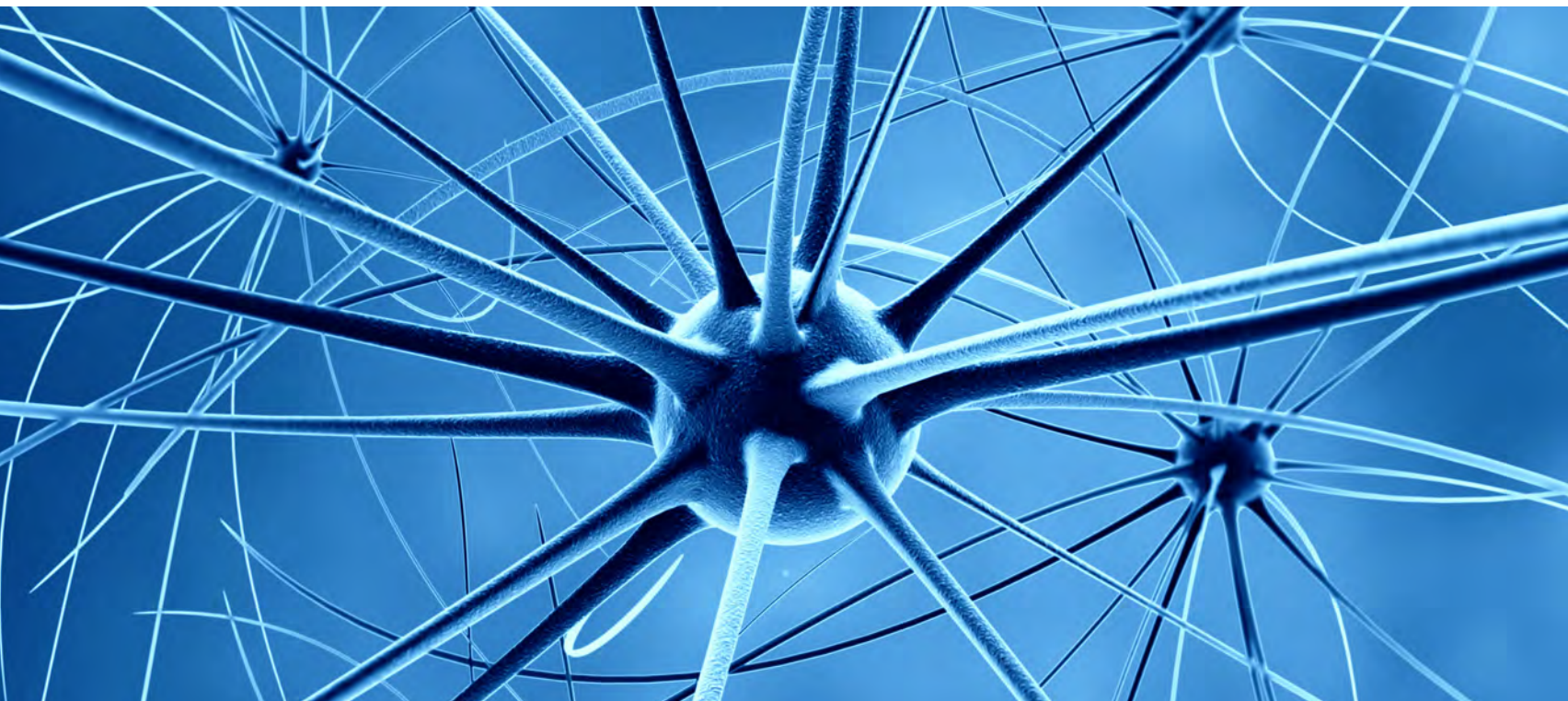


# THE TRANSVERSE MYELITIS ASSOCIATION

# NEWSLETTER

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

Summer 2013



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# THE EDITOR'S COLUMN

Sandy Siegel, PhD

The 2013 Rare Neuro-immunologic Disorders Symposium being held in Dallas this October represents a critical juncture for the TMA in a number of ways. First, the symposium reflects a fundamental declaration about the future of the organization: the TMA will be focused on the most effective ways for people who have these disorders and have experienced significant disabilities to be able to recover function and improve their quality of life. The Dallas symposium also represents the TMA's commitment to the education of our community and to research on all of these disorders.

The executive committee and members of our scientific advisory council held a meeting in March 2012 to chart our near and medium term goals for research. The overwhelming consensus was that our organization needs to be focused on repair and restorative research; this is the research direction that meets the most significant needs of our community across all of the disorders represented under the umbrella of the TMA. We will continue to remain focused on more rapid and effective diagnoses of all of these disorders, including the search for unique biomarkers. We will also remain focused on the most effective acute therapies that allow for the best opportunities for recoveries from the acute event. In order to address the needs and concerns of all of our members, whether they were diagnosed last week, last year or 20 years ago, we must devote our resources to finding ways to repair the spinal cord and restore all of the functions that have been compromised by damage from these attacks. A fundamental need to be able to achieve this is the creation of a comprehensive registry and bio-repository, which allows us to capture longitudinal data regarding these diseases in a systematic and intelligent way. This is particularly important for our spectrum of diseases because there is so much variability in acute onset, the extent of damage and recovery that it is virtually impossible to do research without gathering all this data.

Please review the symposium agenda on our web site; the topics being covered by our two-day education program will offer you insights into the areas that will be included in our research focus. We have framed the agenda around five themes: rehabilitation, drug-based functional recovery, surgical repair strategies, drug-based repair therapies and cell based repair strategies. The physicians, researchers and specialists who will be presenting at our symposium are leaders in their disciplines. It is a unique and critical opportunity for you to learn from experts who you likely do not have access to in your medical care. Having the information and the perspective you gain from this learning will

make you a better advocate for your medical care. By acquiring a sense of what is possible, you will develop realistic expectations about your own medical care. The information will help you to think about how you can be a participant in your medical care and to communicate with your own physicians about your course of treatment.

We will do our best to make this information available on our website for those people who are unable to make it to Dallas. Those who come to the symposium will have the opportunity to ask questions, and perhaps as important, will have the opportunity to meet and develop relationships with other people from our community. We have found over the years that these connections are among the most important outcomes of our education programs.

You will also have the opportunity to enroll in a natural history study at University of Texas Southwestern. This is a critical piece of research that will serve as the foundation for future research and will create the opportunity and possibility that pharmaceutical companies would consider research on TM, NMO and other rare neuro-immune diseases in the future. Without a natural history study, this research is not likely to occur. Thus, your attendance at this symposium is critical... for yourselves and for the future of research.

We have worked hard to keep the cost of the symposium as low as possible for our members. We have very reasonably priced rooms at The Embassy Suites Hotel in Dallas-Market Center at \$99+tax for Standard King or Double Rooms. Please contact Kodee Walker, Sales Coordinator by phone 214-962-1625 or by email [kodee.walker@hilton.com](mailto:kodee.walker@hilton.com) to make your reservations. The rate availability is subject to room availability. Reserve your room early! For more information, please visit <http://myelitis.org/2013rnds>.

Pauline and I look forward to seeing you in October in Dallas.

Please take good care of yourselves and each other.

*Sandy*







## Our Support Group Network

Since the beginning, we have been very fortunate to build a support group leadership network both in the US and globally. Our members reached out to us from the various corners of the world and pledged their support and commitment to help and support other members. We are so grateful that we now have 75 support group leaders from 34 states in the US and more than 37 leaders from 29 countries internationally leading the charge of educating and supporting others who have been newly diagnosed or who have been living with these rare neuro-immune diseases.

We need more leaders; we have many countries and states with no representation. Also, all of our support group leaders could use help. Every day new members sign up on our website and ask to be connected to others. We do our best to connect a mom or a dad with another parent whose child has the same disease, is in the same region and is of the same age group; or we connect someone who has been living with Transverse Myelitis for 10 years and has never met another soul with another member. But we want to do more. We want to expand this network into a more robust group. We want to provide our support group leaders with resources, guides and online communities where we can all share our experiences as support group leaders and discuss what more we can do to help others.

To do this, we would like to hear from you and your experiences as a support group leader. Over the next few weeks, we will be reaching out to our support group leaders to seek your opinion and feedback on how we can move forward and how we can best achieve our goals. In the meantime, if you have any thoughts, please feel free to email us at [supportgroup@myelitis.org](mailto:supportgroup@myelitis.org) with your suggestions and recommendations. We also realize that some of you have been providing this service and volunteering for a long time and circumstances and situations may have changed, and you are no longer able to volunteer with us. Please do let us know. We respect and greatly value your time and energy and want to hear from you.



# A LETTER FROM DR. ALLEN DESENA



## Dear Members of the TMA,

As my first year of the James T. Lubin fellowship has wound down and I enter my second year, I would first like to say how grateful I am for this opportunity. I have had the extreme fortune to participate in the care of so many wonderful patients, both adults and children. When I first attended the TMA camp last year, it made me realize why I became a physician in the first place and, every day that I have spent seeing patients with TM, ADEM and NMO, talking with families about acute therapies and plans for rehabilitation, and discussing new and innovative ways to improve care, are days that I cherish and value the experience.

We officially launched our acute clinical trial assessing the efficacy of plasma exchange and IVIg in patients with TM and ADEM. We have enrolled our first patient, and remain committed to this project. We are actively working to improve guidelines and ensure outstanding care for all patients. In our outpatient clinic, we continue to be busy. We typically see up to 10 new pediatric patients per month.

On the research side, we have had one paper accepted for publication in a peer-reviewed journal on a case series of patients with autoimmune encephalitis following a brain infection, giving us some potential insights on why these conditions occur. We also have a second paper in review, describing unique patients with TM who have also had peripheral nerve disease. This phenomena is an ongoing, challenging aspect of TM that we are starting to appreciate more readily. Finally, I presented a poster at CMSC (Consortium of Multiple Sclerosis Centers, a meeting that attracts a lot of providers who care for patients with autoimmune diseases of the brain and spinal cord, not just MS) discussing vitamin D3 and ADEM. Anyone that sees us at our clinic knows we are big advocates of vitamin D3 supplementation for ADEM, NMO and TM patients. In addition, Dr. Greenberg and I have been developing a new approach to classify TM. We have identified a series of different patterns in patients that will hopefully tease out better ways that we can approach evaluation and management. We are hoping to provide a better framework for understanding TM, as we feel that such changes may spur better imaging and more targeted medication and physical therapies.

We remain deeply committed to advocacy and getting the message out about TM and rare autoimmune diseases of the brain and spinal cord- both for providers and affected families. Whether it's participating in conferences on campus or participating in webcasts, we are striving to create awareness about the urgency of assessment that is so vital to get treatments quickly for TM, NMO and ADEM patients. I have been enjoying this opportunity to learn immensely. I am not sure if I could ever express my gratitude to you all strongly enough to express the depths of my emotions. I hope to see many of you soon at TMA camp and at the symposium. As Dr. Greenberg says, we always have an "open-door" policy and welcome all thoughts and questions. Thank you all so much.

Sincerely,

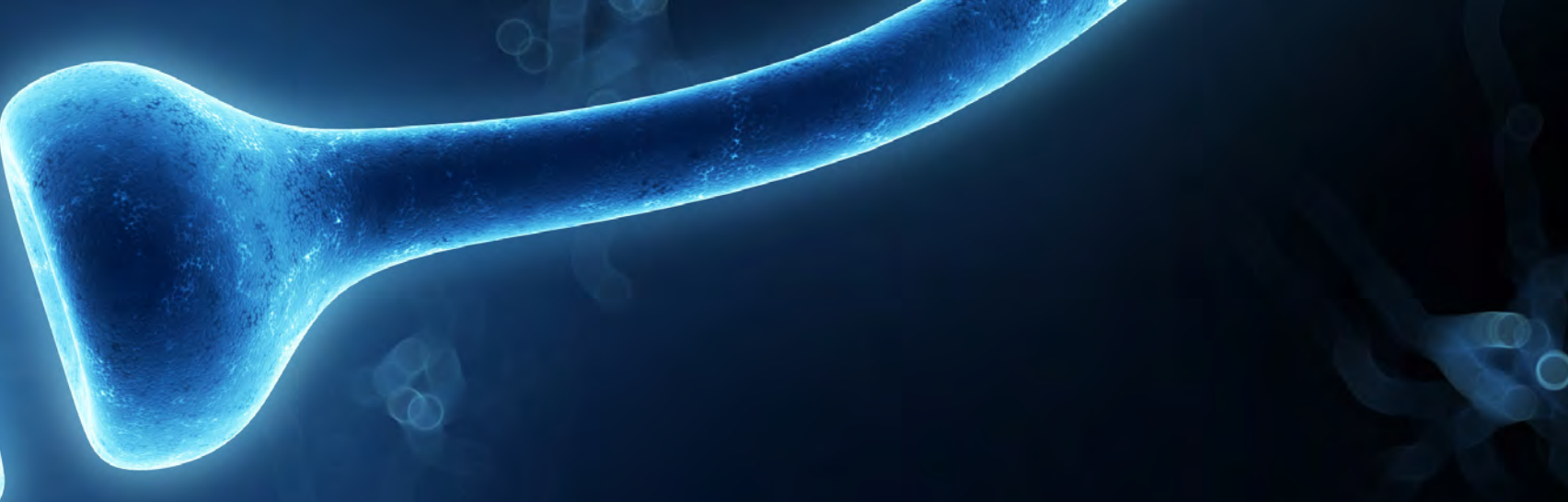
*Allen DeSena*  
July 2013

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*Dr. Allen DeSena is the 2012 recipient of the TMA James T. Lubin Clinician-Scientist Fellowship, a two-year Fellowship that supports the post-residency training of clinicians, who are committed to careers in academic medicine with a specialization in TM, ADEM, NMO, and ON clinical care and research.*







## RESEARCH UPDATE FROM DR. BECKER

First and foremost I would like to thank the Transverse Myelitis Association and its members for the generous support of this important research.

Here is a brief description of what we did in this clinical trial. We randomized subjects into one of four groups. One group used the FES bike once a week. One group used the FES bike three times a week; and one group used it five times a week. The fourth group used the FES bike for cycling only but the electrical stimulation was not turned on. We obtained blood and spinal fluid samples from the participants before they started and after 3 weeks. We are currently testing these samples to learn how electrical stimulation may lead to improvements in function by measuring chemicals such as growth factors and cytokines.

Here is a summary of our progress. After obtaining institutional review board approval for the proposed clinical trial, we began enrolling patients into the study in March 2012. We intended to enroll 16 patients and have done so by the end of the funding period. Out of the 16 enrolled, 14 have completed the study (8 patients have a history of TM, and 5 patients have MS, and 1 patient has a diagnosis of NMO). There was 1 screening failure. One patient did not return for the final study visit. The use of the FES bike was well tolerated in all groups. There were no adverse clinical events noted during the study.

At this time the trial remains open for enrollment. It is our goal to complete assessment on the 16 participants. Preferably we would like to increase the number of TM patients in the study. When we have completed the 16th subject we will perform the laboratory analysis of the blood and spinal fluid samples. We look forward to sharing our findings with the TMA and plan on publishing the data at the national and international level.

Thank you very much for your support.

Sincerely Yours,

Daniel Becker, 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. 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. If you are interested in participating in this study, please contact Shannon Inches at [inches@kennedykrieger.org](mailto:inches@kennedykrieger.org).

*Dr. Becker received a grant in 2012 from the TMA for this study. For more details, please visit <http://myelitis.org/research/supported-research>*



# RISK FACTORS FOR TM COMPARED WITH MS, NMO, AND OTHER NEUROLOGIC DISORDERS IN PEDIATRIC PATIENTS

Kelley M Weinfurter, B.A., School of Medicine, University of California-San Francisco, San Francisco, CA  
 Jennifer Graves, MD, PhD, Neurology, University of California, San Francisco, San Francisco, CA  
 Ellen M Mowry, MD, Neurology, University of California, San Francisco, San Francisco, CA  
 Lauren Krupp, MD, Neurology, Stony Brook University Medical Center, East Setauket, NY  
 Tanuja Chitnis, MD, Partners Pediatric Multiple Sclerosis Center, Massachusetts General Hospital, Boston, MA  
 E Ann Yeh, MD, Division of Neurology, Hospital for Sick Children, University of Toronto, Toronto, ON, Canada  
 Moses Rodriguez, MD, Neurology, Mayo Clinic, Rochester, MN  
 Jayne Ness, MD, Neurology, Children's Hospital Alabama, Birmingham, AL  
 Anita L Belman, MD, Neurology, Stony Brook University Medical Center, East Setauket, NY  
 Marc Patterson, MD, Neurology, Mayo Clinic, Rochester, MN  
 Mark Gorman, MD, Neurology, Boston Children's Hospital, Boston, MA  
 Bianca Weinstock-Guttman, MD, Department of Neurology, State University of New York at Buffalo, Buffalo, Buffalo, NY  
 Judith A James, MD, Rheumatology, Oklahoma Medical Research Foundation, University of Oklahoma, Oklahoma City, OK  
 Emmanuelle Waubant, MD, PhD, Neurology, University of California, San Francisco, San Francisco, CA

**Background:** Transverse myelitis (TM) has substantial clinical overlap, especially on initial presentation, with other autoimmune disorders, including multiple sclerosis (MS) and neuromyelitis optica (NMO). Risk factors for TM are not known.

**Objectives:** We sought to determine if risk factors reported for pediatric MS patients, such as HLA-DRB1\*1501 allele, past infections with common herpes viruses, including Epstein-Barr virus (EBV), cytomegalovirus (CMV), and herpes simplex virus (HSV), and level of 25-hydroxy-vitamin D, were also associated with TM in pediatric patients.

**Methods:** Sera were collected from pediatric TM patients and neurologic controls, and from pediatric MS and NMO patients early in disease course through Stony Brook Pediatric MS Centers and the Accelerated Cure/Guthy Jackson Biobank. Serum 25-hydroxy-vitamin D levels were measured by chemoluminescent immunoassay. Antibodies against EBV (EBNA-1), HSV, and CMV were measured by ELISA. HLA-DRB1 allele status was measured by PCR. Logistic regression models, adjusting for age at draw, were used to compare risk factors between TM and the other groups.

**Results:** Blood samples were collected for patients with TM (n=16), NMO (n=34), MS (n=184), and neurologic controls

(n=31). Median ages at disease onset were 12.3 years (0.4-17.0 years), 11.0 years (1.9-17.3 years), and 14.3 years (1.4-19.2 years) for TM, NMO, and MS, respectively. TM patients were less likely to have been exposed to EBV as compared to MS patients (OR 0.021,  $p < 0.001$ ) and NMO patients (OR 0.154,  $p = 0.054$ ), but had similar frequency as controls (OR 0.62,  $p = 0.573$ ). Vitamin D data are still in progress. No difference was seen in the frequency of DRB1\*1501 allele or exposure to CMV in TM patients as compared to neurologic controls, NMO patients, and MS patients. **Conclusions:** Unlike pediatric and adult MS, EBV exposure does not appear to be associated with TM in pediatric patients. Larger studies are needed to confirm this association.

**Acknowledgements:** TM and some NMO sera were provided by the Accelerated Cure/Guthy Jackson Foundation. The pediatric MS Centers are supported by the NMSS. KW is supported by a grant from the Dean's Office Medical Student Research Program at UCSF. Dr. Graves is supported by the NMSS (Sylvia Lawry award) and the CMSC.

*Poster was originally presented at the Consortium of Multiple Sclerosis Centers (CMSC) – ACTRIMS annual meeting held from May 29- June 1, 2013 in Orlando, FL. <http://tinyurl.com/64qv8nk>.*



## CLINICAL STUDIES OPEN FOR ENROLLMENT

## A Safety, Tolerability and Efficacy Study of V158866 in Central Neuropathic Pain Following Spinal Cord Injury

**INVESTIGATOR:** CHRISTINE N. SANG, MD, MPH | BRIGHAM AND WOMEN'S HOSPITAL, BOSTON, MA

### Study Details

V158866 is an active inhibitor of FAAH1, an enzyme that metabolizes the endocannabinoid called Anandamide (AEA). It is hypothesized that inhibition of FAAH1 can decrease pain without generating side effects in non-activated pathways. Therefore, the primary objective of this study is to investigate the safety and tolerability of V158866 in subjects with central neuropathic pain following spinal cord injury (both traumatic and non-traumatic) and evaluate its analgesic and anti-hyperalgesic effect. The study will consist of four overnight visits to the hospital. All travel to and from the hospital will be reimbursed.

### Eligible Participants

Male and females (not of child-bearing potential) between 18 - 65

years old with a documented spinal cord injury will be eligible to participate in this study. Participants must have central neuropathic pain that is of at least moderate intensity, daily for at least 3 months before study entry. This study will be of no cost to the participant. Your participation is voluntary.

### Contact Information

If you are interested in participating, please contact the Translational Pain Research Group by email at [paintrials@partners.org](mailto:paintrials@partners.org) or call 617-525-7246. For more information, please visit the NIH ClinicalTrials.gov: <http://tinyurl.com/n4vpa47>.

## Safety and Efficacy of Sustained Release Dalfampridine in TM

**INVESTIGATOR:** MICHAEL LEVY, MD, PHD | JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD  
**COLLABORATOR:** ACORDA THERAPEUTICS

### Study Details

The goal of this clinical trial is to test the efficacy of dalfampridine in patients diagnosed with Transverse Myelitis. Dalfampridine is a sustained-release potassium channel blocker that has been shown to be effective in improving gait and other neurologic functions in multiple sclerosis. Dalfampridine has the potential to improve gait and neurologic function in patients with transverse myelitis because of a similar pathogenic process with multiple sclerosis.

### Eligible Participants

Patients (18-65 years) diagnosed with idiopathic transverse myelitis

confirmed by MRI will be eligible to participate in this study.

Diagnosis of any other recurrent CNS disease including multiple sclerosis, recurrent myelitis, or neuromyelitis optica is an exclusion criteria for the study. More criteria for exclusion can be found on our website: <https://myelitis.org/research/clinical-studies-trials>.

### Contact Information

If you are interested in participating, please contact Maureen Mealy, RN at [hopkinstmcenter@jhmi.edu](mailto:hopkinstmcenter@jhmi.edu) and refer to this study by its [www.clinicaltrials.gov](http://www.clinicaltrials.gov) identifier: NCT01446575. For more information, please visit the NIH [www.clinicaltrials.gov](http://www.clinicaltrials.gov) site.

To learn more about other clinical studies and trials, please visit <https://myelitis.org/research/clinical-studies-trials>.



# 2013 RARE NEURO-IMMUNOLOGIC DISORDERS SYMPOSIUM

*Repair and Recovery, Today and in the Future*



*Friday & Saturday | October 25-26, 2013 | Dallas, Texas  
UT Southwestern | T. Boone Pickens Biomedical Building*



The Transverse Myelitis  
Association

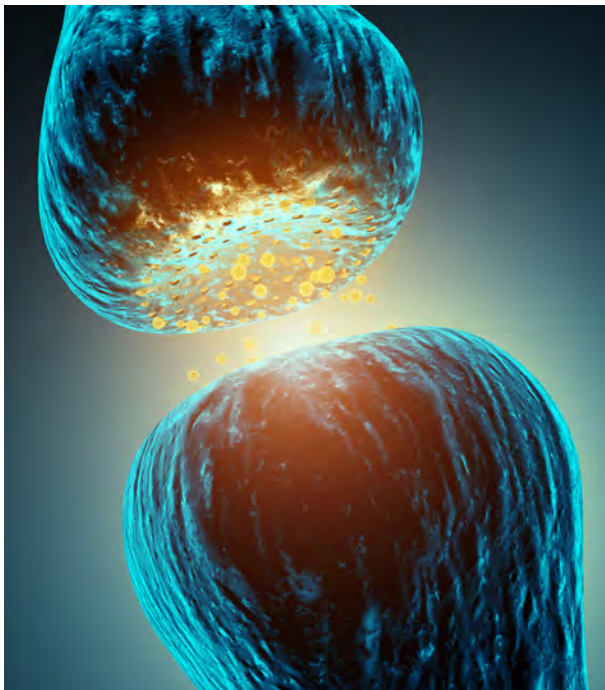
UT SOUTHWESTERN  
MEDICAL CENTER

children's  
MEDICAL CENTER



The Johns Hopkins  
PROJECT RESTORE

The Transverse Myelitis Association, University of Texas at Southwestern in Dallas, TX, Children's Medical Center in Dallas, TX and The Johns Hopkins Project RESTORE in Baltimore, MD are delighted to host the 2013 Rare Neuro-immunologic Disorders Symposium: Repair and Recovery, Today and in The Future.



This symposium will be focused on current strategies and research projects addressing opportunities for recovery of function after CNS damage. The symposium will be held on Oct 25-26, 2013 at University of Texas Southwestern in Dallas, TX.

The focus of this two-day education program is on repair, recovery and restorative therapies. We have framed the agenda around five themes: rehabilitation, drug-based functional recovery, surgical repair strategies, drug-based repair therapies and cell based repair strategies. The symposium is open to patients diagnosed with rare neuro-immune and demyelinating disorders, their families and caregivers and the medical and research community.

In keeping with our mission, we view these events as extremely important and beneficial for the exchange of information regarding research and treatment strategies as well as providing an opportunity to bring together the individuals diagnosed with these diseases and medical community.

**Registration is now open for TMA members and non-members.** For more information on registration and agenda, please visit our website at <http://myelitis.org/2013rnds>.







# Oh, the places you'll go!

## SILENT AUCTION

Jimmy's  
3565 Labore Rd | Vadnais Heights, MN 55110  
Sunday October 6th | 1:00 – 6:00 PM

My name is Maddox Seeger. I am helping to raise awareness and fund research efforts for Transverse Myelitis (TM). This is an autoimmune demyelinating disease that attacks the spinal cord. About 1400 new cases of transverse myelitis are diagnosed each year in the United States, and approximately 33,000 Americans have some type of disability resulting from the disorder.

When I was 2 years old I contracted this disease leaving my left leg partially paralyzed. Now 6 years later I have come to realize that I have a mission to educate and support others. I would like to share my journey and bring awareness to EVERYONE affected by such rare neuro-immune diseases.

You can help by joining me at the Silent Auction or by donating directly to The Transverse Myelitis Association at [www.myelitis.org/donate](http://www.myelitis.org/donate).

100% of the proceeds will benefit the Transverse Myelitis Association to advance research efforts.

For more information please contact my Mom Amy Seeger at (303)-585-1909 or [seegeramy@gmail.com](mailto:seegeramy@gmail.com).

Thank you,  
MADDOX



# GIVE US A HAND TO GET US BACK ON OUR FEET



[WWW.MYELITIS.ORG/WALK](http://WWW.MYELITIS.ORG/WALK)





# ILLINOIS AND MICHIGAN JOIN THE TMA WALK-RUN-N-ROLL CAMPAIGN

As some of you know, the TMA has been promoting a new nationwide awareness campaign to raise funds for the association and related research on rare neuro-immunologic disorders.

Recently, a small group of TMA members in MI and IL came together to be a part of the TMA's Walk-Run-N-Roll awareness campaign. Rebecca shared her hopes and medical concerns for her five-year old son who developed TM at four months of age. He wants nothing more than to be like all the other kids and become a Detroit Tiger; he currently uses bracing, crutches and his wheelchair. He just graduated from kindergarten but struggles daily with the effects of his spinal cord injury caused by TM. Darlene, who developed TM four years ago, has a busy household of teens and young adults, all while juggling being a student herself. Darlene, determined not to be in a wheelchair, walks courageously, haltingly with a cane. This is a snapshot of the people affected by these diseases. You can read more about their stories on the TMA blog - <http://myelitis.org/category/resources/tma-blog> and on the Illinois blog - <http://tmailinois.blogspot.com>.

We invite you to join us in this journey and help raise awareness and funds to advance clinical care and research for rare neuro-immune diseases. So many questions remain unanswered: Why

do some people recover and others do not? Why is everyone affected differently? When can we hope for new remyelination and repair strategies for us?

On October 5th and 6th, we will celebrate the courage and accomplishments of the people who have these rare neuro-immune diseases and their loved ones. This has not been an easy journey for any of us--but we don't have to travel alone. Confronting these illnesses together is crucial.

Please join us in this mission - sign up to join the Michigan Walk-Run-N-Roll on October 5th and the Illinois Walk-Run-N-Roll on October 6th and form your team on Crowdrise ([www.crowdrise.com/thetma](http://www.crowdrise.com/thetma)) by clicking on one of the two fundraising events; invite your friends and family, spread the word. If you are not able to join us in person, you can still get involved and show your support by forming a team -we will walk-run-n-roll for you. For details on how to set up your team, we have developed a guide that you can find by going to: <http://tinyurl.com/pmdgss4>.

We are also proud to share that thanks to our member Michelle Alecia, October 6, 2013 has been proclaimed by Governor Quinn as "Transverse Myelitis Day" in Illinois.

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**ORGANIZE A WALK IN YOUR CITY** If you would like to join this campaign to help the TMA please contact us at [info@myelitis.org](mailto:info@myelitis.org).

October 5  
Michigan - Campus of Harderwyk Ministries  
HOLLAND

October 6  
Illinois - McCollum Park  
DOWNERS GROVE





# THANK YOU NJ, PA, GA AND FL FOR MAKING IT HAPPEN!

The TMA Walk-Run-N-Roll Awareness Campaign of 2013 started with walks in April and May 2013 in four cities in New Jersey, Pennsylvania, Florida and Georgia. We are so grateful to the volunteers and leaders who worked so hard to spread the word about these rare neuro-immune diseases and raised funds to support research and education programs that we offer! Our heartfelt THANK YOU!

## April 13 | New Jersey, Cooper River Park | PENNSAUKEN

Approximately 150 people participated in the 2nd Annual South Jersey Walk, which took place in April this year, much warmer than the March 2012 walk! We were excited to raise approximately \$10,000! But what was truly wonderful about the event was the number of TM'ers present. There were approximately 15 of us, in addition to our families, and we were truly grateful to meet one another, many for the first time. Rob Pall, the chair of New Jersey's TMA Support Group led the walk, and many fellow TM'ers were able to complete the entire 4 mile walk. The Committee is looking forward to a third successful Walk next year.

– Colleen Spaeth



## April 13 | Pennsylvania, Museum Bldg | SOUTH PARK TWP.

Pennsylvania's TMA Walk-Run-N-Roll event was held on April 13, 2013 at South Park. It was a cool brisk morning with blue skies where you needed to wear extra layers- jackets, gloves and even blankets. Excitement was in the air! We were so pleased and blessed to welcome approximately 100 participants. We thank friends and family and teams that helped raise funds to support the various teams led by Brittany Kyper, Maria Hoge, Rhonda Layman, Opeka Repair Auto, Linda & Lee Farley, Melissa Rousseau, Ben Zimmer, Tanya Hileman, Suzan Holt. We raised \$5,900! Thank you to Kate Schramm who took all the pictures! To everyone who was involved in this event, I thank you from the bottom of my heart! You are the best and we could not have done this without you. Thank you! Thank you! It was an unbelievable experience and I hope you enjoyed it as much as I did. Until next time, God Bless, Take Care, and Keep in Touch! To read more and see pictures, please visit the TMA blog: <http://tinyurl.com/nv2delx>.

– Pam Hoge

## April 27 | Georgia, Hunter Park | DOUGLASVILLE

Georgia's 1st annual TMA Walk and Roll event was held on April 27th 2013 at Hunter Memorial Park. We truly have the most caring people in our community. About 100 people attended from all over the state. We were honored that Debbie Capen, Secretary of the TMA and her husband Michael joined us from Lake Havasu City, AZ, and Linda and Gary Hadley joined us from North Carolina. New friendships blossomed; people with TM who had never met another "TMer" shared stories and got to know each other. Project Walk Atlanta and MS Center of Atlanta joined us and shared how they could help and support individuals and families with TM. We had a successful bake sale! Karen Fowler Staab (mother of a child with TM) graciously offered to make her "hamburger" cookies. A week prior, we held a "Spirit Night" to raise funds for the TMA at Texas Roadhouse. A special thank you to all our friends, family and volunteers that made this day so successful!

– Kim Harrison

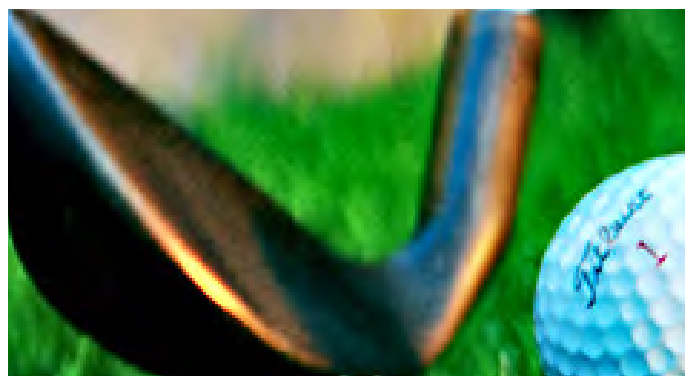
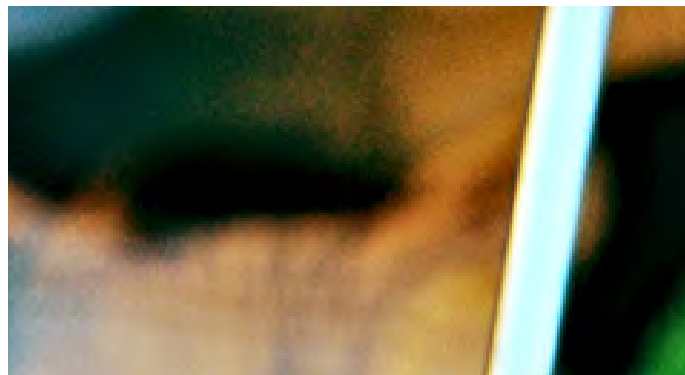
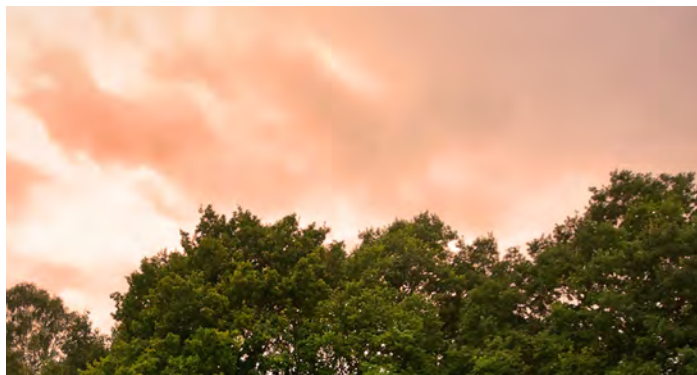


## May 11 | Florida, Riverfront Park | COCOA

Our May 2013 Walk for TM was our way of raising awareness for this debilitating disease that has not only struck our precious daughter but many others. We raised awareness and came close to our fundraising goal but more importantly we offered support to others with TM from Brevard and surrounding counties. It was fulfilling, magical and truly a heartfelt day in our life and the lives of so many others! We look forward to making this a tradition and growing it each year to bring even more awareness to the diseases that the TMA advocates for and financially supporting the TMA so we can find a cause and a cure! One of our participants, Ron Raulerson, shared his experience in a blog for the TMA after the walk, which can be found by going to: <http://tinyurl.com/mjrb5b9>.

– The Robbins Family





## TMA GOLF OUTING IN 2014

We are excited to announce our first golf fundraiser at Cumberland Trails on the far eastside of Columbus on Friday Sept 19, 2014! We are in the very beginning stages of our planning and wanted to reach out to our members to invite you to play, to have you invite your friends and family members who play golf and to seek volunteers to help us with the planning of this event to mark the 20th Anniversary of the TMA.

When Erica and Josh Bush, Pauline and I got together a few months ago, we started talking about the possibility of a golf fundraiser as Erica, Josh and their family are very closely tied to the sport. We want to raise funds for research focused on developing new therapies to restore function after a demyelinating attack. Erica got TM when she was 2 years old. I got involved in doing the work of the TMA when my wife, Pauline, got TM in 1994. Mark and Michele McCloskey have recently joined our planning group. Mark got TM in October 2010. Mark and

Michele feel strongly that we need a fund-raising "infrastructure" that can be sustained to help with the research that will help those already affected, limit the damage from TM attacks, and better understand why these events happen.

It will be a shotgun start between 10am and noon and we are planning a packed lunch, a dinner at the end of the day, perhaps a silent auction and contests to raise funds for the TMA. We need your support to make this event happen. If you would like to get involved in helping us with the planning and execution of this important event, please get in touch with me. We are looking for volunteers with experience and interest in marketing and communications, fundraising through corporate sponsorships, and event planning to join our planning committee.

If you have suggestions or connections to vendors, sponsors, restaurants and would like to connect us, we would greatly appreciate it.

If you would like to play, please respond to the Save The Date Form by going to: [http://eepurl.com/zO\\_g9](http://eepurl.com/zO_g9)

If you have friends and family who you think might be interested in playing, please talk to them about it, make sure the date is on their calendar, and please ask them to complete the form too. Formal invitations with details about registration fees will be sent out in January 2014.

If you have any questions, you can reach me at [ssiegel@myelitis.org](mailto:ssiegel@myelitis.org), Erica at [ericajbush@gmail.com](mailto:ericajbush@gmail.com), Josh at [josh.bush3@gmail.com](mailto:josh.bush3@gmail.com) or Mark and Michele at [markmcclous@yahoo.com](mailto:markmcclous@yahoo.com).

We hope that you are doing well.

Take care,

Sandy





# Transverse Myelitis & COACHING

## BARBARA BABCOCK

During the past year I researched the impact of coaching on the wellbeing of people with Transverse Myelitis and their primary caregivers for my MA in Psychological Coaching. 'Coaching is unlocking a person's potential to maximise their own performance. It is helping them to learn rather than teaching them' (Whitmore, 2002). Coaching is done via a series of purposeful conversations which enables an individual to move towards his or her goals.

Given my personal experience of TM, being a committee member of the TM Society and seeing others affected wanting to make change but not sure how, I identified psychological coaching as another intervention to enable this population to achieve their potential and enhance their quality of life within the realities of having TM. Including the primary carer (whether s/he was a spouse, partner, parent, child, sibling, relative or friend) made us recognize that others are also affected and they may desire/need emotional/psychological support.

Five members of the TM Society took part in the research - two mother-daughter pairs and one mother. They each received up to 6 coaching sessions.

The findings confirmed that coaching enhanced clients' wellbeing. Addressing the following issues, which were related to the clients' goals, contributed to the clients' improved sense of wellbeing.

- Developing clients' abilities to take control of issues that they found stressful. This enhanced their capabilities to care for themselves as individuals and in relationship with others.
- Learning to live with the uncertainty that comes with living with TM (for example, not knowing how well or not one will feel from day to day), so that it does not cause anxiety.
- Loss in the context of a chronic condition.
- Reciprocity and roles within the context of family dynamics, which improved family relationships for all clients.

One client reported reduced stress and hence less TM symptoms as a result of learning to manage herself differently in relation to family members. Another client reported being better able to manage her chronic pain and feeling more calm as a result of becoming aware of how her internal thought process was not helping her take care of herself and learning how to change it. Another client learned how to view the actions of others and issues differently so that she did not feel as much stress. All the mothers learned how to give responsibility for solving their adult children's problems back to their children.

Over the coming year, I hope to write articles based on my research and share them with you.

As of April 13, 2013, I am also the new chair of the TM Society in the UK.

*The TM Society, started in 2004, is a registered charity in England and Wales, with over 1000 members. All members of the worldwide TM Association living in UK are automatically members of TM Society as well. The aim of the society is to offer support and information to all those who may have, or know someone with Transverse Myelitis and its associated conditions such as NMO (Devic's Disease), ADEM and others. The TM Society provides support via Support Group meetings held around the country, and has held UK TM Conferences which have included world-class speakers and leaders in their fields.*





## TM AWARENESS DAY BRISBANE

On May 17 people gathered for the 4th annual TM Awareness Day in Brisbane. David Riley, President of the Spinal Injuries Association (SIA) Management Committee, opened the day with a warm welcome and introduction. Among those who attended was Professor Graham Martin (last year's key note speaker) with his wife Jan by his side.

The first guest speaker was Priscilla Maxwell who gave an interactive presentation about 'Mindfulness and Meditation' engaging all with her calm and insightful understanding of the topic and its usefulness when dealing with stress, pain and emotional challenges faced by people with TM and their families on a daily basis. Dr. Benjamin Greenberg from the TM Clinic at the University of Texas Southwestern in Dallas followed with a dynamic audiovisual presentation about 'Restoring Function after Transverse Myelitis: Where We Are and Where We Are Going'. Ben opened with a very clear and frank explanation of the effects of TM on a person and finished with an update of the current research and understanding of the condition along with advice about continued recovery and restoration. Two very clear messages came out of Ben's presentation:

1. Never give up - use it or lose it, prompting all to continue taking charge of their own recovery and never ceasing therapy of the body and mind.
2. Most people with TM use around 10 times the energy to take every step, a very clear message to all of the struggles we face every day.

Finally Ben spoke of his desire to visit Australia along with some of his colleagues within the next year and hopes to establish face to face contact with doctors to open the lines of communication on rare neuroimmunological diseases.



Ben's presentation can be viewed here - <http://www.spinal.com.au/services/support-networks/transverse-myelitis>.

The day was a great success as people mingled and shared their own stories during breaks from formal presentations. Much discussion about TM Day has occurred since May 17th reaching out to the wider TM network through social media and personal contact. Finally Professor Graham Martin generously gave all members in attendance a copy of his newly released book 'Taking Charge:

A Journey of Recovery'. This too has prompted discussion and is a compelling read for all those with TM, NMO and ADEM and their families.

Thank you to the wonderful efforts of Liz Conway and Jeanette Kretschmann for their hard work in organising the day, the SIA for hosting the Event and all those who attended. Graham Martin's book is available at [www.familyconcernpublishing.com.au](http://www.familyconcernpublishing.com.au).

- Louise Remifton - TM Facilitator  
Spinal Injuries Association, Brisbane

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.



# RECOVERY NEVER STOPS

## & Other Wisdoms from the Regional Transverse Myelitis Clinical Care Symposium in Baltimore

Baltimore is quite a drive from Michigan but when I first heard about the Regional Transverse Myelitis Clinical Care Symposium hosted by The Johns Hopkins Transverse Myelitis Center (JHTMC), Kennedy Krieger Institute and the TMA in June, I knew we needed to be there. As much as we want our son to be seen by the physicians and therapists at Johns Hopkins and Kennedy Krieger, we struggle with the distance, cost, and the sheer effort of the fight with our insurance company to bridge the gap between us. The regional symposium was an opportunity for us to further educate ourselves, to become better equipped to advocate on behalf of our son with our insurance companies and the physicians we have available to us here at home. We needed to hear directly from the experts and obtain our information straight from the source leading the way in the diagnosis, treatments, and rehabilitation for transverse myelitis patients.

The JHTMC Symposium was so worth our weekend drive! The program was encapsulated within a day and held at the Bloomberg Children's Center, an accessible venue. The agenda covered a breadth of topics with breaks and lunch. Almost every topic spoke to the struggles we face or questions we have concerning our son's psychiatric/cognitive effects in transverse myelitis, bowel and bladder management, pain and spasticity management, and the current research studies in transverse myelitis. The speakers included physicians, nurses, and therapists, each delivering their expertise on treatments and research in a clear, concise manner. Nearly all of the topics covered could certainly warrant their own day of discussion but given the time limitations, the information offered was very useful and helped us gain a better understanding of the disorder affecting our son.

Particularly interesting to us was Dr. Kaplin's presentation on cognition and depression in the transverse myelitis population. The information he provided has really stuck with me as something to watch in our son. We've always wondered if and how our son's transverse myelitis plays into his abilities with school and comprehension. Dr. Kaplin shared findings from research done at family camp last summer that confirmed for us that our son might indeed need that slightly extra help at school that his siblings or peers may not, because of his diagnosis. Disconcerting and eye-opening to me was the rate of depression and suicide in the patient population...a topic that has stuck with me since and one to be very vigilant about...our main focus is to never lose hope. For someone to lose their life because of the feeling of hopelessness from transverse myelitis would be one too many.



Dr. Becker provided details of research related to myelin regeneration and the direct correlation with advanced therapies. He reiterated the fact that we have fought about with our physicians, therapists and insurance companies since our son was released from the rehabilitation hospital as a baby - recovery never stops and rehabilitation should never stop!

An open panel for Q&A was offered at the end of the day with all of the speakers, a great opportunity for clarification of topics and questions that may not have been addressed.

The program moved swiftly enough to keep everyone's attention and interest, yet

didn't go too quickly that information was lost on the audience. The coordinators, volunteers and the staff speaking at the event were very kind, cordial and accessible. I was so struck by the approachable demeanor and willingness of the physicians, nurses, and therapists to speak with patients and caregivers. We have had appointments with other clinicians/hospitals that wouldn't give us the amount of time that these individuals were giving more so while giving up a part of their weekend for the purpose of educating patients and caregivers. Whether you are a patient or a caregiver, we highly recommend attending one of the symposiums if you are able to do so. As parents of a child with this diagnosis, we believe the

additional information provided through the symposium will further assist us with the educational, medical and every day needs of our son. We are so thankful for the TMA and the Centers of Excellence for these opportunities to learn more about these rare disorders that we simply can't find in our local medical community. All lectures were recorded and are available on the TMA website <http://tinyurl.com/o576uu2>.

*- Rebecca Whitney (mom of 3, youngest diagnosed with TM at 4 months of age)*

## IN THEIR OWN WORDS ARTICLES

In each issue of the Journals and Newsletters, 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 your 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.

## 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>.

# VOLUNTEER PATIENT PROGRAM

I have had Transverse Myelitis for 25 years now and despite having seen numerous doctors over the years, I seldom see one who is familiar with TM so when I saw a small poster asking for Volunteer Patients who have a long term condition and who were willing to talk to medical students, I jumped at the chance.

I am fortunate enough to live within 10 miles of St Andrews University which has an excellent medical school. After contacting the





patient coordinator, I was delighted to be accepted on their programme and was even more pleased to discover the professor in charge was particularly interested in my case. She had heard of TM but never seen it and seemed really pleased to use me. Apparently when a student sees an unusual condition like TM while they are training, they never forget it.

The main theme of the programme is to allow the students to feel like they are actually holding a proper consultation with a 'real' patient. The students are normally in groups of 5, each group with a tutor who is a qualified doctor. There is one volunteer patient to each group of students. The students (especially first year) are often more nervous than the patient so I ask them to refer to me by my christian name in an effort to put them at ease. The students ask me to relate my medical history, i.e. what happened at onset, symptoms, what treatment I received, what medication I take etc. They can then ask questions and generally one or two take notes. I tell them that no subject is taboo and they can ask me about any and all aspects of my condition. I make a point of telling them that having a long term condition not only affects the patient, but has an equally devastating effect on family members too. Each session lasts approx 25 - 30 minutes then I move on to the next group, usually covering 4 groups at each meeting.

I have been talking to medical students for 2 years now and hope to continue. During the first year I spoke exclusively to first year students but have since been able to speak to second and third years. My main reason for getting involved in this programme is to inform as many people in the medical profession as possible about Transverse Myelitis and its affects. I tell them that no matter what branch of medicine they end up in, they will have seen TM and hopefully remember and be more able to diagnose it quickly if confronted with it in the future.

The students benefit greatly from having direct contact with actual patients, which in turn makes them better prepared for their first attempts at diagnosing and treating a wide variety of conditions. From my personal point of view, I find it quite therapeutic, and really enjoy meeting the students and like to think I am making a small contribution to student training. I would also hope that my experience will encourage other TM sufferers to look for similar programmes in their area and if there are none, perhaps they can persuade other universities to look at the possibility of introducing this type of training for their medical students.

*- Sandy Smith  
Transverse Myelitis Scotland*

## 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 either by going online to <http://tinyurl.com/bswg6yp> or via email at [info@myelitis.org](mailto: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 this way. 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.

## NEED FOR CAUTION ON SOCIAL MEDIA

Recently, we have been made aware of events concerning some of our pediatric patients with disabilities being approached online through social networking sites by child predators. We have always felt that social networking sites provide unique opportunities for getting families and patients together to share experiences. However, we strongly encourage all families, especially those with children, to ensure that their privacy settings are set appropriately so that strangers do not have access to any personal information. Also, we need to be wary of any individuals that are aggressively seeking to "meet up" with you and/or your children. Often, these people may appear to be friends and/or may masquerade as patients themselves. If you hear online from a suspicious individual, we recommend that you contact the authorities immediately and cease contact with the individual. Thank you.





### **WELCOME JASON ROBBINS TO THE BOARD OF DIRECTORS!**

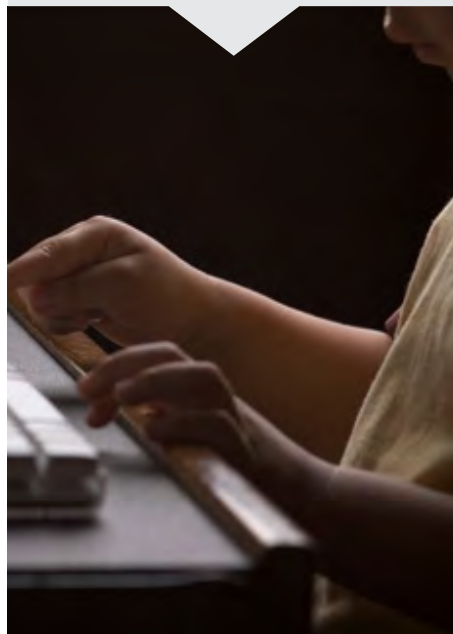
We are honored to announce that Jason Robbins from Merritt Island, FL has joined the TMA Board of Directors. Jason Robbins is a graduate of the University of Florida and St. Thomas University School of Law where he earned his Juris Doctorate. He is a member of the Florida Bar, American Bar Association and the Florida Worker's Compensation section of the Florida Bar. In November 2011, Jason and Tina's 10-year-old daughter, Sarah, was diagnosed with Transverse Myelitis. Sarah is a fighter and has been unwavering in her fight to get her lower body and legs moving again. She serves as an inspiration to Jason, his wife, Tina, and the family.

### **RENEW YOUR TMA MEMBERSHIP!**

The membership of The Transverse Myelitis Association includes persons with rare neuro-immunologic 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 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!



### **PODCAST RECORDING IS NOW ONLINE!**

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

You can listen to the recording of Dr. Greenberg and Dr. DeSena by going to <http://tinyurl.com/pbd3np4>.





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## ANNOUNCEMENTS

**2013 Rare Neuro-Immunologic Disorders Symposium:** Oct 25-26, 2013, please make your hotel reservations early. Details inside.

## DONATE

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