 years. In 1991 I caught a virus. After a week of having this virus, I began to get numb around my abdomen. My experience with doctors was a nightmare as they didn't know what was happening. They began looking for cancer with MRIs, spinal taps, and blood tests. The numbness was now moving down both of my legs and I was getting severe pain in my middle back. Since they didn't know what was happening, I did not receive any steroid treatment. They did more tests. While they were desperately trying to figure it out, both legs became paralyzed.

The pain I had in my back felt as though I was being sawed in half. I was in bed for three months. I couldn't even put a sheet on my body, it was so painful. After three months of tests and three neurologists, they did not come to a conclusion as to what had happened. They told me that nature would have to take its course to see if I would come back to normal once again. I never heard of the word "Myelitis**."** Eventually I began to walk again; I had dead legs, back pain, fatigue, and other symptoms.

I did learn how to walk. It took almost a full year to be able to stand alone and walk without a walker or wheelchair. I am one of the one-third who came back half way. I still had some numbness, but was able to return to work.

In 2006 it happened again; fifteen years later. I had been on a drug for a skin condition for about one and a half years. I did some research on this medication and asked the doctor if it could damage my immune system. I explained that I have had four reoccurrences of cancer and nerve damage in my spinal cord in 1991. I was told that it wouldn't cause an immune system problem. Well, as you can probably guess, it did! It affected my immune system and the attack was on again. For the last six months, I have been falling due to muscle weakness and lack of tone and my left leg is pretty numb. My right leg does have some numbness, but is much stronger. I went to a new neurologist and was diagnosed with TM.

Can I recover once again? I will! The inflammation in my spine is gone. I still have a little banding around my abdomen and some fatigue. I am in therapy to keep my legs flexible. I am able to work, with help of a walker and wheelchair. I am grateful that I am not totally paralyzed and do not have bladder or bowel incontinence.

I just discovered the TM forum four months ago and what a wealth of information and friendship. Locating the John Hopkins website has given me so much information on TM and it has answered all my questions. I thought the TMA might have a Northern California Support Group. I would love to be a part of one, but there isn't one at this time.

I have decided to start one. Lodi is between Stockton and Sacramento, California. My office phone is (209) 334-0412; home (209) 334-0771 Cell: (209) 986-8011 and email address is judymae@softcom.net and judymae@pacbell.com. If you are interested in participating in a support group and live in Northern California, please contact me.

Judy Melcher

What we do for ourselves will die, but what we do for others will live and last for eternity.

San Diego TM Support Group
Christine Davis

The TMA has a large number of members in San Diego County. I would like to start a TM support group in our area and I am hoping that others will be interested in getting involved.

My background with TM is relatively new. My diagnosis in June, 2005 left me confused and scared. The TMA website was like a beacon in the storm of my reality. Logging in and chatting with others in the same situation was such a relief. The advice and support was imperative to my confidence and ability to continue facing the challenges every day brings. Without the TMA I shudder to think how the depression and pain would have affected me permanently.

So I feel it would be even more beneficial for us all to come together in person; to share our experiences and know we are still strong! Computers are great, but they make it difficult to convey the emotional rollercoaster this diagnosis can bring.

Perhaps you or other members have some ideas as to where we can meet? In Balboa Park there is a Veteran's gymnasium that I know can accommodate a fairly large group and has facilities for easy accessibility and food preparation. Any suggestions would be welcomed. Please feel free to email me at: DrDavis@SDoptometry.com. I look forward to hearing from you.

Georgia TM Support Group
Charlene B. Daise

I would like to take this opportunity to introduce myself to the Transverse Myelitis community and simultaneously thank you for giving me an opportunity to share my story. Prior to my diagnosis, I lived and worked very hard to ensure that the emotional and physical needs of my three children were provided. I often dreamed of how life would be once they were adults and my role as primary caregiver would diminish. When my youngest child graduated from high school, it was finally time to think about me. I cautiously examined my personal needs as well as professional aspirations in public education and decided it was time to step out of the box and work independent of all existing systems.

Five years later, I was happily and successfully working; serving diverse groups of people in different cities, strategically planning how to cultivate each community's resources in an effort to build better cities. Suddenly and without any warning, my wings were clipped. On Thanksgiving Day 2002, I experienced my first attack of TM. Its manifestation was a burning, sharp and electrifying pain on the right side of my head radiating to the neck. The pain and my response horrified family members. We were bewildered but a medical emergency room was fifteen minutes away and there we went. While in the ER, a second pain attack occurred. This time the residual effect left one side weaker. We had no idea this was the beginning of one of the most arduous experiences that could be imposed upon a family and their friends.

Six months later, I had been medically examined by multiple doctors, i.e., neurologists, internists, dermatologist. Each prescribed an abundance of pain killers, anti-depressants, and other drugs. My body was weakening from the condition, but no diagnosis was determined until one night in one of the most distressed physical states of my life, an ER doctor at Crawford Long Hospital in Atlanta gave me hope. He spoke confidently about their ability to treat the problem rather than the symptom. Within a few days, a wonderful neuromuscular physician, Dr. Jackie Washington, ordered the first MRI, diagnosed the illness, inspired me to remain positive and referred me to a neurosurgeon.

The next seven and a half months were spent between hospitals and rehabilitation centers. I endured two surgeries on my spinal cord along with steroid therapy. However, I was completely paralyzed from the neck to my feet and not responding to medication. At this time, my treatment plans were modified by a persistent, compassionate, and talented neurologist, Dr. Donald Orr. His recommendation included plasma exchanges, and I received eleven treatments. Once we completed the third or fourth exchange, movement returned in one toe. My internist, Dr. Jimmie Williams, worked and walked closely with me, as well. His calm and relaxed persona during early morning daily visits set the tone for me to successfully complete multiple MRIs, CAT and PET scans, therapies (occupational/physical), ICU, threats of pulmonary challenges, spasms, blood clots in both legs and constant pricks from a team of friendly techs.

With C 3, C 4 injuries, I required twenty-four hour care for seventeen

and one half months. Family members, including aging parents, scheduled hours of providing me with constant care. There were many friends and volunteers from churches who readily and willing came to assist me. Pastoral visits gave me hope and this remains a critical role in my rehabilitation process today as I am now able to walk and use my hands. Both hands were manipulated twice.

I believe one of the strongest and most profound impacts in recovering from any disappointment is to have a venue that encourages dialogue about the problem. Secondly, we must be supportive of each other as we all learn "how not to give up." A wise woman once told me, "Information is power." Certainly, a traumatic unexpected chronic illness might suggest that your life is over, but for me, I feel a strong sense of a "new beginning."

I am very excited about initiating a support group in Georgia. I live in Decatur. The TMA has a large number of members in our state and I am hoping that many of you will be interested in getting involved. You can reach me either at my email address: cdaise@bellsouth.net or by phone at: (404)289-7590. If you write to me by email, please include TMA in the subject line so as to avoid being identified as spam. I am looking forward to hearing from you.

Kentucky TM Support Group
Andy Johnson

Catheter, lumbar puncture, and *physical therapy* are words we never want to hear when talking to a physician about our healthcare. In February 2005, though, I lay in a hospital bed in the University of Kentucky Medical Center (Lexington, KY) with my legs numb from the waist down, listening as the doctors and nurses used those words to tell me about things that applied to *my* body!

I had spent most of Sunday, February 20th, grading my students' essays, and I looked forward to taking a break to watch *The Simpsons*. When I sat on the floor to try a different sitting position, though, an intense pain flared from my lower back throughout my legs. The pain was so strong, I could barely breathe, but I thought I'd just pulled a muscle. When the pain turned to paralysis in both legs, though, I knew it was more serious. Unable to even support my weight on my knees, I called my girlfriend, Emily, who rushed over and called an ambulance. Later, she would recall with laughter that I had told her how relieved I was that I had vacuumed my carpet earlier that day; I didn't want the EMTs to think I lived in filth. It was embarrassing enough to have them put my 36-year-old body on a stretcher and carry me to the ambulance.

The next two days were filled with tedium, fear, and frustration, including four hours in the UK Med Center waiting room, then 26 hours in the ER while various medical staff stabbed at my feet and legs with pins. One doctor, convinced I was faking it, demanded I try to walk, and stood watching unsympathetically when, still unable to support my own weight, I fell to the floor and bruised my knees. Months afterward, my feet still showed scars from his attempts to test my nerve responses by gouging me with the sharp end of a wooden swab he'd snapped in two.

Many people find the confines of an MRI claustrophobic, but during my nearly week-long stay in the hospital, I underwent five trips to the magnetic cocoon. I didn't mind it, though, because at least no one was stabbing me while I was in it. Despite the machine's loud hammering and humming, I felt peaceful. Much less peaceful was the lumbar puncture (aka spinal tap). I had one when I was five years old during a bout of encephalitis, and the memory of its penetrating pain had stayed with me throughout the years. I was disappointed to learn that my memory was not faulty; the procedure felt like the doctor was trying to pull the nerves of my spinal cord out through the needle she'd sunk in my back. After that, the CT scan and electrical conduction tests (electrical stimuli applied to my hands, feet, and head) were a breeze. The myriad of tests pointed toward a diagnosis of Transverse Myelitis (you probably knew that already, though, didn't you?), but I would require several follow-up neurological tests to rule out Multiple Sclerosis.

The UK Med Center released me on February 25 to Cardinal Hill Rehabilitation Hospital in Lexington, Kentucky for physical therapy. By the time I left UK, I could move my right leg fairly well, but my left was still immobile and numb. I couldn't stand on my own. I spent a week at Cardinal Hill, regaining feeling in my legs and relearning how to stand and walk without help. The staff there was wonderful, but the experience wasn't a vacation. The doctors removed my catheter while at UK, but the Cardinal Hill staff had to measure my daily "output" and scan my bladder to make sure it was functioning efficiently. My stomach was covered with bruises from the Heparin shots I received several times a day to prevent my legs from developing blood clots.

On March 3, my HMO had determined that I had received enough in-patient medical care and sent me home. I could shuffle around with a walker and required a chair for the shower. A week afterward, I went back to my full-time job as a staff associate in the English Department at UK and returned to the class I was teaching, though I needed a wheelchair to get there.

Since then, I have progressed from using a cane to walking with only occasional use of ankle braces (mainly for stability). I still have some weakness in my left foot, which causes me to limp and prevents me from running, and I struggle with fatigue from walking and general activity. Despite the challenges, I managed to finish my course work for the Ph.D. in English this semester and plan to take the exams in the fall semester. My outpatient physical therapy appointments have gone from twice a week to once every three weeks. Of course, there is no way to tell if I will rehabilitate any further, let alone completely. There are so many others with TM, though, who suffered much stronger attacks and deal with more physical challenges than I. I was extremely fortunate to have the constant support of Emily, who rarely left my side throughout my time in both hospitals and rearranged my apartment to make it safer for my impaired walking. She also filled in for me while I was out of the classroom. My family and friends, too, were strong sources of encouragement, care, and humor.

Emily and I are forming a support group for Kentuckians affected by Transverse Myelitis and related neuroimmunologic diseases. We hope to create a community of encouragement for not only those with TM, but also for the families, friends, and physicians who feel the impact of the disease as well.

If you are interested in participating in our Kentucky Support Group, please either write me via email at Andy.Johnson@uky.edu or feel free to call at (859)552-5480.

ADEM, NMO, ON, Recurrent TM, TM with Lupus, Sarcoidosis, Sjogren's and HIV: Finding Each Other to Share Information and Support

We are trying to assist people who have the very rare neuroimmunologic disorders find each other for the purpose of sharing information and support. We are creating the lists identified below for that purpose. If you have one of these neuroimmunologic disorders and would like to be added to the list and then receive a copy of the list, please send us your information. I only share these lists with people who are willing to be added to the lists.

1. Acute Disseminated Encephalomyelitis (ADEM);
2. Neuromyelitis Optica (NMO) or Devics disease;
3. Recurrent Transverse Myelitis;
4. TM with SLE (Lupus).
5. TM with Sarcoidosis;
6. TM with Sjogren's syndrome
7. TM or NMO with HIV; and
8. Optic Neuritis.

If you are interested in being added to one of these lists and then periodically receiving a copy of the list, you can send me your contact information either by email or through the postal service. Please send me your full name, complete postal address, phone number and email address (if you have one). Be sure you clearly identify to which list you would like to be added.

Sandy Siegel
1787 Sutter Parkway
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Helping to Fund the Work of Your TMA

The TMA does not charge membership fees. We operate exclusively on the basis of the generous and voluntary support of our members. There are numerous ways for everyone to help support the TMA, even if you are not in a position to make a financial contribution. Please consider getting involved in one of the fundraising efforts supported by the TMA.

Donate your cell phones
You can donate your unused cell phones to help raise funds for The Transverse Myelitis Association. Go to: http://cellphones.myelitis.org.

Inkjet Recycling
The Transverse Myelitis Association has partnered with a recycling company to collect and recycle empty inkjet printer cartridges, and empty toner cartridges from laser printers and copiers. All you have to do is visit the TMA inkjet recycling page at: http://recycle.myelitis.org.

Awareness Wristbands
You can show your support for The Transverse Myelitis Association and help raise awareness by ordering wristbands. To order using PayPal or by credit card, please log on to the web page at: http://www.myelitis.org/wristbands.htm. You can also order the wristbands by sending an email to: wristbands@myelitis.org or call (937) 453-9832.

Donations
We always welcome and are grateful for a donation to the TMA. Please make a check or money order payable to The Transverse Myelitis Association and mail it to:
The Transverse Myelitis Association
Paula Lazzeri, Treasurer
10105 167th PL NE
Redmond, WA 98052-3125

If you are a teacher, a student or a parent of a student and would like to establish the Reading for Rachel Program in your school, everything you will need to get the program started can be found on the Reading for Rachel web site: http://www.readingforrachel.org/ All funds received by The Transverse Myelitis Association for the Reading for Rachel Program are used exclusively for research to better understand TM, to find treatments for the symptoms of TM, and to ultimately find a cure. If you are interested in starting the Reading for Rachel program in your school, you can also contact Cathy Dorocak, Rachel's Mom and International Chair of the Reading for Rachel Program: cathy@readingforrachel.org (440) 572-5574.

Thank you!

The TMA Equipment Exchange
Darian Vietzke

Please get involved in the TMA Equipment Exchange. You will see the link to the Equipment Exchange on the column of links on the main page of the TMA web site. The program is intended to assist our community in exchanging surplus equipment with each other for the cost of shipping only. We encourage all of you to begin to list your equipment as soon as possible. The more equipment that is listed, the more individuals in our community will be helped. If you have any questions as you begin to use the program, please use the help link on the equipment exchange web site. If you have any comments or questions regarding the TMA Equipment Exchange, please send an e-mail to: exchange@myelitis.org. Thank you for your support!

Contacting the TMA by Email

When writing email messages to the officers of the TMA or to support group leaders, please use TMA, Transverse Myelitis, TM, ADEM, NMO or ON in the subject header of the message. Please be sure to include a title in the subject header. The volume of emails that we receive and the way spam filters work makes it increasingly difficult to sort through emails to find legitimate messages.

I personally receive more than 600 email messages a week. The majority of these emails are spam. As I am only able to read my email messages on the weekends, my first job on Friday evenings entails sorting through this enormous number of messages to determine which are infected with some kind of evil intent, which are benign junk, and which are important communications from people making connection with the TMA. I am always concerned and vigilant about deleting a legitimate message.

Also, if you would like to send an attachment, it is always a prudent approach to send an email notifying the person that you are going to follow up your message with a second email that includes the attachment; and explain the nature of the attachment. I will not open an email with an attachment unless I know the person who is sending it.

Cyberspace used to be a small and friendly place. It is no longer. I am heavily invested in hardware and software to protect what evil lurks behind every message that hits our server. From firewalls to spamware to adware to spyware to virus and worm scanning software – all of these approaches are required to protect your important information.

So, if you want to be sure that we see it, save it and open it, please include a subject header in your message and use words that will identify you as a person interested in contacting the TMA. We appreciate your help!

Medical Advisory Board

TMA Support Group National and International Leaders

All of the TMA Support Groups are for people who have any of the neuroimmunologic disorders. We encourage everyone to get involved, including family members, physicians and other medical professionals.

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