

THE TRANSVERSE MYELITIS ASSOCIATION JOURNAL

...advocating for those with acute disseminated encephalomyelitis,
neuromyelitis optica, optic neuritis and transverse myelitis

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THE EDITOR'S LETTER

Sandy Siegel, PhD



Dear Readers,

If you've recently made a donation to the TMA, we are grateful, and we are asking you to make us a regular part of your generous giving. If you have never made a donation to the TMA, we are asking you to please begin supporting this organization, and to regularly support our efforts. If you have friends and family who can help, please let them know how the TMA has helped you and ask them for their support. No matter what you are able to afford, we need your support. And if you are unable to support us financially, we are asking for you to volunteer your time. There are many different ways that you can help



us. Your help and your support will ensure that we continue to exist and that we are able to continue the work we are engaged in to help our community.

The most important decision we made as The Transverse Myelitis Association was to professionalize our organization. Geoff Treglown made that a possibility for us with his amazingly generous contribution. For some people, when they think about what this means for us, paying people to do the work is going to be what comes to mind most readily. And that is why this is the focus of my column, because that really isn't what is most significant about this decision. The TMA has truly gone through a dramatic transformation. I could spend an entire journal describing for you the work that has been accomplished this year to create the foundations for moving us from a small, all-volunteer operation to a professional organization. I'll spare you ... but please take my word for it that the amount of effort and time and complex work has been truly staggering.

That our organization has dramatically changed is so evident to me, because I live with the TMA every single day. I am confident that these changes are going to become very apparent to you, as well, if they have not already done so. And I am equally confident that these actions are going to change the future quality of life for the members of our community.

We are very proud of our achievements over the past 18 years; our web site, the support network, the TM and NMO Centers, our publications, the family camps, our symposia ... we have done a lot to help the community over this time. But there was only so much we could get done with our limited resources; and I am talking about much more than money when I refer to resources. We had a way of looking at our work which was limited by our experience and skills. Professionalizing the TMA, and more specifically, bringing Chitra Krishnan in to be our Executive Director and to lead our organization, has and will move the organization into directions and accomplishments that go so far beyond what we could have possibly imagined.

What does this mean for you? I have every expectation that from the programs and initiatives that Chitra is planning and putting into place as I am writing this that the following results will be achieved. We are going to attract more physicians and researchers into our discipline; there will be more specialists in TM and NMO and we will hopefully attract our first specialist in ADEM. There will be more research in these disorders and there will be movement in the direction of multi-centered studies, including research on the most effective acute therapies. We will focus on making sure that research is conducted on restorative therapies, so that no matter whether you've had one of these disorders for one year or for twenty years, there is hope for you that some recovery will be possible. We will make dramatic improvements in the way clinical care is made available in our community. We will expand and intensify our education efforts such that there is a wider and deeper understanding of these disorders for patients and their families and in the medical community. We will also more effectively engage our community such that all of you become much more active participants in educating physicians and researchers about the rare neuroimmunologic disorders. We are also going to make it possible for the people in our community to more actively engage in offering guidance and support to people who need this help and in ways that no one else is able to offer because of your experiences. The changes are dramatic; you will be watching them happen, not ten years from now, but now and tomorrow. And I am so hopeful that you will be able to derive the direct benefits from this work. And our concerns and focus are not about our members in the United States. We have the same concerns for our community in Bangladesh as we do in Birmingham. We think about and strategize about how to extend our reach and our influence as a part of everything we do.

The creativity, expansion, intensification and acceleration of this work is going to have to be matched by an expansion of support from our community in a manner that we haven't seen in the past. Make no mistake about it; this editorial column is a call to critical action. We are going to need a much greater and regular level of support from our community. None



of what we have planned is going to happen without that support. Our organization continues to grow. We currently have well over 9,000 members from across the globe. For most years, our donations are made by about 500 people per year. The TMA will cease to exist if we can't make the case to all of our members that their support is needed to fund our mission and our efforts. If you or a family member has ADEM, NMO, ON or TM, we need your regular support. No one else is going to do this for us. I've been at this for about 18 years, and I've learned that while the general public might be interested in a story about one of our children for about ten minutes after reading an article or watching a piece on the local news, the words "acute disseminated encephalomyelitis" go in one ear and out the other, and they go back to focusing on their own issues. No one understands or cares about our issues; it is us or no one. Please don't look over your shoulders for where help is going to come from; we all have to look in the mirror.

For the first time in 18 years, I can say to you that the TMA has a future. Why was I unable to say that before? If something happened to Jim, Debbie or I, we had no idea whether anyone would step up to take over this work. That possibility did not seem promising. If you look at the history of volunteer not for profits, what you will find is that they generally have very short histories. It is remarkable that we were able to sustain the organization and the work for as long as we did, but we knew that we had a shelf life. From my rate of cell decay, I'm acutely aware that I have more years behind me than ahead of me. As a full-fledged baby boomer, my ultimate demise still comes as a total shock. While professionalizing has offered us a future, what has really created the great opportunity for us is Chitra's acceptance of the Executive Director Position.

A few years ago, I was at a family camp with a small group of physicians who are the core of our medical community. These physicians have a clinical and research interest, but most importantly, they have developed an intense emotional connection to our community. They want for us to succeed as much as I do, because they understand how critical our mission is to people who have these disorders. From this deep

emotional connection, they have been working with me to develop a strategy for us to not just continue to exist, but for us to flourish and create the programs for our community that can make a profound difference in our member's lives. During this conversation, they gave me a to-do list of what I needed to accomplish to ensure that the TMA would develop to achieve our ultimate goals. At the top of the list was to attract Chitra into the executive director position.

I had been hounding Chitra for years about taking on the executive director job. For many reasons, it was just not the right time for her. Our stars all finally aligned, and Chitra very enthusiastically accepted the offer that was made to her. Chitra is the game changer for us.

I wrote extensively about Chitra in our last journal, so I am not going to repeat all of the qualifications that Chitra brings to this job. If the executive director would have been anyone other than Chitra, we would have spent the last year training this person, teaching them about the disorders, explaining how our organization worked and then hoping that this person would develop an emotional connection to our community and a passion for the work. We spent the last year doing none of this; Chitra came prepackaged and more than totally prepared for this position. My job has been to support Chitra's efforts and to assist her in doing all of the incredibly complex work to meet our professional, legal, regulatory and financial obligations.

Chitra's education and experience are in biology and public health. She was a Research Associate at the TM Center and continues to be an adjunct faculty member at Johns Hopkins. She helped to found, organize and run Project RESTORE as its first executive director. She played a fundamental role in organizing and planning all of the science and clinical symposia that were coordinated between the TM Center and the TMA. Chitra was a researcher and is an author on more publications about TM than likely any other person, beside Dr. Douglas Kerr. Chitra knows all of the clinicians and researchers very well from our community, because she either worked with them



directly or she was involved in their work through the scientific and medical community. Chitra has a great deal of experience working with government health agencies and also working with foundations that support medical research and other health efforts. Chitra also has extensive experience in the not for profit and health organization community through her work at Ashoka. There is absolutely no one who would come into this position with the qualifications, background, character, knowledge, and passion as does Chitra. This fact is at the forefront of my mind every single day. And I need for it to be in your thoughts, as well. We will not get another Chitra. We need to make this work for Chitra, and we need to get her to a place where she can hire and train others to do this work as she is doing it and will continue to do it into the future ... with our support.

I am so grateful that there is a TMA. If you had an attack this past year from any one of these disorders and are recently diagnosed, I know that you understand why I am grateful. I have no doubt that the information you have received from us helped you to understand what was going on with you or your loved one and also helped you advocate for your medical care. If you have attended our family camps or symposia, I know that you understand the source of my gratitude. If you regularly participate in our support networking, I also know that you understand my feelings. For those people who have NMO or recurrent TM or recurrent ADEM or have one of the rheumatic disorders associated with their TM or NMO, I know that they are acutely aware of our purpose, because their disorders are, so unfortunately, a part of their lives and at the surface of their thinking and concerns daily.

I am going to explain to you the source of my gratitude; as the husband of a person who was diagnosed with idiopathic or acute TM in 1994 – 18 years ago. For many people who have an ADEM or TM diagnosis who have gone for years without a new attack, people's lives go on and in some ways, people don't think much about what it is that happened to them years ago. If a person is paralyzed, the cause at some point in time can become irrelevant. Whether from an inflammatory attack, a spinal tumor, a stroke or

a car accident, the results can be very similar; loss of motor function, spasticity, bowel, bladder and sexual dysfunction, and the other symptoms that arise from spinal cord damage.

What I have learned from my 18 years of experience with Pauline and with thousands of other people with these disorders is that the damage caused by the inflammatory attack is not the same as the damage caused by a trauma. Pauline's symptoms are not a monotone. In my way of thinking about the damage caused by a demyelinating attack, the damage as compared to a trauma where the cord might actually be severed can be less severe but in some ways much more complicated. For many people with TM or ADEM or NMO, there remain signals going between the spinal cord and the brain, but those signals can be dysfunctional in many complicated ways depending on which motor or sensory nerves were impacted. The disorder might be called transverse myelitis, but in fact, the damage is rarely across the entire cord, it is rather from within the cord, and in what looks to an anthropologist as a somewhat random pattern. It is rare for a person with TM or NMO or ADEM to lose complete motor function or complete sensation below the attack. I am grateful that we have physicians and researchers who are focused on these rare demyelinating disorders and who think about how the damage is caused, and how the damage might be repaired or function restored. And this is critically important to keep in mind. While researchers who are focused on traumatic spinal injuries might develop medications or procedures that could have a corollary benefit for a person with a demyelinating disorder, their clinical trials will almost certainly not include people with demyelinating disorders, and people from our community will not be on the top of their list for receiving treatment should one be developed.

There are changes in Pauline's symptoms all the time, and it is hard to keep up with all of the possibilities that could account for these changes. Some days her bladder works fairly well, and other days it hardly works at all. Some days her nerve pain is manageable and there are times when she is awake all night because of the severity of her pain. She has a cold, symptoms



change, the weather gets cold, her symptoms change, she has tons of stress at work, and her symptoms change, I do something that annoys her, her symptoms change. It is imperative that the medical community develop a better understanding of why these changes occur and to find ways to alleviate the severe symptoms that occur in people and can cause such devastating suffering.

There has been a lot of research done on traumatic spinal cord injury. There has been no research done on treatments or rehabilitation in any of these disorders. We really do not have any scientific evidence upon which to base the treatment of any of these symptoms. There hasn't been a single study or clinical trial for any treatment or any drug to treat symptoms in ADEM, NMO or TM. We don't know if a person would do better on one drug as opposed to another, because the studies have never been done. If you have one of these disorders, your rehabilitation is going to precisely mirror the therapies used for a person with a traumatic spinal cord injury. Is it appropriate to treat a person with a demyelinating disorder precisely as one would a traumatic spinal cord injury patient? I don't know. And rehabilitation medicine does not know the answer to that question either, because there has not been a single study to demonstrate that these therapies are effective for demyelinating disorders.

The TMA is going to play a critical role in ensuring that the research that needs to be done is going to get done. We are creating all of the strategies and we are developing the infrastructure to make all of this research possible. Chitra works on these issues every single day. The fellowship program will attract more clinicians and researchers into the discipline. We are supporting the TM and NMO Centers and will work to expand these centers so that there are more of them across the country and around the world. We will encourage and facilitate multi-centered studies. And we will raise money to support this research. The pharmaceutical companies are not doing any research on TM or ADEM. The major government agencies that fund medical research, such as the NIH and the CDC, are not supporting any research on ADEM, NMO or TM. If there is going to be research on

ADEM or TM, it is fairly obvious to me that it will only happen because the TMA raises the money to support this research. The TMA needs to exist and we need to flourish.

Pauline experienced a significant setback about a year and half ago that reminded me, again, why I am so grateful that we have a Transverse Myelitis Association. Last summer Pauline was working in the garden. She was on the ground planting flowers and she was bitten by some small insects. By the time she got back into the house, she had some ugly red welts on her legs that appeared as though she had some kind of allergic reaction to the bites. A few days after she experienced this reaction, she lost almost all motor function below her waist. The inflammatory attack Pauline had 18 years ago caused her to lose all motor function below her waist and caused sensory dysfunction and left Pauline with significant bowel and bladder issues. Over a period of about 18 months to two years, she recovered to be able to walk with two canes. She could walk around our house without her canes. She would fall periodically, but she was walking. After the allergic reaction, Pauline could barely move her legs or stand, even with her canes. And she lost bladder function.

Pauline's neurologist ran all of the tests to rule out a new inflammatory attack and to also rule out that there was any peripheral nerve damage. She also ruled out that there was any kind of infection that might explain the significant worsening of symptoms. Over the past year, Pauline has recovered some motor strength but she has definitely lost function from whatever happened last summer. She can no longer walk without her canes, she has lost significant motor strength, and she is spending more time in her chair outside of the house. We have no idea what happened. We have discussed her experience with all of her physicians, including all of the doctors who are associated with the TMA. They have their notions, but they don't have a definitive answer. Pauline is definitely not the only person who has had this kind of experience; I hear about it on the phone periodically. These kinds of experiences also make me wonder about what happens to a person who has had myelin and nerve damage in their spinal cord or brain or optic nerve and then goes through



the aging process. What happens to all of this damage while a person ages? There are just so many horrible mysteries that remain about these disorders. But I am grateful every day that there is a TMA – because without it, who would ask why and what chance would we possibly have to finding the answers.

I don't want to scare people. Believe me, I wish everyone recovery or stability and the highest possible quality of life. If I didn't want that for Pauline and for everyone else, I sure wouldn't be involved in doing this work. That is what drives me every single day to pick up the phone or to respond to the emails or to sit at my computer to do this writing. But I know that these disorders cause problems for people and those problems don't end after the first two years from the attack. And so unfortunately, for the recurrent variants of these disorders, the problems are at every turn. We have so much important work in front of us.

There is another critically important reason we need to exist. Sometime this week, it is very likely that a 6 month old child is going to experience an inflammatory attack in their spinal cord. They might go to bed the night before totally happy and healthy ... by morning, they are going to be paralyzed, likely from the neck down, because in the very young children, the attacks tend to be high on the cord, and severe, and impact everything. What are the best therapies for this child to ensure that the attack is arrested as quickly as possible? We don't know. What are the most effective restorative therapies for this child in order to give him or her the best chance to move or to walk or to breathe on their own? We don't know. That we don't know is totally unacceptable to me. That we don't know why this happens to people is unacceptable to me. We have no idea what causes the immune system to attack the central nervous system. It is too late for Pauline. Knowing the best acute therapy or the best rehabilitation practices after an attack won't have a significant impact on Pauline's quality of life. But if Pauline doesn't care about these answers and if she doesn't care about this child, then no one is going to care about this child. Why? Because if our community isn't concerned about finding these answers, who will? The only people who care about ADEM, NMO, ON

and TM are the people who have these disorders, their families and close friends and the handful of doctors around the country who specialize in these disorders. Not only does the rest of the world not care, they've never heard of these disorders. Why would they care; there is a greater chance that they are going to get hit by a truck than have their immune system attack myelin in their spinal cord.

We have to pay it forward! We are the ones who have to care for this child and for all of the people in the future who are going to have one of these horrible attacks.

The Transverse Myelitis Association has to continue to exist and we have to be supported to achieve the critical goals that we have before us. We need for everyone to be involved in this support. If you can afford to help us with substantial support, we are grateful for that support. If you can only give a little, we are going to be equally grateful for that support. We need for everyone to be involved in supporting this effort. If only 500 people out of our 9,000 plus membership are willing to support us, as has been the case for us in the past, this effort will not succeed. That is the sad fact. And we won't go back to being an all-volunteer organization. We just can't sustain the TMA in that fashion and there just isn't a way to achieve our goals with that approach. If you can give, we are asking you to make us a part of your regular giving. And if you have skills to help us in our effort, please get involved. We need for people who have skills in database work or programming or writers or fundraisers, or bloggers or people with clerical and administrative skills to come forward to offer your experience and talents to the TMA. We need your help!

I need for this organization to succeed for Pauline; I need for it to succeed for all of you. Please help me to make that happen. Please do what you can. We can make a difference for each of you. I believe that in my heart of hearts. But we can only do this work and accomplish our goals if you help us make it possible with your regular support.

Thank you! Thank you for reading my words and



thank you for thinking about my request for your help. I want the best for Pauline and I want the very best for all of you. Please help me to make that happen.

Pauline and I would like to wish all of you a wonderful new year, filled with GOOD HEALTH, happiness and peace. Please take care of yourselves and each other.

ANNOUNCING A PODCAST WITH DR. BENJAMIN GREENBERG AND DR. ALLEN DESENA

The Transverse Myelitis Association is proud to announce our collaboration with Rare Genomics Institute, for an upcoming Podcast Series, Ask the Experts. Rare Genomics Institute (RGI) is a non-profit organization that gives families afflicted by rare genetic disorders access to genome sequencing and expert analysis. RGI helps patients with orphan diseases initiate and fund personalized research projects through a dedicated crowd-funding platform and a highly selective network of leading academic scientists and commercial institutions across the globe.

Our first Ask the Expert Podcast featuring Drs. Benjamin Greenberg and Allen DeSena from the University of Texas Southwestern in Dallas, moderated by RGI's president, Dr. Jimmy Lin will be held on February 7, 2013 at 7 pm EST.

The podcast will begin with a 30 minute discussion of recent developments in technology applicable to rare diseases. We will feature two mouse-modeling experts who will discuss how mice are used in scientific research. Specifically, the discussion will help us better understand how scientists develop mouse models and how they can be used to advance research for rare diseases.

This will be followed by a discussion focused on the management of symptoms that affect individuals who have been diagnosed with the rare neuro-immunological disorders (Transverse Myelitis, Acute

Disseminated Encephalomyelitis, Optic Neuritis and Neuromyelitis Optica). There will also be an opportunity for you to submit questions prior to the call and live via social media.

Please check our website <http://www.myelitis.org> for more details to join the live conference call and submit your questions. If you are unable to join the live discussion, look for our downloadable version (both text and audio versions) to be available shortly after the podcast.

WE DON'T WANT TO LOSE YOU

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes via email at info@myelitis.org.

For those that wish to receive our communications by postal mail: the Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates. We save a considerable amount of money by doing our mailings in this fashion. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you, after your grace period, and this class of mail is not returned to the sender. The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current.

Your diligence is greatly appreciated.



TM AND COGNITIVE FUNCTIONING

Lana Harder, , PhD, ABPP

Transverse myelitis (TM) has been traditionally thought of as a condition that only affects the spinal cord, causing numbness, weakness, walking difficulty, bowel/bladder dysfunction and sometimes pain. Children affected by this condition often need accommodations at school based on physical limitations. These accommodations are required under federal law for individuals with disabilities and are necessary for such children to fully participate in the academic environment.

While cognitive problems in pediatric TM have been reported anecdotally, until now, these have not been systematically investigated. Along with my colleagues at the Transverse Myelitis Clinic located at the Children's Medical Center of Dallas and University of Texas Southwestern Medical Center, we have recently published the first paper describing cognitive functioning in 24 pediatric patients between the ages of 5 and 18 diagnosed with idiopathic TM in the Multiple Sclerosis Journal. The average age of the children in the study was about 9.67 years and the children we enrolled in this study had normal brain MRIs. All children with TM were administered a neuropsychological battery and were assessed for emotional functioning, symptoms of fatigue, mobility and school performance. Although, as a group, scores generally fell within the average range, performance varied widely within specific domains of functions. Our study results suggest that in addition to fine-motor problems, children diagnosed with TM also exhibit difficulties in attention (in 40.9% of the study participants) and memory (in 33% of the study participants) and to a lesser extent, in the areas of processing speed and verbal fluency. About 30% of the parents also validated sub-clinical attention problems on standardized rating. Table 1 provides details on skill areas tested and percentage of TM patients who had problems in each domain.

Do medication, mood, and/or fatigue play a role?

Given their potential impact on cognitive functioning,

Table 1: Percentage of TM Patients with Cognitive Problems

Skill Area	Percentage
Paper/Pencil Coordination	28.60
Visual Perception	4.50
Fine-Motor Coordination	
Dominant Hand	40.90
Non-dominant Hand	45.50
Auditory Attention	40.90
Processing Speed	20.00
Verbal Fluency	25.00
Simple Attention	5.60
Complex Attention	11.10
Motor-Free Processing Speed	10.00
Verbal Memory	29.20
Recognition Memory	25.00

medication use, emotional functioning, and fatigue symptoms were examined. Approximately 46% of the children with TM were on some type of medication. Notably, 30% percent experienced at least some degree of symptoms associated with depression. Elevated symptoms of fatigue were common and were reported by both the children and their parents. Of note, however, the data suggested that neither medication nor mood played a role in cognitive functioning. Data suggests, however, that fatigue may play an important role in cognitive functioning. Additional studies are needed to explore these variables in more depth. Such information provides important information for determining targeted treatment. This research also highlights the need for comprehensive evaluations and care for children affected by TM.

What are the implications?

Overall, although a small retrospective study, these findings have important implications for daily functioning particularly in the area of school functioning. Indeed, we found that 33% of patients in this cohort experienced school problems at the time they were evaluated. Where historically, cognitive testing is generally only thought to be indicated



when there is obvious brain involvement, this study sheds light on the need for such testing in rare neuro-immunologic diseases such as TM that affect the spinal cord.

Given the cognitive problems observed in TM, educational support services to address cognitive problems in the classroom are likely to be beneficial to these affected students. Examples of such services include extended time for exams, seating near the front of the classroom to reduce distractions, specific memory strategies to enhance learning, use of lists and a planner to maximize memory for assignments and other daily activities, note-taking assistance to address fine-motor skills weaknesses, the ability to dictate responses or long writing assignments, and frequent breaks during homework or class work to address fatigue and attention difficulties.

We hope that our work helps lay the foundation for larger prospective studies examining cognitive functioning in TM and that we can learn more about the role of central nervous system (CNS) inflammation on cognition and be able to systematically help families of children with these rare disorders.

If you suspect that your son or daughter with TM or other CNS demyelinating disease may be experiencing cognitive problems (e.g., difficulty paying attention, memory problems, etc.) and/or general difficulty with school performance (e.g., learning problems, declining grades, etc.), it is recommended that you consult with your physician regarding a referral for neuropsychological testing. It may be useful to mention this recently published study as a rationale for such an evaluation.

DON'T LET HIPAA PREVENT LOVED ONES FROM HELPING

HIPAA is the Health Insurance Portability and Accountability Act, a law to protect your private health information. While the law protects the privacy of your medical information, it can prevent a loved one

from seeing your medical records to help you out. So what can you do to make sure this does not happen? You need to authorize people you will rely on to have access to your medical information. There are two key ways to do this:

Health Proxy – This healthcare proxy document that appoints an agent to make healthcare decisions for you should have HIPAA language. If you don't see mention of HIPAA, it doesn't have this and you need to revise it.

HIPAA Release – This is a special document that merely authorizes a person to see your medical records. HIPAA release is a simple and short one- or two-page document that authorizes someone to see your medical information.

So, plan for the unexpected. When you need a loved one to be able to monitor your care you will be glad you did. For a consumer-friendly version of the HIPAA law, go to <http://www.hhs.gov/ocr/privacy>.

IN THEIR OWN WORDS ARTICLES

In each issue of the Journal, we will bring you a column that presents the experiences of our members. The stories are presented In Their Own Words by way of letters we receive from members like you. We are most appreciative of the willingness to share very personal stories. It is our hope that through the sharing of these experiences, we will all learn something about each other and about ourselves. It is our hope that the stories will help us all realize that we are not alone. It is important to bear in mind that the stories are not written by The Transverse Myelitis Association but come from our members. It is also important to note that the newsletters and journals are archived on our web site. Should someone do an Internet search of your name, your article is likely to be identified in his or her search results. You may submit your stories by sending them either by email or through the postal service to Sandy Siegel. Please be sure to clearly state that The Transverse Myelitis Association has your permission to publish your article.



A LETTER FROM DR. ALLEN DESENA, JAMES T. LUBIN FELLOW

Allen DeSena, MD

Greetings Members and Friends of The Transverse Myelitis Association!

I began my fellowship in July 2012 as the first recipient of the TMA's James T. Lubin Fellow focused on Rare Neuro-immunologic Disorders. The beginning of the academic year was unusually busy. My fellowship has two principal components – advanced clinical training and research. I am a member of a large team at the University of Texas Southwestern Medical Center and Children's Medical Center of Dallas and work closely with Drs. Greenberg, Graves and Harder.

Through July and August, we received an average of about 4 new patients per week at the Children's Medical Center of Dallas for TM and other neuro-immunologic disorders, specifically ADEM, pediatric MS, and autoimmune encephalitis. By the time the first three months of my fellowship were complete, I had seen more cases of neuro-immunologic disorders than many practicing neurologists! Dr. Greenberg, Dr. Graves and myself could not recall a summer and fall as busy as 2012.

In the outpatient setting, we have been having full clinics 2-3 times per month at Children's. We have had to add some new clinics just to keep up with the demand. We have had some great successes! One little girl with ADEM experienced swelling extending throughout her spinal cord and her entire brainstem. She was in a coma for several days. She was treated with steroids and plasma exchange and aggressive inpatient rehabilitation. We were thrilled to see her walk into our clinic about one month after discharge. She and her family worked very hard to achieve great success.

On the research side, we are preparing for a clinical trial comparing plasma exchange to IVIG in patients treated for acute TM or ADEM. We have 2 research papers about to be submitted that are in the final revision stages. The first is a retrospective review of idiopathic TM cases over the past 5-6 years, looking

specifically at response to various therapies. Our second paper is a case series reviewing an unusual variant of TM we are witnessing in children. In this TM "variant" (we are still discussing classification and "naming") proximal nerve roots just outside the spinal cord are affected and the clinical course of those patients is different from traditional TM patients. We believe this work will help lay the foundation for improved classification of TM patients into subtypes based on deficits and response to therapy. The results of this work will be made available through TMA publications and the website.

In addition to our clinical work and research, we have other therapies that may impact both acute TM and ADEM. We have started to administer high doses of intravenous methotrexate in patients with severe refractory autoimmune encephalitis. For our patients who are beyond the acute setting, we are exploring a variety of novel treatment options that may restore function or preserve muscle health while natural healing occurs (more on this to come!).

One of the most rewarding aspects of this fellowship has been the community of patients and families to whom I have been introduced. The extended family of the TMA has graciously welcomed me in and supported my efforts to advance my training. I am truly blessed and excited to have this opportunity, and I feel fortunate for this chance to contribute to a better understanding about TM and related disorders. This is only the beginning of my commitment to advancing the cause of improved recoveries for more kids and adults who have been affected by TM and ADEM.

I wish you all a very Happy New Year and look forward to sharing more updates later this year.



CLINICAL STUDIES & TRIALS

A LONGITUDINAL STUDY OF NEUROMYELITIS OPTICA AND TRANSVERSE MYELITIS

Investigator: Benjamin Greenberg, MD, MHS
University of Texas Southwestern Medical Center,
Dallas, TX

This observational study seeks to determine the biologic causes of inflammation in patients with Neuromyelitis Optica (NMO), Neuromyelitis Optica Spectrum Disorder, Transverse Myelitis and Optic Neuritis. While patients will be treated according to decisions with their treating physician, this study will collect data and samples from patients prospectively to gain a better understanding of the disease. The study is seeking to understand why some patients respond to medications, while others do not; and what happens biologically, preceding relapses. Gathering these data and samples will allow researchers to identify new ways of diagnosing and treating these diseases. Data and samples will be shared with researchers around the world to support collaborative efforts to treat these conditions.

Eligible Participants:

The study is enrolling females age 18 or older with NMO. Participants do not need to have been pregnant in the past to participate. Participants can be NMO antibody positive or negative as long as they carry the diagnosis of NMO. Participation would involve completing a survey that will be administered over the phone and should take 10-20 minutes of your time. There is no monetary compensation. There is no cost to you. You will not receive any personal health benefits as a result of your participation in this research study. We hope that the results will help us better understand NMO, and might benefit patients with NMO in the future. Your participation is voluntary.

Contact information:

Morgan C. McCreary, BS | (214) 645-0561
Morgan.McCreary@utsouthwestern.edu

THE EFFECT OF PREGNANCY ON NEUROMYELITIS OPTICA

Investigator: Eric Klawiter, MD
Massachusetts General Hospital, Harvard Medical
School, Boston, MA

This research is being conducted to study the effect of pregnancy on Neuromyelitis Optica (NMO). It commonly affects females of childbearing age. To date, women's health issues in NMO have not been studied in detail. Determining the effect of pregnancy on the NMO disease course is of great importance in counseling patients on family planning. Information will also be gathered on the incidence of complications of pregnancy and the incidence of miscarriages.

Eligible Participants:

The study is enrolling females age 18 or older with NMO. Participants do not need to have been pregnant in the past to participate. Participants can be NMO antibody positive or negative as long as they carry the diagnosis of NMO. Participation would involve completing a survey that will be administered over the phone and should take 10-20 minutes of your time. There is no monetary compensation. There is no cost to you. You will not receive any personal health benefits as a result of your participation in this research study. We hope that the results will help us better understand NMO, and might benefit patients with NMO in the future. Your participation is voluntary.

Contact information:

Dr. Eric Klawiter | (617) 726-7643



FES IMPACT ON CNS GROWTH FACTORS IN TM, NMO AND OTHER, NEUROINFLAMMATORY DISORDERS

Investigator: Daniel Becker, MD

Hugo W. Moser Research Institute at Kennedy Krieger, Baltimore, MD

This research is being conducted to evaluate change in function (spasticity, strength, and sensation) in individuals with inflammatory myelopathies in response to functional electrical stimulation (FES) cycling therapy. The study will also evaluate the changes in CSF growth factors, neurotrophins, and inflammatory cytokines in response to FES stimulation. A correlation between changes in function and changes in the cerebrospinal fluid (CSF) neurotrophic/inflammatory milieu will provide evidence of biochemical changes that may mediate neurological repair following FES cycle therapy. This data will be crucial for the design of a phase 2/3 clinical trial evaluating the efficacy of FES in patients with inflammatory myelopathies.

Eligible Participants:

The study is enrolling people with transverse myelitis, neuromyelitis optica, and multiple sclerosis. The study involves coming to Kennedy Krieger Institute in Baltimore MD for a total of 3 weeks. Participants will use the FES bike either once, three times, or five times per week. At the beginning and at the end of the study, you will undergo a detailed clinical exam in addition to blood draw and spinal tap.

Contact information:

Shannon Inches | inches@kennedykrieger.org

THE ACCELERATED CURE PROJECT REPOSITORY

The Accelerated Cure Project Repository is a collection of biological samples and data from people with Multiple Sclerosis (MS) and other demyelinating diseases, their affected and unaffected relatives, and unaffected, unrelated matched controls. The demyelinating diseases represented are: MS and Clinically Isolated Syndromes (CIS), Transverse Myelitis (TM), Neuromyelitis Optica (NMO) or Devic's, Acute Disseminated Encephalomyelitis (ADEM), and Optic Neuritis (ON). Combining samples from people with these similar-but-different conditions into a single collection not only saves money due to the efficiency of a single operation, but also enhances research as it allows scientists to easily compare different demyelinating diseases in their studies.

Eligible Participants:

Although at a reduced level, enrollment is open based on certain criteria, however if you are not eligible to participate at this time, we will put you on a waiting list to be contacted once full enrollment resumes. If you have been diagnosed with TM, NMO, ADEM, ON, or MS and have not already enrolled in the ACP repository, we invite you to learn more about sharing your samples and data with researchers around the world. Participation consists of a blood draw and an extensive interview at one of the ten clinics (collection sites) located across the US. This is not a treatment study. There are no drugs involved.

Contact information:

acceleratedcure.org/impact/repository/collectionsites
Sara Loud | (781) 487-0032.

All up to-date information on clinical studies and trials can be found on
<http://myelitis.org/research/clinical-studies-trials>.



UTSW-TMA-JHU 2013 RARE NEURO-IMMUNOLOGIC DISORDERS SYMPOSIUM: REPAIR AND RECOVERY, TODAY AND IN THE FUTURE

Combining a research and education symposium focused on the latest recovery and repair research with the launch of a ground breaking natural history study of TM, ADEM, NMO and ON.

The University of Texas at Southwestern (UTSW), the Transverse Myelitis Association (TMA) and the Johns Hopkins University Project RESTORE (JHU) are hosting the 2013 Rare Neuro-immunologic Disorders Symposium in Dallas. This symposium focused on repair and recovery will be a ground-breaking research and education opportunity. Participants will be offered a two-day education program that will be focused on restorative therapies. Participants will also have the opportunity to enroll in a longitudinal natural history study (an application will have to be completed for enrollment before the symposium to qualify).

The Symposium will be held on Friday, October 25 and Saturday, October 26, 2013 in Dallas. If you live outside of Dallas, you should plan on arriving Thursday evening, as the program and research will begin early on Friday morning. Details regarding the hotel, the specific location of the program, the education program agenda and the application process to enroll in the study will be provided on the TMA web site as soon as we have these plans completed. We wanted to be sure to get this information communicated to our community so that you can begin your planning and get these dates on your calendars.

What is the latest in rehabilitation options? How are drugs that promote repair progressing in clinical trials? Where do we stand relative to stem cell research? Whether you have been recently diagnosed or have had one of these disorders for decades, this education program will offer an opportunity to learn about treatments and research on restorative therapies, learn about approaches to improve your quality of life and in the long term will provide you with great hope for your future.

The initiation of this natural history study is a critical

component of basic research to understand these disorders and also is fundamental to our ability to conduct further meaningful research, to develop treatments and procedures for people who have each of these disorders. There has never been a natural history study done in ADEM or NMO or ON or TM. For those individuals who are accepted into this long-term study, physicians and researchers are going to collect information about your unique case from the onset of your disorder through the acute phase of the disorder to the present and long-term. You will be followed such that each person will add to our long-term and intensive understanding of the progression and development of each disorder.

What is the significance and impact of a natural history study? There are many needs in rare disease research. For patients with transverse myelitis, neuromyelitis optica, acute disseminated encephalomyelitis and optic neuritis, the needs are many. We need better approaches to diagnosis. We need better acute care treatments. We need better methods of symptom management. We need therapies that repair damage. All of these needs exist in a sea of needs from patients with other diseases. There are limited dollars to be spent by the NIH, foundations and pharmaceutical companies; how can we as a community garner attention and research efforts for TM, NMO, ADEM and ON?

There are multiple drugs and therapies in development that could have potential for repairing damage done to the central nervous system after immune attacks, yet based on market size; multiple sclerosis receives the majority of attention. And why not? MS patients outnumber TM/NMO patients 100:1. Thus, from a business perspective it is far more lucrative to treat MS than rare diseases. Yet, against these odds, there are opportunities to make TM, NMO, ADEM and ON



ideal candidates for research into repair strategies. Pharmaceutical companies spend billions of dollars on research and have a tremendous need to reduce the risk of failure in expensive clinical trials. If there were conditions with excellent data about the natural history of what happens to patients, those conditions would be easier to study. Companies would be able to design more efficient trials and decrease their risk/expense. Establishment of a longitudinal study for TM/NMO/ADEM/ON would create a dataset and patient cohort that would attract the attention of researchers and biotech companies.

You have the opportunity to become a part of a study that could dramatically change the future of research on these disorders and could become the basis for the long term improvement in the quality of life for the people in our community. We urge you to get involved. When you receive the details of the application process, please act as quickly as possible. There are going to be a limited number of people who may be accommodated in the study, and you are not going to want to miss out on this incredible opportunity. We will be asking people who are accepted into the study to bring their medical records, lab reports and MRI images to the symposium. We will identify for you specifically what is needed, but if you have an interest in participating, you should begin to collect these materials if you have not already done so. And it is a great idea that you have copies of these materials for yourself in any event.

The education program will go on for two days concurrent with the initiation of the natural history study. The education will be focused exclusively on restorative therapies, from rehabilitation therapies, to bracing and orthotics, to stem cell research. The details of the program will be made available as soon as the agenda is completed. The presenters in this program will be leaders in their disciplines. Our education programs are exceptional and you will definitely leave the symposium with critical information that will better define what your long term expectations should be about treatment and also make you a much more effective advocate for your medical care.

Please get the dates onto your calendar. Please check our web site regularly for the detailed information about the study application process and the logistics arrangements for the symposium. We are looking forward to seeing you in Dallas in October 2013.

TMA FAMILY CAMP AT CCK

The TMA Family Camp at The Center for Courageous Kids (CCK) will be held this summer from July 24 (Wednesday) through July 28 (Sunday). If you have a child with ADEM, NMO, ON or TM and they are between the ages of 5 and 17, please apply to camp! Please email us at info@myelitis.org if your child does not fall between these ages and you would like to apply to camp. The applications are available on the CCK web site at: <http://www.thecenterforcourageouskids.org/camperapp.html>. More than 20 families have applied to camp. Please do not procrastinate; there is limited space at camp, and we don't want for you to miss out on this incredible experience.

We will be providing an excellent education program at camp for the parents. We bring in experts in the rare neuroimmunologic disorders and you will be able to spend time with these specialists throughout the entire camp. The camp is a wonderful facility that is totally accessible and their accessible recreation program is entirely inclusive.

You can learn more about CCK by visiting their web site and by reading the stories and blogs about camp on the TMA web site.

Please also get involved in TMA Kids, as this group is helping to support our efforts to make camp possible for the families who will attend and are also raising funds for families who are unable to afford travel to camp. You can find information about TMA Kids at: <http://myelitis.org/get-involved/tma-kids>.



TROUBLE IN PARADISE

Peter Ross - In Their Own Words

In early May 2009, after a long bout with the worst case of the flu I've ever had, I was stricken with an attack of Transverse Myelitis. It started while I was on a plane from my home in St. Croix, U.S. Virgin Islands to Beaufort, SC for a vacation with my mother and daughters for my mother's 80th birthday.

At first my left foot felt like it was falling asleep. I was sure I had tweaked my back and it was pinching a nerve, shutting feeling in my left foot. By the time I was airborne, the entire left leg was numb and the right foot started to get numb as well. I changed planes in Miami and had trouble walking. I was reluctant to get off the plane and go to Jackson Hospital, as I knew that Savannah Memorial was a teaching hospital as my mother had been hospitalized there.

By the time we landed in Savannah, at 10 PM some five hours later, I was paralyzed from the waist down and it felt as if the paralysis was moving up into my upper torso. My left hand was also getting numb and not working properly. I was carried off the plane by a baggage handler and put on the luggage conveyor belt into the terminal. An ambulance carried me to Savannah Memorial and my blood pressure rose to 225/130. I was freaking out.

The emergency room was filled to capacity and the first doctor who attended to me told me that I had a bad case of sciatica. He wrote up my discharge and told me to get up and walk out. Had it not been for the young nurses there, he would have put me out on the street. After the nurses convinced him that I was in fact paralyzed, he ordered a steroid shot, as the paralysis was beginning to shut down my respiratory system and I was having trouble breathing.

My mother and daughters arrived at the hospital emergency room the next morning and kept up their vigil for the next three days in the emergency room. I was wheeled around the hospital for different tests, X-rays, CAT Scans, spinal taps and blood work as

neurologists, internists and orthopedic doctors argued over what was causing my paralysis.

After nearly a week of doctors arguing inside and outside of my hospital room, a nurse handed me a printout of some research she had done on what the doctors were arguing about. Transverse Myelitis. The neurologist finally said that Transverse Myelitis was his suspicion and an internist said to me, "you are a zebra. You know when the posse comes into town and you hear the hoof beats, you know they're riding horses, and then every great once in awhile you hear the hoof beat of a zebra. That would be you"??

After my suspected diagnosis was made, an endless stream of doctors and interns came in to my room to examine me head to toe and ask redundant, nonsensical questions. They were lined up to see the zebra. I was shown a frayed electrical cord and told that that was what my spinal nerve ending looked like. I was short-circuited and the signal could not travel to my legs and feet.

I stayed on the intensive care floor for over a week and it was determined that because I had been in such excellent physical shape, that I was a candidate for rehabilitation. I couldn't believe that it was even an issue. I was transferred over to the Physical Therapy Ward for evaluation, where I was told it was doubtful that I would be able to walk without a walker or cane, if at all. I was given my own room and wheelchair and told to stay in bed and that if I had the need to go to the bathroom, someone would come and help me. It was amazing how quickly my body had atrophied and I had little, if any, ability to raise my legs. The sheets felt like sandpaper on my upper legs and I could not feel my feet. I spent two days in physical evaluation, testing my dexterity, balance, strength and agility. It seemed as though my legs weighed a couple of hundred pounds each. I was bound and determined to somehow walk out of the hospital.



I was finally placed with a group of other non-walkers who had suffered various spinal problems from a myriad of injuries or conditions. One lady had suffered a stroke from brain cancer surgery, another was seriously injured in an automobile accident, another had torn his knee playing tennis and one 85 year old man had hip replacement surgery. We all shared our tales of woe, but no one in my group felt sorry for themselves. We all had one thing in common, we wanted to walk again. So we pulled for each other, gave encouragement and watched as we struggled to first stand up.

The therapists were wonderful. It did feel a bit demeaning as they helped you get in your wheelchair, get on the toilet, waited for you to poop, helped you bathe, get in and out of the shower. I would zoom down the hallways to my therapy sessions, anxious to push the envelope. It took about a week of exercise to be able to stand while holding some sort of grab bar. I was blessed to have quality nurses and three young physical therapists who were very passionate about their work and went above and beyond in caring for all of their patients.

After two weeks of working to regain strength, and to attain balance and agility, I took my first steps with the aid of my therapists. I then graduated to walking Frankenstein-like on my own. By the end of the third week, I was able to walk up and down stairs holding onto the handrail. After almost a month in Savannah Memorial, I walked, or should say shuffled, out to the cab to take me to the airport to fly home to St. Croix. Somehow I willed myself through the Savannah and Miami Airports, getting people along the way to help me carry my small luggage bag for fear I would tip over. I remember arriving home and being intimidated by the ten steps I needed to walk up, to get in my apartment.

I immediately began physical therapy at Beeston Hill Health Club on St. Croix, where I massaged, stretched, lifted weights, relearned how to float, tread water in the pool and walked on the tread mill. Slowly my strength returned, but my balance and agility lagged behind, as I still could not feel my feet, nor wiggle my

toes. I worked for an hour and a half each day, but could not do much, nor walk much afterward. Thank you Brandon, Jean and crew. Despite not feeling my feet, I started driving, very slowly and carefully. I was prone to occasional falls and trips, as my left leg was way behind in recovery. I started to refer to my leg as "obstinate lefty." I was also very susceptible to leg cramps and spasticity, which became painful and made walking extremely difficult.

I was going to a holistic doctor, as all modern medicine was offering me were drugs to ward away my symptoms. No thanks. I tried acupuncture. After about a month, my acupuncturist stuck a needle in my left calf and it felt like he had thrust a sword into my leg. The pain was excruciating, but it was the first time I had felt anything in my left leg. From then on, the spasticity was gone and I could finally curl my toes.

I began to hit the tennis ball with my friends Rick, Justin, Raymond, Jason and Ian. It was heaven, even though my feet would cramp up and I couldn't move laterally. They hit the ball right to me and we began playing matches, with a new set of rules, "hit it to Peter." Yeah! However, I was still unsure on my feet and constantly felt like I was going to "tip over."

I kept myself busy mentally building a website and trying to start a new business. After a year and a half of physical therapy, some part time work, I got a job helping to manage a photovoltaic project on St. Thomas. I traipsed around and managed to shuffle between St. Thomas and St. Croix. In November of 2010, I received a call from a company I had worked for South Carolina. Would I consider coming to run a project in Ft. Knox, KY? Well I had just started the PV project, but this paid much more and would be for 3-5 years. I had to go, but could I physically sustain myself?

I arrived in Radcliff, KY just in time to spend a lonely Christmas and New Year at the Holiday Inn Express. I had done this before; arriving, not knowing a soul and being in charge of about 100 employees. Would my physical limitations inhibit my ability to lead? There was an obvious resistance to my authority, by two



of the key members of the management staff. I had learned over the past year and a half that stress was my enemy and could shut my central nervous system down in a New York minute. I had to gather myself and ease into this overwhelming job. I was managing military housing and working with Army Generals, Colonels, Sergeant Majors, a myriad of soldier families and a resistant workforce in the middle of nowhere. I paced myself and slowly began the job of changing the face of the project, by a process I call addition by subtraction; or weeding out the bad apples. I also moved to Louisville, KY about 45 minutes away from Ft. Knox, where there were restaurants, shopping, entertainment and less stress. I got a place with a small gym and began to settle in. I enjoyed working out again, but was still having difficulties with my balance. My left leg still seemed to just be along for the ride and I would have to drag it with me.

I started to look around for an acupuncturist. I was getting regular massage, but it was more soothing than therapeutic. Someone recommended a reflexology therapist, in Louisville. In February, 2011 I began to go once a week and started to see subtle changes almost immediately. Tom would be massaging my right foot and my left leg would start jumping; it was almost as if the circuits were reconnecting on my right and left leg. My left leg became more responsive and my sense of balance became much more acute. The effects of reflexology therapy have been cumulative and I have gained both better balance and agility. If I don't go to the gym and I don't go to reflexology, I begin to lose my connectivity and almost feel the atrophy creeping back into my legs. Tom has told me that the pressure technique that he uses stimulates and re-energizes neural pathways, which were compromised by my condition. By stimulating nerve flow along these pathways, sensory articulation is re-introduced to all parts of the nervous system. Overtime, dormant or compromised areas of the central nervous system (CNS) and peripheral nervous system (PNS) are actually re-trained to function at optimum sensory levels and feeling, as well as sensory communication, is gradually or partially restored. Tom said that my exercise routine supports the reflexology treatment by "exercising" the nervous system, especially with

my aerobic exercise regimen. Aerobic exercise and weight training strengthens atrophied tissue while stimulating nerve flow.

The most pronounced improvement in my treatment/condition has to do with my balance. From the outset, Tom told me that as there was reintroduced nerve flow throughout my entire nervous system, it would stimulate neural activity within the inner ear giving these mechanisms an increased "sense" of feeling the terrain beneath my feet. This actually gave me an increased sense of stability and rhythm to enable me to confidently put one foot in front of the other. I have actually begun to lightly "jog".

At first my process was like two steps forward; one step back, but my progress has been steady. Because some of the neural pathways are compromised (short circuited) it may never be fully restored. I now see Tom for reflexology therapy about 3 times per month. While Tom has had experience with neuropathy in general, he has never dealt with transverse myelitis. It is our hope that with continued treatment, we can get my body to a point where I may see him for maintenance only.

Thank You,

*Peter Ross
4006 Waterford Circle #6
Louisville, KY 40207*

FACEBOOK

Find The Transverse Myelitis Association on Facebook! It is a great way to support the TMA and is a wonderful way to network with people in our community. Please take the time to become a fan of our page by clicking "Like", and tell your friends and family about our community's page. Facebook is a great way for us to raise awareness about these disorders and your experiences. Our link is <http://www.facebook.com/myelitis>.



THE MAN IN THE BUBBLE

Allen Rucker - In Their Own Words



We are so proud to have Allen as a regular contributor to the TMA Journal. Allen contracted TM in 1996 at the age of 51, and was paralyzed from the attack at the T-10 level. Allen published a memoir about his life after getting TM; “The Best Seat in the House.” It is now available in paperback. As his memoir so brilliantly conveys, Allen is on a journey. That journey has taken him into a life as a speaker and an advocate for the transverse myelitis and disability communities. Through his many speaking engagements, his appearance on the Montel Williams Show, and as a contributing writer for ABILITY and New Mobility Magazines, Allen is raising awareness about transverse myelitis. He is the author and co-author of numerous books of humor and non-fiction. “The Sopranos Family Cookbook,” one of three books he’s written about the Sopranos, was a New York Times #1 bestseller. Allen is the chair of the WGA Writers with Disabilities Committee. He lives in LA with his wife, Ann-Marie. They have two sons.

Forward: for many of us with TM, getting sick is a way of life. If you are a complete paralytic like me, getting sick usually means getting an infection. The worst such infection that has ever invaded my battered body came a couple of months back and like all infections, it came without warning. It didn’t kill me, but it sure shook me up.

If you are old enough, you might remember the mid-70’s TV-movie called “The Boy In The Plastic Bubble.” Starring a young, ex-Sweat Hog named John Travolta, it was a ripped-from-the-headlines story of a kid whose immune system is so out of whack that any exposure to any pathogen – bacteria, virus, or fungi -- was potentially life-threatening. Consequently, his whole life is spent inside a big, plastic, see-through bubble house.

Or you may have caught the classic Seinfeld episode on the same subject, entitled “Bubble Boy.” George Costanza visits a fan of Jerry’s who lives in the same kind of bubble. They get into an argument about “Trivial Pursuit” and George accidentally rips a hole in the bubble, almost killing the boy in the process. It’s hilarious.

What a sad fate, you’re saying, to be so susceptible to every bacteria or virus floating around that you have to live in an air-tight, sterilized bubble. Well, recently, as a T-10 para who is prone to infection, I’ve felt exactly like that: a man in a bubble without the bubble.

We all get infections, right, often appearing out of the blue. The last one I got, the Big One of 2012, put me in the hospital and scared the hell out of me. On a quiet Saturday morning came the fever, chills, and vomiting. By the time I landed in the ER, a rash appeared on my right calf. A couple of hours later, the whole leg looked like a piece of raw meat and I felt like, ah, dog remains. For days. Maybe you’ve had this particular kind of bacterial attack that inflames the subcutaneous layers of skin – it’s called cellulitis.



The problem was, my very competent medical team a) couldn't identify the offending bacteria causing the cellulitis, and b) didn't really know how to treat it. When you ask your lead doctor what's going on and he says, "We have no idea," you know the fun has just begun. Trying to combat an unknown pathogen is like throwing darts at a board. Vancomycin, reputedly the biggest bazooka in the antibiotic arsenal, couldn't kill it, so my infectious disease specialist started mixing antibiotic cocktails. She tried Vanco with a drug called Zosyn, which caused me to break out in hives. Then it was Vanco with Flagyl, which then lead to Vanco with Flagyl and Astreonam, the magic potion. Four days into this nightmare, this last trio began to work and the infection receded. I finally left the hospital with all parties still scratching their collective head – what the hell was that?

Soon after I got home, the New York Times ran a piece on the "microbiome," the 100 trillion – yes, trillion – microbes that hang around our bodies. There are, they report, over 500 species of bacteria alone that live in the human mouth. Most of those bugs, in the mouth and elsewhere, are apparently beneficial, as the researchers are quick to point out. Well, the bug that attacked my leg was not so friendly. The entry point for this scoundrel was probably the small, extremely clean problem wound on my ankle, but where in the microbiome did it come from before that? The down comforter? The dog licking my leg in the middle of the night? The doorknob touched by the cookie-selling Girl Scout, then touched by my wife, who then touched me?

A germaphobe, re Wikipedia, is a person with "a pathological fear of contamination and germs." Think of the TV character, Monk. But what do you call a person whose pathological fear of contamination seems pretty well-grounded in reality? Short of moving into a one-bedroom bubble, what should I do? Start wearing a face mask like the Japanese do during flu season. Avoid all human touch, including hand-shaking and cheek-pecking, use my elbows to eat a burrito, and cover this key board with bubble wrap? God knows what might happen if I get on a plane or go to a ballgame. The secret may be to steam-sanitize

my wheelchair and never get out of it. You think I'm kidding but an episode like my encounter with that nameless leg-chewer can easily turn a concern into an obsession. Of course, preventative measure #1 is no skin breakage, anywhere, ever. No nicking your ankle getting out of the bathtub or bumping your knee in a crowded elevator. And a completely sterile toilet routine that would make an ICU nurse proud. Wash your hands fifty times a day. And never touch your dog, cat, or any problematic part of your own body again without surgical gloves.

I guess I'm a slow learner, but it's taken me sixteen long years of paralysis to finally see things clearly: no matter what the good-bacteria-loving scientists say, infection-avoidance is war, an endless battle to the death, and the moment you let your attention waver, you're going to get hit from behind. Bacteria never sleep, even when you do. Every fifteen minutes, a bacteria cell splits into two bacteria cells. And they are smart – they mutate at the drop of a hat.

I have to stop now so I can get the bubble wrap to cover my keyboard. The enemy is out there, lurking, plotting, waiting to attack. Kill it before it kills you, or at least makes you debilitatingly sick.

RENEW YOUR TMA MEMBERSHIP

The membership of The Transverse Myelitis Association includes persons with the rare neuroimmunologic disorders of the central nervous system, their family members and caregivers and the medical professionals who treat people with these disorders. The Transverse Myelitis Association was established in 1994 as an organization dedicated to advocacy for those who have these disorders.

Please sign up again if you are already a member and update your membership information by completing our newly designed member survey made possible by a partnership with TraitWise on <http://www.myelitis.org/join>. We look forward to sharing the latest information on research and education opportunities and keeping in touch!



DOG DAYS

Dog Days, written by Barbara Sattler, explores relationships between mother- daughter, friends, men and women and dogs and humans. It is a time of crisis for Kristin White. Twenty-five year old Kristin is released from prison after doing time for a crime she did not commit. Kristin is involved with two men. Self-centered Josh who lets her take the rap for his drug deal, and Kelly, a good but judgmental man she meets while still on parole.

Written by a former criminal defense attorney and Superior Court Judge, the book follows Kristin's journey through the criminal justice system from arrest through sentencing with a focus on her relationship with her lawyer and one of her cell mates.

On parole Kristin struggles to find employment. Sara, a psychic and dog communicator who owns The Dignified Dog -a dog training and day care facility- finally hires her. There she meets Samantha, a smart, sensitive black lab and Theodore, a small brown dog of mixed parentage: they help Kristin understand loyalty and compassion. With the help of Sara, her co-workers and various canines, Kristin starts to grow up and find out what matters in life. Kristin's growth is tested when Josh is once again responsible for another horrible event in Kristin's life.

Dog Days is available through Amazon, Kindle and other e-readers. All proceeds from the sale of this book will benefit the Transverse Myelitis Association.

180 MEDICAL SCHOLARSHIP

180 Medical is honored to have started a scholarship program to help those with transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida and spinal cord injuries. Realizing the financial burdens that exist for many of the families affected by these diseases, 180 Medical developed the 180 Medical Scholarship Program to honor these young adults pursuing goals of higher education.

Eligibility

High School Seniors: To be eligible, a student must be a high school graduate (or graduating senior), and have been accepted to a two-year or four-year college in the United States. They must plan on attending school full time (at least 12 hours) in the upcoming fall semester, and they must have transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida, or a spinal cord injury.

College Students: To be eligible, a student must plan on continuing to attend a two-year or a four-year college in the United States in the upcoming fall semester. They must attend class at least 12 credit hours a semester and have transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida, or a spinal cord injury.

The Scholarship Award

Three \$1,000 scholarships will be awarded to those who demonstrate perseverance, courage, good will, and have made the best of their condition. These are one-time scholarships (not annual). Applicants are allowed to apply in subsequent years.

Deadline

The scholarship runs from January 1 to June 1. Visit www.180medical.com/scholarships for application instructions and up-to-date scholarship information.

Application Process

To be in consideration for a scholarship award, you must include the following:

- Completed Application. Visit 180medical.com scholarships to download the scholarship application.
- Typed questions and essay, 750 word maximum. More information can be found on the Application Document.
- Physician's statement of diagnosis
- Most recent official transcript
- Document verifying acceptance by college (or current enrollment)



Send all materials to:*180 Medical**Attn: Scholarship Committee**5324 W. Reno, Suite A**Oklahoma City, OK 73127***Facebook**

Join 180 Medical on Facebook to stay up to date with all of the scholarship news. They will announce scholarship winners on Facebook.

www.facebook.com/180medical

Questions?

If you have any questions please contact scholarships@180medical.com.

PRIVACY ON THE INTERNET

The information we provide on our web site and in our publications to our membership is one of the most important functions of The Transverse Myelitis Association. When you share your information in an In Their Own Words Column, you change lives. I hear from people every day who are inspired and informed by these writings. The access our support group leaders provide to people in their communities is invaluable. To know that you are not going through this experience alone or to find support and information in your community is truly a blessing for people. Sharing information in our publications and on our web site is a selfless, kind and generous act, and we are all grateful for your participation. It is also very important to understand and accept that once this information is posted on our web site, it is available to anyone who has a computer and internet access across the globe. This ubiquitous access is the incredible value and also the bane of the information technology age. So, we want and need for you to be generous about sharing this information, but we also want for you to be informed and judicious about making these decisions to share information. If you do not want to be found in a web search or you do not want for your information to be identified in a web search, please do not write an article for the newsletter or journal and please do not volunteer to be a support group leader.

In addition to the information in our publications, it is important to bear in mind that any postings you put on a message board or in a list-serve group can also be accessed through a web search. It is almost always the case that if you are wanting anonymity in your life, the less you put out there electronically, the better, and that includes email messages, because once you hit that send button, you have no control over what the person does with that information on the receiving end.

It is also critically important to bear in mind that The Transverse Myelitis Association does not put membership information on our web site or post it electronically anywhere. If you want privacy, we do what we can to help you achieve that end. Please help us by making informed decisions in regards to what you submit for publication and what you post on the web site on our message boards and in the list serve groups. The TMA functions so effectively as a support network, because so many of you are willing to share and to help others. We urge you to continue to do so; we depend on your willingness to do so. But we don't want for you to participate in this sharing, if this activity is going to compromise any concerns you might have about privacy. Be smart and be realistic about how the internet works and what is private and what is public about the internet.

The Transverse Myelitis Association is proud to be a source of information about ADEM, NMO, ON and TM. 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 medications, treatments, 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 medications, treatments, products or services mentioned.





TMA ANNUAL WALK-RUN-N-ROLL CAMPAIGN

Uniting against rare neuro-immunologic disorders

The Transverse Myelitis Association will be launching a nationwide campaign to increase awareness and funds for research and programs that the TMA offers, such as our James T. Lubin Fellowship and our education programs.

The first Annual South Jersey Walk, (<http://www.vimeo.com/40105783>) organized by Colleen Spaeth and her daughter Mandy Edwards in 2012, sparked the idea for our campaign. The walk proved to be a huge success and they raised about \$11,000. Colleen and Mandy have shared their experience and a guide for doing a TMA Walk in an article that appeared in The TMA 2012 Fall Newsletter, which created a huge momentum for walks in many different states.



South Jersey Team at the First Working Meeting

Our goal is for the TMA Walk-Run-Roll Awareness Campaign to be launched in 10 different cities across the nation over the course of three months, from April to June 2013. The 10 cities will design the events based on their creativity and feasibility for different venues, themes and distances. All of the events will be promoted under the “10 cities – 1000 people – \$100,000” motto.

We have heard from some you in our community of volunteers across the country and are excited to start planning this walk-run-roll event with you.

FLORIDA – MAY 11TH 2013 We are holding our First Annual Central Florida Transverse Myelitis Walk in Honor of my daughter Sarah Robbins. We are excited for the opportunity to raise money for Transverse Myelitis awareness and for the Transverse Myelitis Association that funds the research to find a cause and a cure! It will take place at Riverfront Park in Cocoa, FL located close to our home in Merritt Island! We ask that anyone living with this disorder in our local area please contact me at 321-626-4149 for more information! Look us up on our Facebook page: <http://tinyurl.com/asg3coe>.

— Tina Robbins

GEORGIA – APRIL 27TH, 2013 – On April 27th, 2013, beginning at 9:00 a.m., Georgia will proudly be a part of the TMA’s 1st annual Transverse Myelitis Walk-Run-N-Roll Awareness Campaign “10 cities- 1000 people – \$100,000.” Our event, Georgia TM Walk and Roll will be held at Hunter Memorial Park, Douglasville, GA. This venue has a flat surface and will allow wheel chairs, scooters, walkers, or sneakers, whatever anyone chooses to make it around the track. Come out and enjoy a day of fun and meet new friends. Currently, Georgia has the following TM members working on fundraising and coordinating the event: Ginna Hamilton, Kim Harrison, Brian Harrison, Pamela Clark, Stephanie Miller and Amanda Diskey. The following organizations have agreed to promote this event: MS Center of Atlanta, Shepherd Center of Atlanta and Project Walk Atlanta. With the grass roots efforts by the team members we anticipate a successful event! Look us up on our Facebook page: <http://tinyurl.com/abu39f5>.

— Kim Harrison

NEW JERSEY – APRIL 13TH, 2013 – The Second Annual South Jersey Transverse Myelitis Walk will take place on Saturday, April 13th, beginning at 10 a.m., at Cooper River Park in Pennsauken, New Jersey. Our goal of \$10,000, which we thought at the time was quite lofty, was met, so this year our lofty goal is



\$20,000. We are hoping that other TM communities will join us! Please contact us at 856-429-1554, if you would like to help in our lofty endeavor and make the Walk-Run-N-Roll Campaign happen!

— Colleen Spaeth

Our volunteer leaders are actively planning the event in **Florida, Georgia, Illinois, Maryland, New Jersey, Pennsylvania, and Washington**. If you live in one of these states, please watch our web site and future publications announcing the details of these events. We urge everyone to get involved.

We are looking for more leaders to help us organize more walks across the country. If you would like to join this campaign to help the TMA raise awareness please contact us at krishnan@myelitis.org. We look forward to making a difference with you!

This is our first effort at an organized national fundraising event. It is vital for all of our members to get involved in all communities and cities to raise awareness for this important cause. We hope to make this a signature event for the TMA!

We look forward to keeping you posted on our website, <http://www.myelitis.org/get-involved/walk-run-n-roll-campaign> with latest updates on the Walk-Run-Roll Campaign and city-specific information on the different walks!

THE GRINCH WHO STOLE MY PAIN PILLS

Barbara Sattler - In Their Own Words

I thought I was prepared for any emergency, but I wasn't. I had a small stash of extra pills in case I ran out because my doctor was unreachable, my doctor refused to give me pain meds or I lost them. I wasn't prepared for a burglary.

On a Sunday afternoon, a few weeks ago, my husband and I returned home from the University of Arizona basketball game to find our house burglarized. We

were only gone a few hours, our two dogs (one quite large) were in the backyard, and a car was visible in front of the house. Besides breaking a window, the housebreaker made off with a laptop, some odds and ends and a small sum of cash. I was angry but relieved as it could have been much worse.

Several hours later I realized the thief had taken my pain meds. Except for the few I carry with me, my pills were gone. Not only had the burglar taken my current prescription but the small stash I'd slowly accumulated over the years in case of an emergency.

Losing my meds could have been a bigger disaster. Luckily, I have a great relationship with my neurologist who gave me another prescription. I've had doctors in the past who would have refused, accusing me of lying.

I drove to the pharmacy feeling like I'd dodged a bullet until they told me they wouldn't fill it; it was too soon. I explained about the burglary and said I would pay for the meds if insurance wouldn't. The clerk listened but said they had to verify the Rx with my doc in spite of his signature and, they needed a copy of the police report.

Which leads me to the lessons I learned:

- Find a doctor that you can trust who trusts you.
- Have a few days' supply of pills and store them in separate places.
- Make sure you file a police report as your doc, pharmacy, or health insurance carrier may want to see it.
- Don't keep all of your drugs in the same place.

I spoke with some support group members about this experience. One of our group members keeps her pills locked in a gun safe. That's the best use of a gun safe that I've ever heard. I've begun storing my pills in different places. I only keep a few in the Rx bottle hoping the next thief will assume that's all I have. I have others in an aspirin bottle, some in my purse and some in the car.

Another lesson I learned was to use the burglar alarm we had installed after the last burglary we had 15 years ago.



SUPPORTING THE GOALS OF THE TMA: STORIES FROM THE COMMUNITY AND HOW YOU CAN HELP!



HALLOWEEN FUNDRAISER! My passion for setting up this fundraiser stems from helping children, like my niece Sarah Robbins. Sarah was diagnosed with Transverse Myelitis in November 2011. The TMA has helped my family in many ways and as a proud Aunt, I wanted to show my support. My way of giving back to the TMA was to organize a small Halloween fundraiser. We are new to our neighborhood and thought this also would be a great way to meet neighbors and educate them about TM. We ended up cooking some meatball subs, baked some cupcakes, and put out a cooler of beer and wine. We made poster boards with pictures of Sarah and her parents (my sister and brother-in-law) and a description board about what TM is and about the TMA. There was no price tag for the goodies, just donate what you can. We raised \$120.00 and, more importantly, my neighbors were very generous & curious to know what TM is. I will continue to support the TMA and hope to become a Patient Ambassador for 2013.

— Debbie DeMarco, Florida

GARAGE SALES, BAKE SALES AND SUPERHERO BIRTHDAY PARTY! Raising funds while raising three kids aged 3-7 (one of which has an incomplete spinal cord injury from Transverse Myelitis) – really? It sounded so overwhelming and still does. But when I started looking at things we were already doing and

just reworked them a bit to be focused on the great cause of raising money for kids and their families that are struggling with TM, it suddenly became easier. It has become a family goal for us after having the amazing opportunity to attend our first TMA family camp this past summer. What an incredible whole family experience and motivator for our kids to all say, “yes, we need to raise lots of money so we and more of our TMA friends can get to camp next year!”

One thing we have done every year, sometimes twice a year, is a garage sale. Yes! Getting money for people to come and take away your old stuff! The key we found is to be clean and organized (mom has an infatuation with databases, categorizing and stickers), so I love cleaning out toys, clothes, anything months before the garage sale! Now to make it a TM fundraiser. We’ve made posters with lots of pictures and an information sheet about our son, Andrew, and his adventure with the mysterious neurological condition called Transverse Myelitis (TM).



Once people realize the funds are going to a good cause, they even donate extra money into a provided “TM jar.” This year (our 3rd) we decided to add on



a bake sale table that the boys got to run when they were home from school (and help their math skills while teaching them the goodness of volunteer work). Our neighbors and friends have even started donating their organized, labeled goods and or items to sell at the bake sale. This fall garage/bake sale raised \$1300 for The Transverse Myelitis Association and kids camp. Next 2013 sale we are getting TMA hats made and putting articles in the newspaper to continue to spread awareness!

Another fundraiser we decided to try this December was turning Andrew's Superhero birthday party into a fundraiser for the TMA! We had a record number of his old playgroup, preschool friends and new kindergarten friends he wanted to invite (over 40). So, with Drew's agreement that we would get him the one big gift he really wanted for his birthday (Teenage Mutant Ninja Turtle Lair) in exchange for his invites to say "Please consider donating to The Transverse Myelitis Association by check in lieu of gifts". While many friends did donate or some preferred to bring a gift, many donated and still brought him a gift! He was so spoiled, but we still raised over \$400! We just had to pay for the subdivision clubhouse space and we did all the games and entertainment. Yes, it was a lot of work, but so gratifying to know that it has raised so much awareness for Transverse Myelitis in our community (and probably answered many questions his new kindergarten friends and their families had

about his condition).

My goal for the near future fundraiser is to participate in the TMA run/walk national fundraiser and can't wait to find out more details soon. Yes, it is a little unsettling because I have never participated in a race or fundraiser like this before, but at the same time an exciting new challenge. If you'd like more information about any of these ideas or have new ideas for me, please contact me anytime thebaziles@aol.com. Please don't feel overwhelmed as you begin fundraising projects for the New Year, as any funds or awareness raised is better than none.

— Liz Beutel, Illinois

RACING, ST. PADDY'S DAY AND RECYCLING! Fundraising for TM has been a small way to give back to a wonderful community of families that walk through this journey that we call life with TM. These events increase awareness of the disease, raise money for research and support the TMA Family Camp. We have reached out for donations to our family and friends in our annual Christmas letter. We have had other one-time events such as a jewelry party with "Premier Design Jewelry" or evening at a local bar on St. Paddy's day and auctioned off many items/services that were donated by local businesses. This past summer, a second annual event was held at Raceway 7 in Ohio, where our extended family sold tickets Friday nights to Racing Fans and then raffled off



"Autographed Side Panels of Local Race Cars". Many Local Dirt Track Race Car Drivers donated these Side Panels. An ongoing endeavor is collecting Aluminum Cans or Pop-tabs and recycling them for money for TM. This coming spring we are organizing a Walk/Run in Pittsburgh, Pennsylvania. If anyone is interested in helping in the Pittsburgh area, please contact Pam or Morgan Hoge by email hoge5@verizon.net or phone 724-942-3874. We definitely could not have done any of these events without the Love, Support, and Faith of our extended Families and Friends.

— Pam and Morgan Hoge, Pennsylvania

MAKING A STOCK GIFT – There are advantageous tax benefits available by donating appreciated securities (stocks, mutual funds, or bonds) to the TMA. It is a great way to help support our critical programs.

Please contact Linda Malecky at lamalecky@myelitis.org or 215-499-9335 if you are interested in making a gift of appreciated securities to the TMA.

INKJET AND TONER RECYCLING PROGRAM - The Transverse Myelitis Association has partnered with the Funding Factory Recycling Program to collect empty inkjet and toner cartridges. This is an important fund raising effort for the Association. Please go to our web site at <http://www.myelitis.org/donate/recycle>. Once you register, you can order pre-paid UPS return labels that you put on any box you have. When you fill in the information, use your own name as the "Organization" name, but also, please use ID Number 63960 as the beneficiary. This ensures that the TMA will be receiving the benefits of the collected cartridges. When filling out the contact information, the form asks for a "title." You can list "other" and put "supporter" for your title. Once the company has your information and you request shipping labels, they will ship them to you to place on the boxes. Once the boxes are filled, you can take them to any place that picks up UPS packages (such as "Mailboxes, ETC.").

SEARCH THE INTERNET AND RAISE MONEY FOR THE TMA - You can raise money every time you search the web, at [iSearchiGive.com](http://www.iSearchiGive.com). Make it your homepage and

use it to find everything from news on the economy, to mood-lifting jokes (we recommend the latter). The Transverse Myelitis Association gets a penny (or more!) every time you search. Believe it or not, it adds up quickly and best of all, it costs you NOTHING! Start iGiving at: <http://www.iSearchiGive.com/TMA>

SHOP ONLINE AND GIVE - There are numerous online shopping opportunities, as well as sales on eBay, which can be made through the following link: <http://www.myelitis.org/donate/shop-and-give>. A percentage of the sales are donated to the TMA.

CAFÉ PRESS - Shop for items with The Transverse Myelitis Association logo to raise awareness and show your support! Visit <http://www.cafepress.com/myelitis>

EBAY GIVING WORKS - Support the TMA with the eBay Giving Works program. We want to help connect our community of individuals diagnosed with rare neuro-immunologic disorders. When you sell an item on eBay you can make a tax-deductible donation of all or a percentage of the proceeds of the sale to the TMA. Learn more at <http://www.myelitis.org/donate/shop-and-give/eBay>.

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

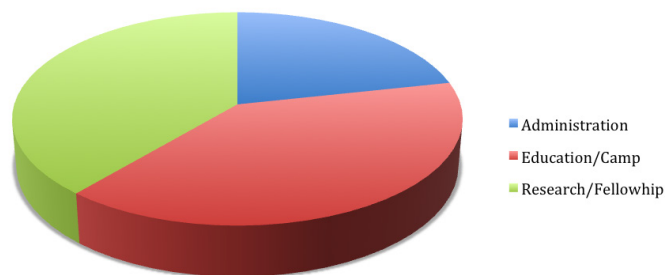


TMA FINANCIAL SUMMARY

Thanks to your generosity and hard work, we have raised close to \$200,000 this year! We greatly appreciate all the garage sales, family fundraisers and events you have organized. Our heartfelt gratitude to the Foundations who have supported us this year.

Below, we provide a breakdown of 2012 expenses. We will make our annual 990 report available on our website when it is filed.

TMA 2012 EXPENSE BREAKDOWN



Administrative expenses consist of costs incurred to manage the TMA, including government filings, accounting, and fundraising. Every (in fact daily) effort is made to minimize administrative costs. In addition to the incredible amount of time devoted by Chitra Krishnan to run the TMA, the Board of Directors and our community volunteers have dedicated hundreds of volunteer hours to the organization this year.

Major program expenses (education, camp, research and Fellowship) in 2012 include the annual TMA Camp at Center for Courageous Kids in Scottsville, KY; member publications; development and maintenance of the TMA website; the James T. Lubin Fellowship which was awarded to Dr. Allen DeSena at UTSW, and research grants awarded to Dr. Daniel Becker at Kennedy Krieger Institute and Dr. Carlos Pardo at Johns Hopkins University.

THANK YOU FOR SUPPORTING THE TMA

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer services to our membership; they also make possible the expansion of services to our existing and future members.

2012 CHASE COMMUNITY GIVING AWARD

Through the help of our members, friends and partners, The Transverse Myelitis Association has been awarded \$10,000 through the Chase Community Giving Fall 2012 Program. This unique effort has harnessed the power of social networking to give individuals and communities a voice in corporate philanthropy. Engaging over 3.8 million users, the online community helped decide where Chase will contribute a portion of their philanthropy funds, as well as which charities would share in over \$5 million at stake.

With nearly 700 votes, The Transverse Myelitis Association was one of the selected charities amongst over 30,000 other participants. The Transverse Myelitis Association would like to give its great thanks to the Chase Community Giving Program organizers and our many TMA friends in the US and abroad who helped us and voted for us.

We would also like to congratulate the Egypt Cancer Network, the winner of the 2012 Chase Community Giving Award.

Once again, thank you all for your support!





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ANNOUNCEMENTS

Family Camp: July 24-28, 2013, submit your application online as soon as possible on
<http://www.thecenterforcourageouskids.org/camperapp.html>

Membership Form: Fill out the form on <http://www.myelitis.org/join>. Please help us keep your information current and help clinicians and researchers better understand these disorders.

DONATE

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