The Transverse Myelitis Association Newsletter

Volume 7 Issue 1 Fall 2006

From the Editor
Sandy Siegel

When a person is diagnosed with TM, ADEM or NMO they and their family begin a journey, which is filled with fear, anxiety, frustration and isolation. We all know this to be true, because this was our collective experience. The Transverse Myelitis Association is dedicated to providing a support network to offer the emotional support people need to battle this fear, anxiety, frustration and isolation. Our state and country support groups form the essential structure of this network.

The Transverse Myelitis Association exists because of the basic goodness of human beings. There isn't a single person in the Association who is motivated to do this work because it is their job. We are all motivated by a desire to reach out to help people in need, to foster a higher quality of life for people and to create a better community and a better world. This value in Judaism is reflected in the commandment, *Tikun Olam*, to heal the world. It is my fundamental belief that human beings are good, and we are all about the need to heal the world. If I didn't believe this in the core of my being, I wouldn't be doing this work.

These values are shared by the other TMA officers, by the incredible support group leaders we have around the world, by our members who get involved in fundraising and awareness campaigns, by the people who help with our mailings and other administrative work, and by the wonderful medical professionals we have on our advisory board. All of this work is done by people who want to make a positive difference in their world, in their communities, in their families and for themselves. The people who benefit most from doing this work are the people who do the work. The joy of delivering help always exceeds the sense of gratitude felt on the receiving end.

If you are seeking an opportunity to grow from your own adversity; if you are looking for a way to make a difference in your community; if you are seeking an opportunity to heal the world, I have a really excellent offer to make you. If you live in a state or country that has a support group, please call the support group leader and tell them that you want to help with this important work.

If you live in a state or country that does not have a support group, we need for you to consider starting one. I know that people can be overwhelmed by the idea of taking on a leadership role. How much time will it involve? Will I be able to help people when they contact me? I am so tired most of the time from taking care of myself and/or my family and working, how would I ever have the energy to do this work?

You can do this! We don't have a rigid program that all support group leaders must adhere to. We are grateful for people's willingness to volunteer their time and energy and allow great latitude for people to define their level of activity.

Here are the minimum qualifications and activities that we ask of support group leaders. You need a computer with internet access at home and you need to check your emails on a regular basis. You need to be able to communicate in English. You need common sense and you need to care. When we get a new member from your state or country, you need to contact them either by phone or email. Think about the first weeks and months after you received your diagnosis – what would that phone call or email have meant for you! Whether you meet with your group will depend on many different factors, including travel distances. Some of our groups meet often, some meet once a year, and some do not have meetings at all. Groups have found many effective ways to share information and support. Jim will be able to help you with creative ways to communicate with each other. You will not be working alone, and other support group leaders will be able to offer you great suggestions.

There are a number of administrative tasks that will require your assistance. We will ask you to help us keep your members' postal, telephone and email information current. When we have important information to disseminate to our members, we will ask for your help in contacting people in your group. If your native language is other than English, we will ask for help in communicating with your members. We will encourage you to help us get important articles translated into your language and to make these available on our web site. We will ask you to consider helping us with mailing our publications, and if you have the ability, we may ask you to help us by printing our publications locally.

We need people to volunteer to start support groups in Brazil and India. Once you take the lead, others will follow. You will not be doing this work alone; others will be willing to

help. We also need someone to start a support group in Canada. There are people in Canada who have provided us with great help, but as yet, no one has been willing to take the lead to get a group going. We should have a support group in every province.

There are countries around the globe that have sufficient numbers of our members that support groups could offer great help – Bangladesh, Colombia, Italy, Mexico, Pakistan, the Philippines, Portugal, Spain and Venezuela.

I know you can do this work, because I am doing it, and you are no different from me. I have no special training or education or life experience that prepared me for the most important work I have done in my life. I just care. Caring for Pauline motivated me to find ways to make her life better. Caring for human beings motivated me to find ways to make a positive difference in your life. That's all it takes!

If you care and you are ready to heal the world, please write me or call.

Please take good care of yourselves and each other.

© The Transverse Myelitis Association Journal and Newsletter are published by The Transverse Myelitis Association, Seattle, Washington and Powell, Ohio. Copyright 2006 by The Transverse Myelitis Association. All rights reserved. No part of this publication may be reproduced in any form or by any electronic or mechanical means without permission in writing from the publisher. We ask that other publications contact us for permission to reprint any article from The Transverse Myelitis Association Journal and Newsletter.

A Recipe for Recovery: Transplanted Embryonic Stem Cells Used To Create Neuromuscular Junctions and Restore Function in Paralyzed Rats

Douglas A. Kerr, MD, PhD

Dr. Douglas A. Kerr and a team of researchers recently published the results of a study that documents their use of embryonic stem cells to replace damaged motor neurons and restore function in paralyzed adult rats. Dr. Kerr has graciously accepted our invitation to write an article for the TMA newsletter, which provides us with a description of this groundbreaking study. A citation to the originally published article is provided below.

The significance of this work for the TMA community cannot be overstated. Dr. Kerr's studies are focused on animals that have experienced spinal cord impairment from a virus that simulates neuronal damage typical of transverse myelitis. It has been Dr. Kerr's contention that transverse myelitis provides an excellent model for understanding and working through the restoration of myelin and nerve function. The damage caused by an inflammatory attack from TM can be fairly small and might offer more controlled conditions for restorative research. In these cases, it is possible that small amounts of myelin and nerve restoration could bring about significant recovery of function for a person. Additionally, for the majority of people with monophasic TM, once the repair has been administered, there would likely not be risk of future damage, as is the case currently with multiple sclerosis.

What is learned from the transverse myelitis model will be an important first step in developing wider treatments for more complex conditions, such as multiple sclerosis, ALS, Parkinson's disease or traumatic injuries to the spinal cord.

Original Publication: Deepa M. Deshpande, MS, MBIOT, Yun-Sook Kim, PhD, Tara Martinez, BS, Jessica Carmen, PhD, Sonny Dike, MD, Irina Shats, MS, Lee L. Rubin, PhD, Jennifer Drummond, BA, Chitra Krishnan, MHS, Ahmet Hoke, MD, PhD, Nicholas Maragakis, MD, Jeremy Shefner, MD, PhD, Jeffrey D. Rothstein, MD, PhD, and Douglas A. Kerr, MD PhD, "Recovery from Paralysis in Adult Rats Using Embryonic Stem Cells" Annals of Neurology 2006; 60:32–44

The Johns Hopkins study represents the first published account of the repair of a motor neuron circuit in an adult animal. Our research provides compelling evidence of embryonic stem cells' potential for healing. We engineered new, completed, fully-working motor neuron circuits -- neurons stretching from spinal cord to target muscles -- in paralyzed adult animals. We demonstrated that the motor neuron circuit was anatomically repaired (embryonic stem cell-derived motor neurons replaced motor neurons that were destroyed) and that the animals had restored motor function. This work builds on previous studies, which are cited in our article recently published in the Annals of Neurology (2006).

During the process of early development in humans and in all animals, motor neurons grow in the spinal cord. These motor neurons (axons) leave the spinal cord and grow out into the body's periphery and connect to muscles. When the brain tells a set of muscles to move in your hand, this activity involves a motor neuron circuit that goes from the brain down through the spinal cord. It exits the spinal cord and travels up the arm to your hand.

This is a very long way for a motor neuron to grow. The nerves are connected to muscle and they stimulate chemical-electrical activity, which moves the hand.

During this process of development, motor neuron growth is completed, and axons no longer grow outside of the spinal cord. As adults, our cells no longer respond to the early developmental cues, because those cues are usually gone. That's why we don't recover well from severe injuries.

The great challenge of our work was to show that cells can be made to re-trace complex pathways of nerve development, which are long shut off in adult mammals. Our research is the proof of principle that we can recapture and replicate what happens in early stages of motor neuron development and use what we have learned about that process to repair damaged nervous systems. We asked what was there when motor neurons were born, and specifically what let motor neurons extend outward. Then we tried to bring that environment back, in the presence of adaptable, receptive stem cells.

The approach we used is analogous to an electrical repair. Paralysis is like turning on a light switch and the light doesn't go on. The connectivity is messed up because there was damage within the pathway (spinal cord) between the switch (brain) and the light bulb (muscle). We've asked stem cells to go where needed to fix the circuit.

For a brief period after a nerve dies, it leaves behind what's essentially an empty shell, with some scaffolding and non-nerve substances remaining. But with embryonic stem (ES) cell injections at the right time and place, and by adding the right cues, we've learned to restore the biological 'memory' for growing neurons, which is clearly still in place. The motor circuit engineering combines recent discoveries on stem cell differentiation, a growing understanding of early development of the nervous system, and insights into behavior of the nervous system in traumatic injury. Our research has created a protocol or a cookbook recipe to restore lost nerve function.

The rats in our study were paralyzed; they had virus-damaged spinal cords, which modeled nerve disease. The rats lost motor neurons to an aggressive infection with Sindbis virus -- one that, in rodents, specifically targets motor neurons and kills them.

The repair protocol begins in our study with the differentiation of mouse (ES) cells into spinal motor neurons. This is accomplished by exposing ES cells to retinoic acid (RA) and sonic hedgehog (Shh) protein. We've learned that this exposure in the first weeks of life directs ES cells into motor neurons. The differentiating ES cells were placed in a substance 3.5 days later that contained dbcAMP, a growth factor that increases the survival of the cells and also allows the new axons to extend into the peripheral nervous system.

Sixty thousand mouse (ES) cells were injected into the ventral gray matter of the lumbar spinal cords of the paralyzed adult rats 28 days after they were inoculated with the motor neuron-killing virus. At the time of transplantation, approximately 12,000 of the cells can be identified from their characteristics as early motor neurons.

We understood from previous research that extending new motor neurons in an adult nervous system meant overcoming a number of hurdles. One involved myelin, the fatty material that insulates mature motor neurons. Like the coating on electrical wire, myelin prevents weakening of the traveling electrical impulse and lets it continue long distances. In humans, the myelinated sciatic nerve, for example, exits the spinal cord and extends to the leg muscles it activates, carrying impulses several feet. Once laid down, however, myelin inhibits further nerve growth. This is nature's way of discouraging excessive wiring in the nervous system. We had to overcome inhibition from myelin lingering in the dead nerve pathways.

Two recently-developed agents, rolipram and dbcAMP, were used to overcome myelin-mediated axon repulsion. As noted earlier, dbcAMP was used in the transplant solution to stimulate axonal growth and survival. Rolipram was administered to the rats subcutaneously and served to neutralize the inhibitory effects of myelin on axonal outgrowth; Rolipram allowed the axons to grow through the spinal cord and to extend slightly into the outlying nervous system.

The next hurdle involved the stimulation of axon growth out into the periphery, attracting them to skeletal muscle targets, and providing cues to stimulate the formation of neuromuscular junctions between the newly transplanted motor axons and the existing paralyzed muscles. Based on the earlier work of our research team member, Ahmet Hoke, we knew that GDNF (glial cell–derived neurotrophic factor) is a powerful stimulator of neuron growth. At the time we transplanted ES cells into the spinal cord, we also transplanted glial cells into the remains of the newly-dead (from the virus) sciatic nerve at a point near its former leg muscle contacts. The GDNF attracted the extending motor neurons, "luring" them to the muscle targets. To ensure a continuous supply of GDNF, we relied on injected fetal mouse neural stem cells, a known source of the molecule. Our study demonstrated that GDNF did attract the ES cell-derived motor axons and stimulated the creation of neuromuscular junctions. Finally, we administered CsA to inhibit the rejection of the transplanted ES cells.

The ES cell-derived motor neurons were distinguishable from host (existing) motor neurons as the transplanted neurons were "programmed" to express GFP (green fluorescent protein). We were thus able to both observe and count these new motor neurons within the rat spinal cords and sciatic nerves.

At three months from the time of transplantation some 4,100 new motor neurons were created in the spinal cord. Roughly 200 exited the cord and 120 reached skeletal muscle, forming typical nerve-muscle junctions, with appropriate, typical chemical markers. Microscopically, the neurons and their muscle associations appear identical to natural ones in healthy animals. Through electrophysiological analysis, we were able to demonstrate that the neuromuscular junctions between the transplanted motor neurons and the existing skeletal muscles were functionally active. Fifty of the new neurons were found to carry electrical impulses. Because such testing is time and labor intensive, only a small area of leg muscle was analyzed. The improved ability of treated rats, however, suggests more functional neurons are likely.

Finally, we performed blinded evaluations of functional recovery from a behavioral assessment based on hind-limb grip strength. This assessment progressed for six months from the time of transplantation. Recovery was defined as the ability to flex the leg under the animal and to push off with the foot. Eleven of the 15 treated rats gained significant, though partial, recovery from paralysis. The animals recovered enough muscle strength to bear weight and step with the previously paralyzed hind leg. The rats gained weight, were more mobile in their cages and measures of muscle strength increased.

One of the more important aspects of the study entailed experiments that were designed to determine whether all of the ingredients in the recipe were required to achieve the desired result. We created eight different groups and each was composed of 15 rats. Only one group received all of the treatments in the protocol: intraspinal dbcAMP, subcutaneous rolipram, GDNF cells into the sciatic nerves, and CsA to inhibit rejection of transplanted cells. The remaining seven groups of animals received different combinations of these treatments to determine whether any of these factors were not necessary for the complete restoration of nerve function in the rats. For instance, one group did not receive dbcAMP, another group did not receive rolipram, and so forth. In one of the groups, we tested the importance of using motor neurons in the protocol. This group received ES cells that were differentiated to neural cells rather than motor neurons, and received the full compliment of other treatments. Each of the groups was then tested to assess evidence that implanted motor neurons were forming functional connections to skeletal muscles, that these motor units were functional (electrically active) and that there was functional recovery from hind-limb paralysis (behavioral observations).

The tests demonstrated that of the seven groups that were treated without even one component of the "cocktail," the animals experienced no recovery. Animals that were transplanted with only neurons and not motor neurons did not experience functional recovery. Animals that were not treated with the myelin inhibitors (rolipram and dbcAMP) or with GDNF (to attract axon growth in the peripheral nervous system) did not experience functional recovery. For the group of animals that received all treatments in the protocol, we observed 125 new connections with host skeletal muscle, and we found evidence of 50 of these connections in the hind limb, which were active electrically. We also found that only the animals that experienced the new and active neural muscular junctions experienced observable behavioral recovery.

Our study has developed and defined a protocol for the restoration of motor function in paralyzed rats using mouse embryonic stem cells. The first step in the process involved the transplantation of ES cells that had been differentiated to motor neurons. The ES cells were treated to increase their survival and also to inhibit their rejection by the host animal. The next step entailed the administration of dbcAMP and rolipram to turn off the characteristics of myelin, which prevent the axons from growing outside of the spinal cord and into the periphery where muscles are located in the body. GDNF was then used in the periphery, within the muscle "targets" to attract and stimulate the growth of the axons. The result of this process was the connection of the newly transplanted motor neurons (axons) with the animals' existing muscles to form active neural-muscular junctions. The animals had been paralyzed, because the motor neurons that had been connected to these hind limb muscles had been destroyed. Our transplanted precursor motor neurons, coaxed by our protocol, were able to form functional motor units (active nerve and muscle connections). From the results we have observed in the restoration of function in paralyzed adult rats, we conclude that ES cells represent a potential therapeutic intervention for humans with paralysis.

We are in the process of beginning research to see how well the technique applies to human nerve recovery, using federally-approved human ES cells in larger mammals like pigs. Each of six academic institutions in a new collaboration will tackle a different major question of safety and effectiveness. Questions of tumor-formation, often a

concern with ES cells, of the safety of surgery and of the ES cells' ability to form healthy motor circuits are major questions to answer. Several years of testing and thorough data evaluation would occur before applying to the FDA to approve human clinical trials.

The study was supported by Families of SMA, Andrew's Buddies/Fight SMA, the ALS Association and The Robert Packard Center for ALS Research at Johns Hopkins, the Muscular Dystrophy Association, Wings Over Wall Street, and a grant from the NIH.

Dr. Kerr is a grantee of The Packard Center for ALS Research at Johns Hopkins. He also directs Project RESTORE, a Hopkins-based undertaking to advance therapies for transverse myelitis and multiple sclerosis.

Others on the research team from the Department of Neurology at the Johns Hopkins University School of Medicine include Jeffrey Rothstein, M.D., Ph.D.; Ahmet Hoke, M.D., Ph.D.; Nicholas Maragakis, M.D.; Yun Sook Kim, Ph.D.; Sonny Dike, M.D.; Deepa Deshpande, M.S.; Chitra Krishnan, M.S., and Jennifer Drummond. Researchers from the Department of Molecular Microbiology and Immunology at the Johns Hopkins University Bloomberg School of Public Health include Jessica Carmen, Tara Martinez and Irina Shats. Jeremy Shefner, M.D., Ph.D., of the Department of Neurology at the State University of New York Upstate Medical University, Syracuse, N.Y., also contributed to the study.

Press Conference Remarks on Stem Cell Research
Cody Unser

Cody Unser gave the following address at a press conference in July 2006, which was held in Washington DC the day before HR-810 was voted on in the United States Senate. Her comments were given on behalf of the Christopher Reeve Paralysis Foundation and on behalf of people living with some form of paralysis. In addition to Cody, there was a person with MS and a young girl with Type 1 Diabetes who spoke about the benefits which would derive from stem cell research. This press conference was covered by C-Span.

Cody is a sophomore at the University of Redlands in California. She is majoring in Biopolitics. Her personal goal is to help politicians and scientists develop more effective dialogue through communication, education and compassion. Cody heads the Cody Unser Firststep Foundation, serves on the Board of Ambassadors of Johns Hopkins Project RESTORE and is a member of The Transverse Myelitis Association.

Everyone hopes, dreams, or prays for some miraculous answer to some almost unreachable question. Will I ever walk again? I have hoped, dreamed, and prayed for an answer to my almost unreachable question. Stem cell research is my vital life support; my light at the end of this paralyzing tunnel, and the 'first step' to my recovery and healing from Transverse Myelitis (a rare inflammatory condition) that has left me paralyzed from the chest down for the last seven years. Why am I so confident that this light at the end of the tunnel is so promising? I have seen research strides at Johns Hopkins with my doctor, Doug Kerr, in Baltimore where a paralyzed rat regained the full function of its legs. I was overwhelmed because the answer, no matter what it was, was hope I couldn't ignore.

It was over a year ago when HR-810 was passed in the House of Representatives. If compassion was considered, then we had made our first step to unlocking the answer and ending the suffering for over 100 million Americans. Now more than ever, humanity demands even more compassion. I know there is a lot going on out in the world today, especially in the Middle East, and it isn't ironic that we are given the chance right here and now with HR-810 to better the quality of life for all of humanity. If we can't save the world, we can definitely heal it. I just would like to thank everyone who has been involved with this from the beginning on the political stage and most importantly, to those scientists and researchers who see the hope and the power of stem cell research, never letting the politics crush the potential for a better life. I would like to thank one of my New Mexico Senators, Jeff Bingham, for supporting HR-810, and although it's been a challenge for him, I would like to encourage my other Senator, Pete Domenici, to vote yes on HR-810.

This war is one that has been unnecessary for all who suffer from Parkinson's, paralysis, Diabetes, Alzheimer's, to name a few, to be fighting. I believe in this research and I hope that every Senator who is thus far opposed to stem cell research, and the President who has threatened to veto this bill, will look deeper into their own humanity, one without politics and religion. Stem cell research is a human issue, not a religious and political one simply because human suffering does not discriminate against any one religion and any one political view.

While the answers, cures and treatments lie in the hands of science and medicine, the funding and oversight to ensure efficient, ethical and responsible research lies in the hands of the U.S. Senate. By not voting on H.R. 810, not only do we ensure that these one hundred million patients suffer further, America's leadership position in the fields of science and medicine will also suffer, if our brightest minds are shackled by the darkest political

maneuverings. Currently, hope is making people so desperate that they are leaving the country to other countries who are not foreseeing this issue in an ethical operation. Americans overwhelmingly agree that stem cell research needs to be freed from the politics of Washington, and that the government must provide funding to allow the real work to be done in the laboratories of America, with oversight by the National Institutes of Health.

Over a hundred years ago man couldn't fly. All I want to do is walk again. Stem Cell research is my answer; don't let me and others who are suffering wait any longer. Vote yes on HR-810, a pro-patient, pro-research bill! Thank you all very much!

Recruiting for ACP Study:
Help us to Find the Causes and Cures for TM, ADEM, NMO, MS and the other Neuroimmunologic Disorders
Jana Goins

This year the Johns Hopkins University is working in conjunction with the Accelerated Cure Project for Multiple Sclerosis (ACP) to conduct a large scale research study which will play an important role in determining significant causal factors and disease trends for demyelinating disorders such as Multiple Sclerosis (MS), Transverse Myelitis (TM), Optic Neuritis (ON), Devic's Syndrome (NMO), Acute Disseminated Encephalomyelitis (ADEM) and other related diseases.

Several major academic centers located throughout the country will serve as coordinating project sites, creating a national network of collection sites. Study enrollment is targeted at 10,000 subjects over ten years. Enrolled subjects will be asked to contribute personal data (such as medical history and family information) and biological samples. The personal data collected from all subjects will be combined into a single database while the biological samples will be processed at a central laboratory and stored. The complete anonymity of study participants will be protected. The result will be the creation of a comprehensive information system and specimen repository from which researchers can request samples to conduct in-depth analyses on various disease aspects. This study will play an important role in increasing the current knowledge of demyelinating diseases and therefore aid researchers in the development of better diagnostic techniques and cures for these diseases.

Now this is your chance to help! We are enrolling patients with multiple sclerosis, transverse myelitis, optic neuritis, acute disseminated encephalomyelitis, neuromyelitis optica (Devic's) or clinically isolated syndromes (one demyelinating attack, but not fulfilling the diagnostic criteria for MS). Those who are currently patients at Johns Hopkins will be able to join the study without a referral from their physician, and will just need to contact the Johns Hopkins project coordinator for study enrollment information. Johns Hopkins patients who are aware of their next scheduled clinic date may get in touch with the project coordinator *beforehand* in order to schedule a study meeting during this clinic visit. Subjects participating at Johns Hopkins will be offered a $25 check to compensate for lunch and parking on the day of the visit, but will not be reimbursed for any travel expenses. At this time, patients receiving care outside of Johns Hopkins may be subject to additional enrollment requirements.

Please note, the enrollment requirements and participant compensation may vary by study site. If you are interested in getting involved, please contact your nearest participating center for further information regarding the enrollment process.

In addition to enrolling subjects with one of the specified demyelinating diseases, we are asking participants to refer affected and unaffected relatives as well as unaffected matched "controls" (such as a childhood friend who grew up in the same area as you or a spouse) for participation in the study.

This is a very exciting opportunity for both patients and researchers around the country to take part in a large-scale dynamic project that will work to improve our knowledge about demyelinating diseases. We welcome enthusiasm and positive attitudes! By volunteering your time and effort to this project, you will be making a significant contribution to the development of new treatments, and ultimately a cure, for these diseases.

Participating Centers

Johns Hopkins Medical Institution (Baltimore, MD)
Jana Goins
jgoins3@jhmi.edu
(410)502-6160

UMass Memorial (Worcester, MA)
Janice Weaver
weavej01@UMMHC.ORG
(508)793-6562

Shepherd Center (Atlanta, GA)
Elizabeth Iski
Elizabeth_Iski@shepherd.org
(404)350-3116

University of Texas Southwestern (Dallas, TX)
Gina Remington
Gina.Remington@utsouthwestern.edu
(214)645-0560

Multiple Sclerosis Research Center of New York (New York, NY)
Emily Denicore Eisenberg
edenicore@imsmp.org
(212)265-8070

Study Sponsor

Accelerated Cure Project
Sara Loud
sloud@acceleratedcure.org
(781)487-0032
www.acceleratedcure.org

Neuroimmunologic Disorders Sample Repository:
http://www.acceleratedcure.org/curemap/tissuebank.php

Benjamin M. Greenberg, MD, MHS to Serve on TMA Medical Advisory Board

The officers and board of The Transverse Myelitis Association are pleased and proud to announce that Dr. Benjamin Greenberg will serve on our Medical Advisory Board. Dr. Greenberg is an Assistant Professor in the Department of Neurology, Johns Hopkins School of Medicine. Dr. Greenberg recently accepted the position of Co-Director of the Johns Hopkins Transverse Myelitis Center.

Dr. Greenberg did his residency at Johns Hopkins Hospital and became Chief Resident in 2004. He has worked with Dr. Kerr and the other physicians and scientists at the Johns Hopkins TM Center and developed an interest and focus on TM and the other neuroimmunologic disorders. Dr. Greenberg is also a Post Doctoral Fellow in the Department of Molecular Microbiology and Immunology, Johns Hopkins School of Public Health.

Dr. Greenberg serves on the Accelerated Cure Project, Scientific Advisory Board. Johns Hopkins has assumed the lead role in the development of the ACP registry and repository and Dr. Greenberg is the lead researcher on the project.

Dr. Greenberg's research focus on Transverse Myelitis and the other neuroimmunologic disorders and his specialization in caring for patients with these disorders has and will continue to create a tremendous benefit to our community. We are grateful for Dr. Greenberg's interest in the neuroimmunologic disorders and we are most appreciative of his willingness to serve on the Medical Advisory Board. He is an excellent addition to a group of exceptional medical professionals and wonderful human beings.

National Family Caregivers Month
November 2006

The Transverse Myelitis Association Supports National Family Caregivers Month

And its Caring Every Day Messages

Believe
In Yourself
Protect
Your Health
Reach Out
for Help.

This year there will be a special emphasis on the need for all of us to help family caregivers protect their health in order to have a more satisfying life and be better able to provide their loved one with the best care possible.

The Transverse Myelitis Association is pleased to be an endorser of NFC Month and bring attention to the needs of family caregivers. We encourage you to spread the word about *this initiative to protect family caregivers' health*. Celebrating NFC Month in your community can also help to raise awareness about the TMA and about TM, ADEM, NMO, ON and the other rare neuroimmunologic disorders.

To order a Family Caregiver Kit and participate in *National Family Caregivers Month 2006*, call 800/896-3650 or visit www.thefamilycaregiver.org.

Young Adult's Autumn Retreat November 17-19, 2006

The Transverse Myelitis Association is partnering with Victory Junction Gang Camp (VJGC) to hold a bi-annual autumn retreat weekend for young adults with TM, ADEM, NMO, and ON. The camp is located near Greensboro, North Carolina. The Victory Junction Gang Camp Board has generously offered the TMA an opportunity to bring together our young adult community for a weekend retreat. The weekend will provide a chance for you to meet with others who understand your experiences better than anyone.

Dr. Douglas Kerr, Dr. Adam Kaplin, and Chitra Krishnan from The Johns Hopkins Transverse Myelitis Center will be attending the Retreat Weekend. Cody Unser from the Cody Unser First Step Foundation will also be coming to participate as a camper. In addition to participating in all of the activities, Doug, Adam and Chitra will be available the entire weekend to answer your questions. It will be a great opportunity to get to know these wonderful TM specialists and to learn more about TM. The focus of this camp experience is going to be on a weekend of fun and relaxation and an incredible opportunity for you to meet others your age with TM, NMO and ADEM.

There will be no charge for the young adult retreat weekend; the meals, lodging and activities are free! Your only cost will be transportation to the camp. The Piedmont Triad Airport in Greensboro, North Carolina is approximately 20 miles away and airport pick-ups can be arranged.

We are inviting our members who are between the ages of sixteen and twenty-five to the young adult retreat weekend. If you are planning to attend, please call Stephen Miller at (937)453-9832. You should also begin the application process with Victory Junction Gang Camp. There are

two applications that need to be filled out and sent to VJGC; both are found on their web site: www.victoryjunction.org under the link 'How to Apply.' Please download and complete both the Family Camp application and Camper application. You should mail or fax in your part of the application to VJGC while your physician is filling out the medical portion of the application. If you have any questions or would like any additional information, please get in touch with Stephen or any of the TMA officers.

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. We know that having the opportunity to share your experiences with your peers will be enriching and empowering. We know that you will come away from this retreat with lifelong friendships.

TM-ADEM-NMO Family Camp at Victory Junction August 19-24 2007

The Transverse Myelitis Association is partnering with the Victory Junction Gang Camp in Randleman, North Carolina to hold a bi-annual summer camp for kids ages 7-15 and their families. The camp occasionally accepts those outside of this age range, however, the activities and venues 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. The number of families we can serve on-site is limited to 32 families of up to eight immediate family members. Additional accommodations may be provided off-site for later applicants and/or families who do not require on-site accommodations. It is important that you contact one of the officers of the TMA as quickly as possible, if you are planning to attend the 2007 Family Camp; families will be considered on a first-come, first-serve basis.

Victory Junction Gang Camp is extraordinary in its eagerness to serve the pediatric TM community, including parents and siblings, 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.

A number of our Medical Advisory Board physicians have committed to attending the family camp with their own families, including Drs. Doug Kerr, Adam Kaplin, Ben Greenberg, Frank Pidcock and Greg Barnes. The physicians and Chitra Krishnan will make some formal presentations and they will be available during the week to answer your questions in a non-clinical setting. However, the emphasis is on having a fun week at camp.

There is no cost to attend Victory Junction Gang Camp! Meals, lodging, and all of the fun you can possibly imagine are free to each family. You will, however, need to get yourselves to the camp. 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. If you would like to come to camp, but simply cannot afford the travel expenses, please let us know. We can't promise you'll get there, but we will do what we can to make it happen.

For those families coming from within the United States, applications will be available after January, 2007. Our international members who are planning to attend should contact us as soon as possible. We know that your travel will take time to arrange, and you will need to initiate the process of applying for your travel visas. Please contact Stephen Miller at smiller@myelitis.org; Paula Lazzeri at plazzeri@myelitis.org; or Sandy Siegel at ssiegel@myelitis.org and we will get you started on the process.

We've made several trips to VJGC and have had the opportunity to see the camp in action and to meet the directors and staff. The facility and the people are just amazing. Please check out Victory Junction's website: www.victoryjunction.org and be sure to watch the video. We can't wait for next summer. We know this is going to be a totally transforming experience for your children and for you!

The Transverse Myelitis Association Awards Grant to the Johns Hopkins Transverse Myelitis Center / Project RESTORE

The TMA is pleased to announce the award of a $35,000 grant to The Johns Hopkins Transverse Myelitis Center and Project RESTORE to support a new Research and Administrative Coordinator position. The funding of this position reflects the TMA's commitment to support research on all of the rare neuroimmunologic disorders and to support the provision of the best clinical care to people with these disorders.

This position will provide research and administrative support to the Center's Executive Director. Through the addition of this position, the Center will

expand its fundraising activities and its awareness and outreach programs. The Program Coordinator will increase the Center's ability to write grants to expand research and clinical trials, to organize educational symposia, and to facilitate the coordination of medical care.

The Johns Hopkins Transverse Myelitis Center was established in October 1999 as a multidisciplinary center dedicated to the diagnosis and treatment of acute transverse myelitis (ATM) and to better understanding of the pathophysiology and natural course of the disease. The goals of the center are 1) to provide expert care and treatment for patients in the acute and convalescent phase of rare neuroimmunologic disorders – TM, ADEM and NMO; 2) to extend the spectrum of care through collaborative management of the disease condition by health care providers from multiple disciplines; 3) to develop standard diagnostic criteria and work-up for patients based on clinical research to understand the natural course of the disease; 4) to perform clinical and basic science research in order to comprehend the pathophysiology of ATM; 5) to devise novel therapeutic interventions for patients in the acute and convalescent stages of ATM; 6) to coordinate international symposia as platforms for both physicians and patients to interact and share theories and advances in research and management of ATM; and 7) to publish and disseminate the knowledge gained through clinical practice, research and international symposia to community physicians to target recognition of the disease in the community.

The Johns Hopkins Project RESTORE was launched in August 2004; a multidisciplinary research and clinical collaboration of The Johns Hopkins Transverse Myelitis and Multiple Sclerosis Centers. The goal of this initiative is to develop new diagnostic and therapeutic strategies in the treatment of neuroimmunologic disorders, such as multiple sclerosis (MS) and transverse myelitis (TM). New research studies and clinical trials are made possible through this collaboration.

The Transverse Myelitis Association remains committed to developing a medical center network with a focus on the neuroimmunologic disorders. It is imperative that people have local access to the best clinical care from physicians who have a good understanding of and experience with these disorders. It is critical that the research efforts into these disorders are also expanded and accelerated. This will only happen through increased funding and through the encouragement of collaboration in this work. The TMA's partnership with the Accelerated Cure Project is a significant step in meeting these important goals.

The TMA is interested in balancing our goals of developing this network with our support for the great work that is being done at the Johns Hopkins Transverse Myelitis Center and Project RESTORE. We are thrilled to be able to support this new position at the Center and we are grateful to our generous members for making this support possible.

The 2006 TMA Distinguished Service Award: Dorocaks, Hamiltons, Hoges and Vietzkes

In 2004, The Transverse Myelitis Association began the tradition of recognizing distinguished service to our organization and our community. Chitra Krishnan was so very deservedly the first recipient of this award. The Officers and Board of The Transverse Myelitis Association were honored to select four wonderful families for receipt of the 2006 TMA Distinguished Service Award. The award ceremony was held during the dinner banquet on July 21st at the 2006 International Rare Neuroimmunologic Disorders Symposium in Baltimore. The award was given to Cathy and Dan Dorocak, Jeanne and Tom Hamilton, Pamela and Morgan Hoge and Amy and Darian Vietzke.

Most organizations recognize the contributions that are made by their members. It is hard to imagine that there could be an organization that would have more compelling reasons for this recognition than The Transverse Myelitis Association. All of the work that is done by the TMA for our community is performed by volunteers. No one is ever provided with compensation for their work. This is the case for the officers and board members, for our medical advisory board, for our national and international support group leaders and for the many people we have in our community who are involved in awareness and fundraising activities. What gets done for our community depends entirely on the sacrifices of time, energy, creativity, and resources of our members.

The Hoges, Dorocaks, Hamiltons and Vietzkes have been central to the work of the TMA almost from our inception and their work continues today in spite of the tremendously difficult issues that they face every day of their lives with a child who has been severely impacted with TM. These families each have a child who got TM before they were one year old. The Hoges, Dorocaks, Hamiltons and Vietzkes are being recognized for their work in raising awareness of the neuroimmunologic disorders, in providing information and support to other parents of children with these disorders and for their fundraising activities. The Dorocaks started and participate in the Reading for Rachel Program; the Hamiltons hold Kevin's Cause. Both programs are critical to the TMA's goal to raise money for research on the neuroimmunologic disorders.

Whenever there is a young child stricken with TM, ADEM or NMO, within the first five minutes of my talking to the parents, I provide them

with Darian and Amy's, Morgan and Pamela's, Dan and Cathy's, and Jeanne and Tom's names and telephone numbers. I urge them to get in touch with these four families as quickly as possible. I know that they will learn a great deal from these parents – they've been through it all. And they will receive the compassion and emotional support that they need. These are among the most sensitive, compassionate, caring, kind and generous people I know – and I know many.

And then in the course of my referring to these parents, I always get the following intense pangs of guilt. I know that by having a parent of a newly diagnosed child call these families, they are going to review, reflect on and relive their own experiences with their child. They will have to go through the horrors of the early onset and the incredibly painful challenges that they face every day with their child with TM and with all of their children, because these disorders impact whole families – everyone's life is dramatically changed. The rest of my guilt is suffered by the thoughts and feelings I have about referring a parent of a child who is having a remarkable and good recovery to four sets of parents who had children who were very seriously impacted by TM. I know that this is an extremely difficult experience for them.

I feel very badly about all of this, but I keep sending them. And over the many years I have been doing this, these parents never ask me to stop. They are always available to help others who very desperately need them. They understand what these other parents are going through in a way that I can only imagine. What they offer to these parents in the way of information and support is beyond kind and generous. The TMA, in this very small way, is grateful for the opportunity to recognize their invaluable and critical contributions to the TMA community.

Dr. Sandy Siegel Receives the Johns Hopkins Project RESTORE Distinguished Service Award

Douglas A. Kerr, MD/PhD

On July 21, 2006, Dr. Sandy Siegel became the first recipient of the Project RESTORE Distinguished Service Award in recognition of his service to restore hope, function and lives to patients with Transverse Myelitis. The award was presented by Mr. Bruce Downey, CEO of Barr Pharmaceuticals and Chair of The Johns Hopkins Project RESTORE Board of Ambassadors.

Sandy Siegel has embodied the role of a true ambassador and champion for patients with Transverse Myelitis and other rare neuroimmunologic disorders. He is the President of The Transverse Myelitis Association and his commitment, passion and spirit is truly unparalleled. Sandy's passion for the cause is revealed in the hundreds of emails he responds to from patients all over the world and the countless phone conversations with patients and their physicians in enabling the provision of appropriate and timely clinical care. The Transverse Myelitis Association is a patient support group that also raises funds for research for these rare diseases, one of the very few foundations alive today with no overhead costs! Sandy has championed the cause of the TMA along with the other officers of the Board – Paula Lazzeri, Debbie Capen, Jim Lubin and Stephen Miller and today they have a membership of over 5,800 from all over the world that they reach out to with newsletters and awareness campaigns.

The key note address of the 2nd Biennial International Rare Neuroimmunologic Disorders Symposium held in Baltimore in July 2006 was given by Bruce Downey, the Chairman of The Johns Hopkins Project RESTORE Board of Ambassadors. In presenting Sandy the Project RESTORE Distinguished Service Award, Bruce stated that, "no one can do what Sandy does and no one deserves this award more than he does."

Bruce Downey is the Chairman and CEO of Barr Pharmaceuticals, Inc., one of the largest generic pharmaceutical companies in the United States. He has been with The Johns Hopkins Project RESTORE since its inception in August 2004. Project RESTORE is a multidisciplinary research and clinical collaboration emerging from The Johns Hopkins Transverse Myelitis and Multiple Sclerosis Centers. Project RESTORE is focused on developing new diagnostic and therapeutic strategies in the treatment of neuroimmunologic disorders, such as multiple sclerosis (MS) and transverse myelitis (TM).

Project RESTORE has three principle goals: to recover from acute attacks and illness; to stop progression of disease and disability; and to regenerate nerve cells and myelin. No words can describe the gratitude we, as a community, have for Sandy. Through his dedication and perseverance, and the hard work and dedication of the other TMA officers, we are confident that the goals of Project RESTORE will be achieved.

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.

Support Groups

Alabama TM Support Group
Terry and Jennifer Chapman
Monroeville, AL

I would like to take this opportunity to introduce myself to the Transverse Myelitis family. I would also like to thank everyone who has been so instrumental in providing the information that we have received about this mysterious disease. I am the wife and caregiver to my husband who was diagnosed with TM and Devics disease. I am also the mother of five very loving and healthful children.

There are a lot of people in the state of Alabama whose lives have been affected by this disease. It is for this reason that I would love to start a TM support group. I have talked to some of you who expressed a sincere interest in making this dream a reality. I am hoping and praying that others will also be interested in this much-needed group in our state. It is sad and heartbreaking to see someone suffering from TM, but it is also a blessing to have someone you can relate to and to know that you are not fighting this battle alone.

My husband, Terry, has been suffering with TM since August 26, 2005. What started out as a typical night changed our lives by the next morning. My husband had been complaining of bad pain in his neck and back. He was also experiencing a heavy feeling in his legs and a pins and needles effect in his feet. Terry woke up the next morning and had no feeling in his legs. I immediately called the doctor and he instructed me to get him to his office ASAP. He was sent from this doctor to a neurologist. Everything was still a mystery; however, the neurologist did think quickly and ordered five days of IV steroids, with an oral taper with 60 mg daily. The feeling in his legs eventually returned.

We soon learned that this was just the beginning of a very long fight. Our family basically began a whole new life; a life filled with numerous MRIs, CAT, ICU and countless new medications. Terry has had to endure blood clots in one leg, horrible spasms, and severe stomach pain which we later learned is called banding.

On January 6th of this year we almost lost him. He had just completed a series of IV steroids, five days to be exact. On the fifth day, my husband walked into the hospital to begin his last day of treatments, only to be wheeled out four hours later. He was so sick that he could barely hold his head up. When I asked the nurse what was happening, she told me that he was just very tired and dried out. She also said to give him plenty of fluids and he would be okay. We arrived home and he was not doing any better; the only thing that he could keep down was milk. The next morning he was non responsive. I immediately took him to the ER and I thank God everyday that I did. By the time we got there his heart rate was very low, his kidney had stopped functioning, his blood pressure was dropping and the doctor did not hear any sound in his stomach. He was dying. All of this was due to an over dosage of IV steroids. He was immediately sent to ICU where he remained until he was stable enough to move to the University of Birmingham, which is about 200 miles away. Under the care of a great neurologist he was on the road to recovery. However, due to the excessive steroid usage he is also diabetic. Each day is a struggle, but he never gives up. He is currently walking aided with a cane. The inflammation in his spine is still there, however, he is currently taking Cytoxin once a month and IV steroids as needed, along with a host of other medications. He is unable to work at this time, but we are grateful that he is not totally paralyzed. His left leg does have some numbness, but is continuing to get stronger each day.

If anyone is interested in participating in a support group, please feel free to contact me. My home phone number is (251)575-1058 and my email address is tjcchap5@yahoo.com I would love to create a community of encouragement, not only for those who suffer with TM, Devics or ADEM, but also for the families, friends, caregivers and physicians who feel the impact of these disorders, as well. Please call or write me via email. We are looking forward to hearing from you.

Colorado TM Support Group
Lamar and Danise Burkes

Our daughter, Kailey, (age 3) was diagnosed with TM on May 20, 2006. Approximately five weeks prior to her diagnosis, Kailey started complaining of periodic back pain. Gradually, over the course of a week or two, the complaints became more frequent, so we took her to the doctor where we were told it was probably just growing pains or a viral illness that had caused some pain in her joints. A few days later she was still in pain and refusing to walk. We took her to the ER at The Children's Hospital in Parker. The ER doctors sent us home after an X-Ray revealed she had quite a bit of bowel backed up and defined this as the cause of her pain.

Three days later she was still in pain and not wanting to walk. We also noticed that she was periodically running a low grade temperature. We took her again to the ER. We finally found a wonderful doctor (Dr. Mandt) who listened to our story and really began to look for something more. He ran a CBC, did a CT-Scan (which revealed swollen lymph nodes up and down her back) and they attempted an MRI, but

they were unable to sedate her properly. We left the hospital late that night.

The following Monday we went to The Children's Hospital in Denver. Kailey was able to get a good MRI, but it did not reveal any significant findings. All urine tests for cultures and infections were also negative.

The following week she seemed better for a few days and then started complaining of her back hurting. We traveled with our family to Houston for a wedding. Kailey continued to complain about back pain so we took her to our old pediatrician; we had moved to Colorado about a year before. After examining Kailey, he recommended we take her to Texas Children's Hospital. This was on May 18th.

Texas Children's Hospital first screened for an infectious disease and then they started looking for a neurological problem. After two MRIs, they diagnosed Kaiely with TM. They performed a spinal tap and ran numerous other tests. They also performed a brain MRI which came back clean. They put her on a heavy dose of steroids for five days in the hospital along with some pain medication. We were sent home with a four-week taper of oral prednisone and Tylenol and Motrin for pain management. In the hospital they also noted her temperature fluctuated between 102.3 and down to 95.6; it seemed to stabilize when she was discharged.

Kailey continued to have back pain and experienced periodic temperatures over 100. Our pediatric neurologist wanted to wait until she was entirely off of the steroids before proceeding with any more testing or lab work. We began doing research on transverse myelitis and found Dr. Douglas Kerr. We wanted our neurologist to get in touch with Dr. Kerr because we were concerned about Kailey's back pain and her problems with walking. The neurologist was reluctant to get in touch with Dr. Kerr. We began discussing Kailey's case directly with Dr. Kerr. We relayed what we learned to our local neurologist and convinced him to do another MRI on Kailey. She was experiencing weakness, pain and bowel and bladder difficulties.

We were quite frustrated with having to fight the neurology team to get things done. We met with the head of the neurology department who helped facilitate getting several neurologists to review her case and they recommended follow-up MRIs. These MRIs from Children's Hospital came back clean. The neurology team began to suspect that Kailey's original MRIs from Texas Children's Hospital had not actually enhanced and that Kailey did not have TM or any other neurological problem.

We felt as though we were back to square one from a diagnostic perspective and were very disappointed and frustrated. The neurology team then referred us to a rheumatologist. The rheumatologist ran a large number of tests and ruled out any rheumatologic disorder. That left us with a three-year-old little girl with back pain, intermittent fevers, bowel and bladder problems, weakness on her right side and no explanation or diagnosis.

In our frustration, we contacted Dr. Kerr again at Johns Hopkins. It was not easy, and it took most of our savings, but we traveled to Baltimore and saw Dr. Kerr on August 8th. Dr. Kerr was, by far, the most amazing neurologist we had seen during our problems with Kailey. He reviewed all of her charts, blood results, MRIs, CT-Scans, and other tests and concluded that Kailey did have TM in the lowest region of her spine. He determined that most of her pain was related to muscle spasms and muscle tension in her lower back. He recommended a more intensive physical therapy regimen and continued monitoring of her bladder and bowels. Dr. Kerr was very encouraged by Kailey's progress and felt she has the ability to almost fully recover.

Kailey has slowly progressed but she continues to have back pain and bladder problems. She can't tell when she is urinating and then when she does, she struggles to empty her bladder. Our pediatrician is discussing these issues with Dr. Kerr. He feels as though Kailey may experience some intermittent episodes of inflammation over the next couple of years. These symptoms may reoccur and she may need some boost therapies with steroids for a few months to keep things moving in a positive direction. He is still very positive about her outlook and feels very strongly that a full recovery is quite possible for Kailey. We continue daily with her physical therapy and our prayers that she will keep progressing and will slowly return to full strength.

From our experience with Kailey, we've learned about the importance of sharing information and support. We are excited to be starting a TM Support Group in Colorado for people with TM, ADEM and NMO. We know that this group is needed in our state and we are looking forward to hearing from you!

Lamar and Danise Burkes
ldburkes@hotmail.com
(720)851-8520

The German TM Society

We are so very proud of Ursula and the German TM support Group members for their work in establishing a formal TM Society. By going through the process of becoming a formal society, in accordance with the laws and administrative rules in their country, they are able to operate and receive

benefits that are otherwise not attainable as an informal organization. They join the United Kingdom TM Society in achieving this very important goal. We encourage all of our international support groups to pursue this approach in your own countries. The Transverse Myelitis Association will assist you in any way we are able. The officers in the German and UK TM Societies will also be able to help you in this process.

Hello, I'm Ursula Mauro, the leader of the German TM support group. On May 6th 2006 we held a German support group meeting in a beautiful hotel in a city near the French border. There were 17 people in attendance from all over Germany, nine people with TM, six caregivers and two children.

In October 2005 our group decided to set up a formal society. We receive financial support from German insurances. They were requiring us to set up a formal society in order for us to continue to receive this support in the future.

Our meeting began with a social hour as people arrived from their long journeys. This gave all of us time to meet and relax before starting our formal meeting. We next began the process of setting up the formal German TM Society. As much of the preparation work had been accomplished before the meeting, we were able to complete our work on the Society in a little more than an hour. Our Committee consists of seven people; a president, a vice president, the secretary, the treasurer and three committee members. I will serve as the first president of the German TM Society.

This part of our meeting was followed by an excellent dinner. We then started our first general meeting of the German TM Society. Our meeting focused on the process of creating more German translations of TM articles. We also talked about how to raise more awareness of TM in Germany, how to support people who email or call for help, and how to manage our internet message forum. We closed our meeting with a discussion about our plans to apply to some of the German health insurances for financial support.

It was a demanding program and we were all pretty tired. We were thrilled that everything went so well and that we were able to complete all of the important items on the agenda. Unfortunately, there was not much time for personal interchange and speaking about our experiences with TM, but our next meeting in autumn will be more relaxed.

One of our members, the secretary of the committee, created a German leaflet for raising awareness and finding new members. Last year we applied for new grants from some health insurances for 2006 and were successful. We have the money for more German translations of articles from the TMA website and for printing our German flyer. All of these translated articles are available at the TMA website. It is our hope that we can help German-speaking peoples with TM and their caregivers attain a more profound understanding about TM.

If you live in Germany, Austria or Switzerland, please get involved in our support group. We are glad about each new member!

Take care!
Ursula

Ursula Mauro
Germany TM Support Group
Neugasse 32
77743 Neuried
phone: 0049-7807-3154
umauro@t-online.de
http://www.myelitis.de

New Support Group in Michigan

Hello, my name is Lynne Myers. I was diagnosed with TM a little over three years ago. For those of you who visit the forums, you are probably familiar with my name. I seem to be on there all the time. I live in south central Michigan in a very small college town; we're talking two whole blocks of town. My husband and I have been married for 27 years and we have two sons who are grown and out on their own (at least for the time being). Prior to becoming ill, I worked as a registered nurse.

Please feel free to contact me anytime. I would love to see Michigan have an active support group up and running. My email address is lynnemyers1@yahoo.com My daytime phone is (269)789-0452.

Wisconsin and Minnesota TM Support Group

Hi! My name is Lynn Seifert. I'm 47 years old. My wife's name is Jodie and we have four children (Erin, Ryan, Emily and Evan), one dog (Hannah) and one cat (Mittens). I live in Pepin, Wisconsin, which is a small town with a population of around 900 on the Mississippi River. I am a barber three days per week and a carpenter three days per week. I was diagnosed with TM about nine years ago. I woke up one morning with both legs asleep from the knees down. Jodie said I was walking like Frankenstein's monster. I was checked at the Mayo Clinic in Rochester, MN, and treated with an IV drip of Solumedrol for three days. It worked but I've been left with decreased sensitivity in my legs from the knees down to my toes. I have the most trouble feeling my toes. I don't always know where my feet are unless I'm looking down while walking and I fatigue easily. My lower legs hurt worse as I tire out, but I am still working.

Just a few months ago Jodie said she found the TMA website on the internet and requested their newsletter. After reading Stephen Miller's article on support groups, I looked for a support group around the Mayo Clinic area in the directory. I could not find one. After much consideration, and many discussions with Jodie (for the first time as I've been unwilling to discuss my situation with anyone until recently), I contacted Mr. Miller to start a support group in my area. He said, "Great! We've needed someone to get this started up there; we don't have support groups in either Minnesota or Wisconsin. Why not do both?"

So, here I am after jumping in feet first and eyes closed, hoping and praying for everyone's patience as I'm learning on the run, so to speak. Mr. Miller asked for my goals, but I don't know as I have any yet as such. I have hopes. I hope to have open lines of communication amongst all of us already diagnosed and those yet to be diagnosed. I hope there are many of us willing to be contacted by those recently diagnosed who need someone to talk to and tell them we are going to be ok. We have all learned to cope, now let's help others. I hope to, at the very least, meet all of you in Minnesota and Wisconsin. I hope to have the knowledge, patience, communication skills, and humor to do this job the justice it deserves. Thank you for this opportunity.

Mr. Lynn Seifert
PO Box 68
Pepin, WI 54759
Home phone: (715)442-5205
Work phone on Thursdays and Fridays: (715)442-5122

I am in the process of setting up email and when it is available, it will be posted on the TMA web site under the link 'support groups.'

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. Transverse Myelitis with SLE (Lupus).
5. Transverse Myelitis with Sarcoidosis;
6. Transverse Myelitis with Sjogren's syndrome
7. Transverse Myelitis 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
Powell OH 43065-8806 USA
ssiegel@myelitis.org

Fundraising and Awareness

Dana's Tennis for the TMA

Hello Everybody! My name is Dana Mathewson and I'm 15 years old. I have had Transverse Myelitis for about four years and I recently did a fundraiser for The Transverse Myelitis Association. It involved one of the things I love most, and that's wheelchair tennis. I have been playing tennis for about two years and I absolutely love it. It's the exact same as regular stand-up tennis except we get two bounces instead of one. We play on the same court, with the same rules, and same point system. It's played worldwide and there are tournaments every three months or so, usually in the California area. I enjoy it so much. I like that tennis is a solo sport, because I am able to see myself improve each time I play. Also, tennis has really helped my self confidence, because it's a sport that you usually play alone, and you really have to work yourself in order to improve, instead of relying on a team. Because I love tennis so much, I decided to have my fundraiser revolve around a tournament I played in this year in May. My fundraiser was a major success and I raised more than 8,400 dollars.

Setting up my fundraiser was really easy and fun! The staff at TMA was incredibly helpful and was with me every step of the way. They set up a website for me, complete with pictures and links, and even set up a way for people to pay with credit cards. They really thought of everything possible in order to make my fundraiser a success. All I had to do was send out emails to my friends and family telling them about my fundraiser and asking them to send me pledges for every game I won or a fixed amount. I was surprised at how quickly people responded to my emails! I got tons of responses the very next day, and continued to receive them for weeks. The

TMA really made my fundraising experience an easy and fun one. After doing this fundraiser, I really feel a sense of pride and I feel honored to be able to raise so much money for such a deserving organization. The TMA does nothing but help others and spread awareness about Transverse Myelitis, and I can't think of another group who deserves the funds more. Overall, fundraising for the TMA was both enjoyable and rewarding, and an experience which I encourage others to experience as well. To start your own fundraiser, just email Sandy Siegel, the president of the TMA, and he'll help you set it up and tell you what you need to do! It's easy and they'll help you every step of the way!

This was my second fundraiser, the first being a "Hop-a-thon," where I would ask people to pledge on how many hops of jump rope I could do each day. If you are thinking about doing your own fundraiser, I suggest having it revolve around something where you are going to be doing something like a sport or some type of competition. It's fun for those that are pledging to your cause to be able to watch your progress and how you are doing in your event. Those are my only words of advice; there are endless ways to raise funds for the TMA. However you do it, it will be greatly appreciated and I can guarantee that you will feel proud of yourself and will be very happy about the fact that you gave back to the community. I know that's how I feel, and it's a great feeling to have.

Maria Raises Awareness and Funds for TM Research in Massachusetts

Leslie Cerio

My daughter, Maria, is eight years old. She was diagnosed with C-2 transverse myelitis at the age of three. Last spring, our approach to TM changed. Until then, TM was essentially a private matter. In an effort to mainstream Maria, we chose not to announce our TM issues. However, more than four years out from Maria's onset, the time finally seemed ripe to start talking about it. Encouraged by a few friends who took our very personal cause to heart, we embarked upon our first fundraising efforts.

I was invited by friends who are members of an organization called the "Mothers Club" to speak at their spring fundraiser, a dinner intended as a ladies night out at the local country club. The highlight of the evening was a fashion show featuring local boutiques and a raffle of gift baskets featuring donations from individuals, as well as local businesses. The "models" were mostly friends and acquaintances (including mothers, fathers and children), as well as my own kids. In the past, this event was a fundraiser for the local food pantry. This would be the first time there would be a guest speaker – me. It was the first time I had ever spoken publicly about TM. I chose to do so for two reasons: first, I believe with every fiber of my being that the outcome of a TM diagnosis can change in my lifetime, in Maria's lifetime, if science is supported; secondly, I wanted to answer any questions in the community about why Maria walks funny and to reveal her as the hero I think that she is. Both reasons, from my perspective, had the prospect of making Maria's life easier.

However, I confess that I probably would never have chosen either this forum (yikes, the country club) or this topic, let alone the publicity, without abundant, overwhelming support from friends. I was reminded of the lesson I learned from the days when Maria was in the hospital: people like to help; it makes them feel good. Even more importantly, I would not have gone public with TM without Maria's endorsement. And while I debated whether Maria and TM should be featured in a newspaper article, Maria saw the issue clearly: "Maybe if someone else is sick, even a grown-up, they'll realize they're not alone," she told me. While I had long debated the other question, what kind of fundraiser would be an appropriate kick-off to TM awareness, Maria immediately appreciated the fashion element of our event. She is, after all, the same child who required her neurologists to do rounds wearing a leopard or cheetah accessory. (In my house of three girls, the leopard phase is starting to fade now, only somewhat.)

In addition to the fashion show, friends organized a "Transverse Myelitis Awareness Week" at Maria's school. This week's events featured a raffle of donated toys, gift certificates and computer games. The principal of the school also spoke on the school TV about our cause and gave the children who were appearing in the fashion show an opportunity to speak about their efforts. The week culminated in a sale of TM wristbands. Maria and her older sister, Gabriella, came home reporting long lines of kids and teachers alike who wanted to purchase the wristbands.

So how did it all end, you might ask? Two hundred fifty women attended the fashion show – a record for this event. Maria was the first to strut down the catwalk, blowing kisses to all in the room. Our synchronized events raised about $5,000. I didn't cry during my speech or the accompanying slideshow depicting Maria in the medieval hospital wheelchair and then, four years later, climbing monkey bars. And I learned again that it takes a village….

The Cure Task Force: 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. As you have likely read in previous newsletters and the journal, the ACP study is focused on finding the causes and cures for ADEM, NMO, ON, MS, and TM.

We have had some really excellent people come forward to do this important work. We need for more people to get involved. We need for you to get involved!

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:

(781)740-8421
lccerio@aol.com

(614)766-1806
ssiegel@myelitis.org

Collectively, we can make a difference for ourselves and for each other. 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!

In addition to funding the ACP study, the TMA will continue to fund TM research, such as the work that is being done by the Johns Hopkins TM Center and Project RESTORE. Your support will help us to fund all of this work and will also help us to motivate other researchers and medical centers to enter our important area of study!

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, MS and ON.

The Christmas Card Campaign: Help Us Fund the Accelerated Cure Project

The TMA is partnering with the Accelerated Cure Project to study the causes of the neuroimmunologic disorders, including TM, MS, NMO and ADEM. TMA newsletters and the journal have provided you with information about the study and what we are trying to accomplish in the way of research and clinical care from a medical center network. In this newsletter we are asking for you to volunteer to participate in this important study. The ACP research will find the causes of these disorders, and by doing so, will provide a foundation for developing acute therapies to stop the attacks, for designing diagnostic tools, and for finding cures for these disorders.

We need your help to make this project a success! To enter one person into the study with TM, NMO or ADEM will cost approximately $2,500. We are going to need thousands of people with these disorders entered into the study in order to achieve meaningful results. There are significant costs associated with this work, because the study involves the collection of comprehensive medical information through a long survey and also the handling of samples from a blood draw. The ACP requires an extensive infrastructure, which includes the companies who are managing the databases of medical information and the blood samples (repository). Each of the medical centers in the network also has a research coordinator. The costs of doing medical research are significant. We all intimately understand what the costs are of not performing this research.

This critically important work needs to be done, and we are all going to need to get involved in order to make it happen. The most successful fundraising activities we engage in are those that focus on our friends and family members.

If we are going to raise this money, the vast majority of it is going to come from you and from your friends and family. Why? Because they are the only people in the universe who know about these conditions and they are really the only people who care! I am not comfortable asking my family for money. I am less comfortable asking my friends for money. I am no different than you. But I have learned to do it, because I have come to accept that this is the only way I can make the difference for Pauline and the so many others of you whom I have come to love and care about so deeply.

I have an idea which I think might make this easier for you to accomplish. I have written a letter and have posted it on our web site. I have included important information about TM and the neuroimmunologic disorders, about the TMA, and why it is important for the TMA to succeed in raising money for research. The letter is created in Word. Since most people have MSWord on their computers, I am encouraging you to personalize this let-

ter. Please include information about how TM or ADEM or NMO have impacted your lives, and why you need for this research to be done.

When you send Christmas cards this year, and every year, please include a copy of this letter in your card. Just fold it and put it into the card. And, if you don't celebrate Christmas, you can include the letter with any regular correspondence you have with your family and friends.

Please type the following address into your web browser to find the fundraising letter. http://www.myelitis.org/fundraisingletter.htm

Scroll down to the bottom of the page to find the link to this letter in Word. Once you have the Word file open, you will be able to edit the text to personalize the letter for your family and friends. If you do not own a computer or have internet access, please have a friend or family member print the letter for you.

In addition to funding the ACP study, the TMA will continue to fund TM research, such as the work that is being done by the Johns Hopkins TM Center and Project RESTORE. Do it for yourselves and do it for the other children and adults in your community who need this research and the great hope that this research brings for all of us.

The cost of adding this letter to your cards will be minimal. The amount of time and energy involved in sending this letter with your cards will be minimal. **The positive impact of sending this letter in your cards can be enormous – for you and for everyone in our community!**

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 our fundraising efforts.

Donate your cell phones
You can donate your 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: www.myelitis.org/wristbands.htm You can also order the wristbands by sending an email to: wristbands@myelitis.org or call (937)453-9832.

Online Shopping
There are numerous online shopping opportunities through the following link: www.myelitis.org/store.htm A percentage of the sales are donated to the TMA.

iGive.com You can shop at more than 650 stores through iGive.com. You can find books, CDs, videos, software, office supplies, groceries, gifts, flowers, cookware, greeting cards and more at the iGive Mall and from top merchants like Barnes & Noble, Drugstore.com, Harry and David, Best Buy, Sharper Image and Dell.

Café Press You can purchase TMA logo items through Café Press.

Amazon.com You can shop at Amazon.com for Books, Music, DVDs, Videos, Toys and more.

eBay
Now you can sell an item on eBay and donate from 10% to 100% of the final sale price to help support the TMA.

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: 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

Donations
We always welcome and are grateful for a donation to the TMA. You can download a donation form to include with your check from the link: www.myelitis.org/donation-form.htm

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

Thank you!

2006 Rare Neuroimmunologic Disorders Symposium on DVD

The 2006 Rare Neuroimmunologic Disorders Symposium was held in Baltimore from July 19th to July 23rd. Both the clinical and science programs were excellent. The leading scientists and clinicians in the neuroimmunologic field attended from around the world. A summary of the presentations from the science program may be found on our web site under the link 'symposia and workshops.' The clinical program was comprehensive and thorough in its treatment of the neuroimmunologic disorders. Presentations covered everything from descriptions of each of the disorders, to acute therapies, to the most up-to-date management strategies for each of the symptoms of these disorders to rehabilitation strategies to restorative therapies.

You can become the most effective advocate for your medical care by educating yourself about your condition. Attending the symposium in Baltimore is one of the best ways to receive this education. We know that travel logistics and the cost make it difficult for everyone to attend. The TMA is committed to making this critical information available to everyone. You can access the presentations as streaming video from our web site under the link 'symposia and workshops.' Look for the 2006 symposium. We also highly recommend viewing the presentations from the 2004 and 2001 symposia and the pediatric presentations from the children's workshop in 2002.

You can also order the 2006 symposium presentations as DVDs. You can buy the DVDs individually for $8 or you can purchase the entire clinical symposium for $80. The shipping and handling charges are an additional $6. Chris and Michelle Powell from Tullyvision are kind enough to handle these orders for us, and have worked hard to reduce the cost of the DVDs. The TMA does not make any profit on these sales; our goal is to get this information to as many people as possible.

You will find the order form included in this newsletter. You can also find the order form posted on our web site under the 'symposia and workshops' link. You can fax, email or mail the order form to Tullyvision using the contact information provided on the form. Payment information is also described on the order form. We are grateful to Chris and Michelle for making this information available to our membership. 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!

Learning about TM and the other neuroimmunologic disorders: Bibliography and Videos on www.myelitis.org

For those of you trying to learn about Transverse Myelitis, Chitra Krishnan has compiled an excellent bibliography about TM. Chitra serves on the TMA Medical Advisory Board, is the Executive Director of Project RESTORE and is the Research Coordinator at the Johns Hopkins TM Center.

You can find the bibliography by typing this address into your web browser:
http://www.myelitis.org/Bibliography.htm

Jim has created links from the articles in the bibliography to Medline; so when you click on the article citation, you can easily get to a copy of the article to read. Additionally, when you are in Medline, you can link to other recently published articles by clicking on the authors' hotlinks.

Another tremendous resource about TM and the other neuroimmunologic disorders is the streaming video that Jim has posted on the web site. The presentations from the 2001 and 2004 symposia and from the 2002 children's workshop are available under the link 'Symposia and Workshop Information' or by typing http://www.myelitis.org/events.htm into your web browser. Jim has the presentations organized as they appeared in each of these symposia and workshop program agendas. You can also find PDF files of the handouts and Power-

Point presentations. The video presentations are also available by going through the Multimedia link from our main web page or by typing http://www.myelitis.org/multimedia.htm into your web browser. The streaming video from the 2006 International Rare Neuroimmunologic Disorders Symposium should be available through these links within the next few months.

The TMA Newsletter and Journal Archives

The TMA announced a new publication schedule and format for our newsletters and journals. A newsletter will be published each fall and spring, and a more extensive journal will be published in January of each year. When people sign up for membership in the TMA, they receive a packet of information which contains the most recently published TMA Journal. The newsletters are not included in the new membership packets.

We encourage people to read the previously published newsletters and journals. They are an excellent source of information about the neuroimmunologic disorders, both through articles written by medical professionals and by people with these disorders and their family members, which describe their personal experiences. Through these publications, you can also learn about research and clinical trials, the TMA, awareness and fundraising efforts, and the support groups around the country and around the world.

All of the newsletters and journals are archived on our web site; you can find them under the link 'newsletters' on the main page of our web site or you can type www.myelitis.org/newsletters/index.html into your web browser. You can view the newsletters and journals as they were published by selecting the PDF files from the column on the right, or you can view them in html format from the column on the left. The html files include an index which makes it very easy to find articles covering specific subjects. Additionally, Jim has installed a search engine for the entire TMA web site, which allows searching for specific subjects. Topics may be searched in the newsletters and journals by using the search engine.

If you have difficulty in finding information about any topic on our web site, and the search engine does not provide you with the results you were seeking, you should always feel free to contact Jim for assistance. You can send Jim a question or a request for help at jlubin@myelitis.org

Medical Advisory Board

Gregory N. Barnes, M.D., Ph.D.
Vanderbilt University
Nashville, TN

James D. Bowen, M.D.
MS Center at Evergreen
Kirkland, WA

Benjamin M. Greenberg, MD, MHS
Johns Hopkins Hospital
Baltimore, MD

Dr. Adam I. Kaplin, M.D., Ph.D.
Johns Hopkins Hospital
Baltimore, MD

Douglas A. Kerr, M.D., Ph.D.
Johns Hopkins Hospital
Baltimore, MD

Chitra Krishnan, M.H.S.
Johns Hopkins Hospital
Baltimore, MD

Charles E. Levy, M.D.
North Florida/South Georgia Veterans Health Service
University of Florida
Gainesville, FL

D. Joanne Lynn, M.D.
The Ohio State University
Columbus, OH

Frank S. Pidcock, M.D.
Kennedy Krieger Institute
Baltimore MD

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. 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. 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!

The Transverse Myelitis Association is proud to be a source of information about Transverse Myelitis and the other neuroimmunologic disorders. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician. The Transverse Myelitis Association does not endorse products, services or manufacturers. Such names appear in this publication solely because they are considered valuable information. The Transverse Myelitis Association assumes no liability whatsoever for the contents or use of any product or service mentioned.

Officers and Board of Directors of The Transverse Myelitis Association

Sanford J. Siegel
President
1787 Sutter Parkway
Powell OH 43065-8806
(614)766-1806
ssiegel@myelitis.org

Stephen J. Miller
Vice President
1717 State Route 72 South
Jamestown OH 45335
(937)453-9832
smiller@myelitis.org

Paula Lazzeri
Treasurer
10105 167th Place NE
Redmond WA 98052
(425)883-7914
plazzeri@myelitis.org

Deborah Capen
Secretary
PO Box 5277
Hemet CA 92544
(951)658-2689
dcapen@myelitis.org

Jim Lubin
Information Technology
Director
jlubin@myelitis.org

Honorary Board of Directors

Deanne Gilmur
Founder
3548 Tahoma Place W
Tacoma WA 98466
(253)565-8156

www.myelitis.org

CHANGE SERVICE REQUESTED

The Transverse Myelitis Association
Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065-8806

NONPROFIT ORG
U.S. POSTAGE PAID
POWELL, OH
PERMIT NO. 6
ZIP CODE 43065