

**THE TRANSVERSE MYELITIS ASSOCIATION**

# NEWSLETTER

**ADVOCATING FOR THOSE WITH ADEM, AFM, NMO, ON & TM**

**SPRING 2015**

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2015 rare  
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*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 EDITOR'S COLUMN | Sandy Siegel, PhD

The first time the TMA community came together was at a meeting and educational program in Columbus, Ohio in 1997. Coming together as a rare disorder community was a truly profound experience and none of us will ever forget that weekend. We quickly came to understand and appreciate the power of coming together with a group of people who understood our experiences in a way that no one else possibly could. We also recognized the importance of offering a support network to our members, as it became obvious for us very quickly that people were seeking support in their local communities. From these critical needs **THE TMA ESTABLISHED THE CONCEPT OF SUPPORT GROUP LEADERS, AND THESE SUPPORT GROUPS WERE INITIATED BY COMMUNITY MEMBERS WHO VOLUNTEERED TO TAKE ON THIS ROLE ACROSS THE COUNTRY AND AROUND THE WORLD.**



As these disorders are rare and our members are geographically spread out across the globe, our hope was that we would be able to get at least one person in each state and each country to be a support group leader. We also hoped that over time with more people getting involved and our membership growing, that we would be able to attract more people who lived in larger cities, states and countries to begin collaborating as support group leaders to serve our members in those geographic areas.

**THE GOALS OF THE SUPPORT GROUP PROGRAM WERE TO OFFER PEOPLE A POINT OF CONTACT WHEN THEY WERE NEWLY DIAGNOSED WITH ADEM, NMO, ON OR TM.**

Pauline, Debbie, Paula and Jim understood what it was like to go through this experience alone because there was no organization when they were diagnosed with TM. We wanted to be sure that to the extent possible, no one would have to go through this experience alone. When a person signed up to become a member of the TMA, and they lived in a state with a support group leader, we sent their membership form to that person and they were asked to contact that person within a few days. We also listed the support group leaders on our website so that any person needing someone to talk to would have someone to reach out to in their area.

**WE WANTED FOR SUPPORT GROUP LEADERS TO HOLD MEETINGS SO THAT PEOPLE HAD THE OPPORTUNITY TO GET TOGETHER ON A PERIODIC BASIS.** Many of the groups did and have continued to hold these meetings. Many of the groups have been really creative in developing and offering medical education programs, and they all have a very important social and emotional support component.

It was also our hope that support group leaders would develop a knowledge base about their region of the world. The TMA is a small organization with limited resources. We can't possibly learn who are the best doctors in your area in each of the specializations, what are the best rehabilitation centers, what are the best medical equipment and supply companies, who are the best orthotists, what are the rules for Medicaid in the state, what other financial resources might be available, where might one find a medical

equipment exchange, and all of the other important resources people regularly need to maximize their quality of life. Our hope was that support group leaders would develop this knowledge base over time through their own experiences and through their networking activities with other members in their cities, states and countries.

While we shared our expectations and hopes with the support group leaders, it was not always feasible for support group leaders to commit the time and resources needed to achieve them, and the level of support being offered varied based on the person, the city, the state and the country. A major part of the problem was that the leadership of the TMA for 18 years included people who had full time jobs and families, and just didn't have the time to devote to maintaining the consistency and level of service our community deserves. We were thrilled to accept help from community members who volunteered to be a support group leader. Some people made an amazing commitment to this work while others had the greatest of intentions, but just didn't have the energy to really do the job. There have been people who served the community well for a period of time, and then were unable to continue due to their own health issues, or the community lost interest in attending support group meetings.

**WE HAVE HAD AN EXCEPTIONAL GROUP OF VOLUNTEERS WHO HAVE MAINTAINED THEIR SUPPORT GROUPS OVER A VERY LONG PERIOD OF TIME AND HAVE DEVELOPED THOSE GROUPS INTO ORGANIZATIONS THAT ARE RECOGNIZED BY THEIR GOVERNMENTS AS FORMAL ORGANIZATIONS WITHIN THE INTERNATIONAL TMA.** Margaret Shearer in Scotland, Errol White in Australia, and Ursula Mauro in Germany have served their communities in such exceptional ways for such a very long period of time. And all of these people also suffer with all of the complications of these disorders. And, there was Geoff Treglown of England who not only started the support network in the UK, Geoff also served all of Europe, with the support of Lew Grey, to make possible the mailing of the TMA publications across Europe. There have been many people across the United States and around the world who have provided a wonderful service to our community for a long time. Thank you!

The TMA has certainly grown and our work has become so much more complex. Our current membership is over 11,000 people and we continue to grow at a rate of about 50 new people per month. We are learning more and more about the rare neuro-immune disorders which magnifies the complexity of information about diagnosis, treatment and rehabilitation. Thus, education and advocacy have become even more critical. Our organization is regularly involved in research, both through advocacy and also direct funding. Our James T. Lubin Fellowship Program has become a very significant success. **OUR EDUCATION PROGRAMS ARE EXPANDING WITH THE SYMPOSIA, THE CAMP PROGRAM AND THE MONTHLY PODCASTS.**

The TMA has become a much more formal organization than we were for the first two decades of our existence. We are no longer the mom and pop operation that motored on the work of volunteers who devoted their evenings and weekends to getting all of this work done. And that is with the exception of Jim, of course, who worked for the TMA 24 hours a day, 7 days a week (or at least when there wasn't a good movie on television). Creating a more formal support group network will mean better service for our members, but it also means a higher level of expectations that needs to be maintained over a long period of time. **THE TMA IS IN THE PROCESS OF BETTER DEFINING THE EXPECTATIONS THAT WE WILL HAVE FOR SUPPORT GROUP LEADERS. WE WILL**

**ALSO DEVOTE RESOURCES TO TRAINING AND EDUCATION, AND WILL DO WHAT WE CAN TO OFFER BETTER SUPPORT TO THESE SPECIAL PEOPLE WHO ARE WILLING TO SERVE IN THIS CAPACITY.**

**“Creating a more formal support group network will mean better service for our members, but it also means a higher level of expectations that need to be maintained over a long period of time.”**

We are very excited about the future of this endeavor. We know that having this support network in your community can make a significant difference in your lives. And that's our mission; we aspire to have the maximum quality of life for our members. We will be launching this new support group program during the symposium that will be held this October in Dallas. There will be a special session devoted to our support group leaders. Our current support group leaders will be contacted about the details. The continued training and education of support group leaders will become a regular part of this program, and our hope is that as these leaders develop better knowledge and skills, everyone will benefit from these efforts.

**IF YOU ARE INTERESTED IN GETTING INVOLVED IN THIS IMPORTANT WORK, AND HAVE THE TIME, ENERGY AND DESIRE TO MAKE A DIFFERENCE IN OTHER PEOPLE'S LIVES, PLEASE LET US KNOW.** We are always looking for people to serve as support group leaders in their cities, states or countries.

Please take good care of yourselves and each other.  
**SANDY**



# SPINAL CORD MRI RESEARCH STUDY FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH TRANSVERSE MYELITIS

Nadia Barakat, PhD, Boston Children's Hospital



**M**y doctoral research efforts focused on establishing diffusion tensor imaging (DTI) as a neurodiagnostic tool in examining the pediatric spinal cord. DTI is an MRI-based technique used to image the diffusion of water in the nervous system. DTI makes it possible to see the location and orientation of white matter tracts in the brain and spinal cord. I successfully demonstrated the feasibility and reliability of diffusion tensor imaging in the pediatric population using a 3-Tesla MRI scanner. This work was awarded the Derek Hardwood-Nash Award for best paper in pediatric neuroradiology by the American Society of Neuroradiology.

During my doctoral training, I also reported an intriguing case study of a child with transverse myelitis whose MRI and diffusion tensor imaging results did not detect any

abnormalities, even though the patient showed clinical deficits. These findings suggested that even though MRI and diffusion tensor imaging provide a strong metric in the evaluation of children with traumatic spinal cord injury, they may not be sensitive in the detection of non-traumatic lesions.

This intriguing case study was the motivation behind a recently funded K-award by the National Institute of Health (NIH). Under the mentorship of Dr. David Borsook, director of the P.A.I.N. Group (<http://www.childrenshospital.org/research-and-innovation/research/centers/center-for-pain-and-the-brain-pain-research-group>) at Boston Children's Hospital and in collaboration with Dr. Mark Gorman, director of the Pediatric Multiple Sclerosis and Related Disorders Program, I plan to use

advanced MRI techniques to measure changes in the spinal cord of children with acute, persistent and resolved transverse myelitis, and define the relationship between these changes and the severity of pain.

**MY PROFESSIONAL ASPIRATION IS TO IMPROVE THE HEALTH OF CHILDREN WITH NEUROLOGICAL DISABILITIES WITH MORE EFFICACIOUS TECHNOLOGIES AND IMAGING TECHNIQUES.** I strongly believe that developing reliable imaging methods which provide a definitive indication of the extent of spinal cord injury and better understanding of pain associated with spinal cord injury may help improve clinical care and prepare for potential human clinical trials for regeneration of spinal cord tissue following injury.

## RELATED PUBLICATIONS:

Barakat et al. Diffusion tensor imaging of the normal pediatric spinal cord using an inner field of view echoplanar imaging sequence. *AJNR Am J Neuroradiol.* 2012 Jun; 33(6): 1127-1133.

Barakat et al. Diffusion tensor imaging in pediatric transverse myelitis: A case study. *J Pediatr Rehabil Med.* 2012; 5(4): 281-286.

Photo Credit ©: Laura Jacobson, Brain Scapes





## ANNOUNCING THE TRANSVERSE MYELITIS CLINIC AT THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

*The University of Alabama at Birmingham is now a designated site for a transverse myelitis clinic. The mission of the UAB transverse myelitis clinic is to provide innovative, comprehensive clinical care and to pioneer therapeutic interventions through novel interdisciplinary research.*

*The goal of this clinic at UAB is to provide comprehensive care for patients with transverse myelitis as well as enhance translational research in transverse myelitis. Specialists in both Neurology and Rehabilitation Medicine will evaluate patients at the UAB clinic. Dr. Khurram Bashir, Professor of Neurology at UAB, has substantial expertise in demyelinating diseases and will lead the Neurology team along with a recent addition to the Department of Neurology, Dr. William Meador. Dr. Bashir participates in the pediatric clinic to establish continuity in transverse myelitis care as children transition to adulthood.*

**DR. AMIE MCLAIN**, Professor and Chair of Physical Medicine and Rehabilitation, is a well-recognized specialist in physiatry and will lead the efforts in Rehabilitation Medicine. Specialists in urology, physical therapy, occupational therapy, speech therapy and orthotics and prosthetics will be enlisted as needed. This will enable patients at the UAB transverse myelitis clinic the opportunity to be evaluated by the necessary specialists in one visit and facilitate comprehensive care through a team approach.

**THE UAB TRANSVERSE MYELITIS CLINIC** will be held on the third Thursday of every month at the Spain Rehabilitation Center located at 1717 6th Avenue South, Birmingham, AL. For information and appointments, contact SRC referral office @ 205.934.4131.

**DR. JAYNE NESS**, a pediatric neurologist and director of the UAB pediatric onset demyelinating disease clinic at Children's Hospital, focuses on children with transverse myelitis. Contact Children's Hospital @ 205.996.7850

Basic and translational research to understand the neuro-immunological mechanisms involved in transverse myelitis is being led by **DR. TARA DESILVA**, an assistant professor in the Department of Physical Medicine and Rehabilitation and Neurobiology, who received an NIH grant to study specific cellular

mechanisms necessary for growth of the insulation around nerve fibers. **DR. CHANDER RAMAN**, Professor in

the Department of Medicine, is NIH funded to study the events necessary for immune cells to become pathogenic. Together, Drs. DeSilva and Raman collaborate to understand how autoimmune neuroinflammatory mechanisms cause immune cells to infiltrate the spinal cord and damage the nerve fiber insulation using animal models of transverse myelitis. With patient consent, the clinic will be collecting blood samples from patients with transverse myelitis for human research studies. These studies will use novel approaches in epigenetic research as part of a collaboration with Dr. Raman, Dr. DeSilva and **DR. HUI HU**, an associate professor in the Department of Microbiology with NIH funding for genomic research on immune cells. Additional human studies will include advanced imaging of the spinal cord with **DR. THOMAS DENNEY**, Professor and Director of the Auburn University MRI Research Center. These studies will utilize 7T magnetic resonance imaging (MRI), which is currently the most sensitive technology for human imaging. The goal of these research endeavors

is to correlate human imaging studies with human blood studies to further our understanding of transverse myelitis. This information will help facilitate our pre-clinical studies in animal models to develop future clinical therapies.

**“Dr. Tara DeSilva and Dr. Chander Raman are collaborating at UAB to understand how autoimmune neuroinflammatory mechanisms cause immune cells to infiltrate the spinal cord and damage the nerve fiber insulation using animal models of transverse myelitis.”**

# PREDICTORS OF RECURRENCE FOLLOWING AN INITIAL EPISODE OF TRANSVERSE MYELITIS

**K**imbrough et al. published a study in 2014 about characteristics that predict recurrence following an acute transverse myelitis event. Because transverse myelitis can occur in several diseases such as multiple sclerosis and neuromyelitis optica (NMO), it is important to distinguish patients with relapsing disease from those with monophasic (one time event) transverse myelitis in order to treat appropriately and reduce the chances of long-term disability. The authors conducted a retrospective study of 192 patients who were referred to the Johns Hopkins Transverse Myelitis Center from 2005 to 2012. These patients were characterized as either having monophasic TM (no relapses after 3 years) or recurrent TM. Those with recurrent TM were categorized into three groups: recurrent myelitis in the spinal cord without a known cause, NMO or NMO Spectrum Disorder, or an autoimmune rheumatologic disease.

All 192 patients were initially diagnosed with monophasic TM. Of those, 82 (42.7%) patients maintained their diagnosis of monophasic idiopathic TM, while 110 (57.3%) patients were eventually diagnosed with recurrent diseases, including 69 patients with NMO/NMOSD, 34 patients with recurrent TM, and 7 patients with autoimmune rheumatologic disease. Of those with NMO/NMOSD, 24 of the 69 cases (35%) had NMO and tested positive for NMO IgG, 7 (10%) cases had NMO but were NMO IgG negative, and 38 (55%) cases were diagnosed as NMOSD. The recurrent group was more likely to be female and African American, with women almost twice as likely

to develop recurrent disease than men. This increased risk is largely because these groups are more likely to develop NMO or NMOSD. Those with longitudinally extensive transverse myelitis (LETM, or a lesion extending more than three vertebral segments) were more likely to have recurrent myelitis and NMO/NMOSD, although LETM also occurred in patients with monophasic disease and non-NMO recurrent TM. Increased white blood cell count in the cerebrospinal fluid, positive IgG (Immunoglobulin G) index, presence of oligoclonal bands in the CSF, vitamin D insufficiency and deficiency, presence of antinuclear antibodies (ANA) greater than or equal to 1:160, and presence of Ro/SSA antibodies were also associated with recurrent disease.

The authors also note that it is unclear whether to treat patients with combinations of risk factors using immunosuppression without knowing for sure if they have recurrent TM, as there have not been clinical trials conducted about this. They suggest closely monitoring patients with idiopathic TM for the first 6-12 months after diagnosis and repeatedly testing for NMO IgG, ANA, and Ro/SSA antibodies.

**GABRIELLE (GG) DEFIEBRE**, *Research Associate at The TMA*

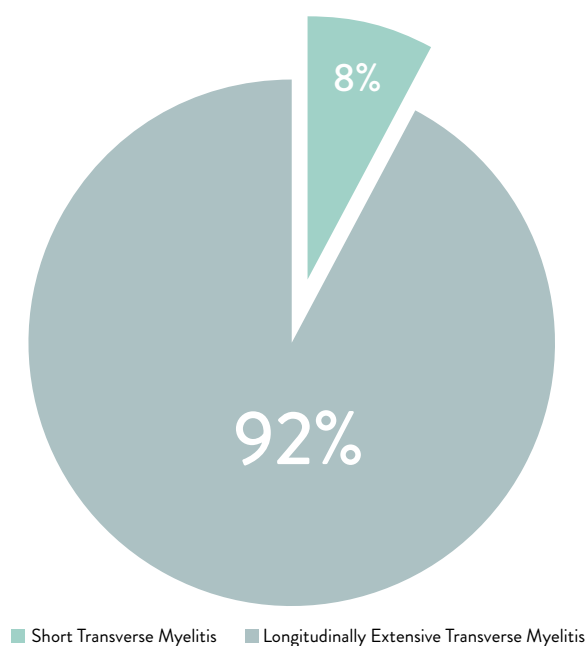
*Original research: Kimbrough DJ, Mealy MA, Simpson A, Levy M. Predictors of recurrence following an initial episode of transverse myelitis. Neurology. 2014;1-6.*



# SHORT MYELITIS LESIONS IN AQUAPORIN-4-IGG-POSITIVE NEUROMYELITIS OPTICA SPECTRUM DISORDERS

**F**lanagan et al. published a study in 2014 to see how often patients with Neuromyelitis Optica Spectrum Disorders (NMOSD) have an initial attack of short transverse myelitis (STM) rather than longitudinally extensive transverse myelitis (LETM). LETM is a lesion extending more than three vertebral sections, while STM is a lesion that extends no more than three vertebral segments. NMO is characterized by LETM and/or aquaporin-4-IgG positivity, and it is important to catch NMO early in the disease in order to treat properly and reduce long-term disability. While NMO is characterized by LETM, STM often occurs in multiple sclerosis (MS), and it is important to differentiate between a diagnosis of NMO and MS because they have different treatment options, but it is unknown how often STM occurs in AQP4-IgG positive NMO.

The authors reviewed medical records of 319 patients who had AQP4-IgG positive NMO or NMOSD. Of these 319 patients, 25 patients (14%) had an initial attack of STM and had an MRI 90 days or less after this attack, and they were included in the study. They also included 27 control patients with STM who were AQP4-IgG negative. The final diagnoses in the control group were relapsing remitting MS (15 patients), monophasic STM (10 patients) and relapsing STM (2 patients). 83% of the 25 patients who had AQP4-IgG positive NMO or NMOSD made the treating physician unsure that the diagnosis should be NMO because the patients' lesions were short. Those with STM had a median delay to diagnosis (5 months) that was greater than patients who had LETM (0 months). They also identified some risk factors for NMO or NMOSD, which included non-white race/ethnicity, older age, tonic spasms, history of autoimmunity, centrally located axial T2-hyperintensities and T1-hypointensities, lack of oligoclonal bands, severe or bilateral optic neuritis without good recovery, and long episodes of nausea or vomiting.



The authors conclude that short lesions are not uncommon in NMO or NMOSD and neurologists should consider this when diagnosing patients to avoid delaying treatment or giving inappropriate treatment. Dr. Benjamin Greenberg, Director of the TM and NMO centers at University of Texas Southwestern in Dallas, recommends all patients with a diagnosis of TM be tested for AQP4-IgG.

**GABRIELLE (GG) DEFIEBRE**, *Research Associate at the TMA*

*Original research: Flanagan EP et al. Short Myelitis Lesions in Aquaporin-4-IgG-Positive Neuromyelitis Optica Spectrum Disorders. JAMA Neurol. 2014;E1-E7.*

# COLLABORATIVE ASSESSMENT OF PEDIATRIC TRANSVERSE MYELITIS UNDERSTAND REVEAL EDUCATE



A PATIENT-FOCUSED, INTERNET-BASED, OBSERVATIONAL RESEARCH STUDY ON PEDIATRIC TRANSVERSE MYELITIS (INCLUDING ACUTE FLACCID MYELITIS) IN NORTH AMERICA FUNDED BY THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

## ELIGIBLE VOLUNTEERS MUST BE

- 1** DIAGNOSED WITH TRANSVERSE MYELITIS OR ACUTE FLACCID MYELITIS
- 2** BETWEEN THE AGES OF 0 – 18 (MUST HAVE BEEN 17 YEARS AT ONSET)
- 3** WITHIN 180 DAYS (SIX MONTHS) OF SYMPTOM ONSET

## CONTACT

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## STUDY DETAILS

- » The study goal is to provide usable data regarding TM severity and recovery to guide therapeutic decisions
- » Participation includes online surveys by the child and/or parent/guardian at baseline, 3, 6, and 12-months
- » Medical data and imaging records are reviewed by the research team

# INCLUSION CRITERIA HAVE BEEN MODIFIED TO INCLUDE CHILDREN DIAGNOSED WITHIN THE LAST SIX MONTHS

*If you or someone you know was diagnosed with TM or AFM within the last **six** months and are less than 18 years old, you are eligible to participate and share your experience. We want to hear from you so we can learn more about TM and AFM and help understand how the treatment you receive affects your outcome.*

**WEBSITE:** <https://myelitis.org/research/clinical-studies-trials>

**CLINICALTRIALS.GOV IDENTIFIER:** NCT02144935

## SUMMARY OF CHILDREN ENROLLED IN THIS STUDY AS OF MAY 2015



3 CHILDREN ENROLLED



IRB APPROVED



The Children's Hospital of Philadelphia®

7 CHILDREN ENROLLED



1 CHILD ENROLLED



International Center for Spinal Cord Injury  
at Kennedy Krieger Institute  
*Research. Restoration. Recovery.*

3 CHILDREN ENROLLED



18 CHILDREN ENROLLED  
(VIRTUAL PARTICIPATION)





# ACUTE FLACCID MYELITIS: WHAT IS IT?

## Benjamin Greenberg, MD, MHS

*We have learned of more cases of a diagnosis called Acute Flaccid Myelitis (AFM) in North America since we held a podcast on this diagnosis (<https://myelitis.org/education/podcasts/update-outbreak-paralysis-us-acute-flaccid-myelitis>) on October 16, 2014.*

*What exactly is AFM? Is this a new diagnosis? Why haven't we heard of it before? Are there treatments? Is there research? We receive many questions from the community and on social media about AFM and have reached out to an expert for answers!*

*Dr. Benjamin Greenberg of the University of Texas Southwestern in Dallas, a leading expert on rare neuro-immune diseases, shares his thoughts and an update with us on AFM.*

### **WHAT IS ACUTE FLACCID MYELITIS (AFM)?**

AFM is a variant of what we call transverse myelitis. The reason for this is based on the clinical definition of transverse myelitis. Simply put, transverse myelitis refers to inflammation of the spinal cord. While AFM has some unique MRI and clinical features, at its core there is inflammation of the spinal cord.

### **WHAT ARE THESE UNIQUE MRI AND CLINICAL FEATURES?**

The abnormalities noted in the MRI are largely restricted to the gray matter in AFM. Clinically, there is evidence of lower motor neuron injury and most patients we see have flaccid weakness, hence the name.

### **WHY WOULD AFM BE CONSIDERED A TYPE OF TM WHEN IT PRESENTS DIFFERENTLY (FLACCID VS. SPASTIC)?**

The variable symptoms seen in AFM and TM are based upon which area of the spinal cord is affected the most. Some upper cells, when damaged, lead to spastic weakness while other cell types are responsible for flaccid weakness. Apart from the MRI variances and clinical features, the

primary difference between AFM and TM is that AFM results in a flaccid weakness or paralysis while TM results in spasticity or spastic paralysis. There are AFM patients that can have both upper and lower motor neuron damage.

### **WHY DO SOME PHYSICIANS CONSIDER IT A "SUB-TYPE" AND OTHERS SAY IT IS DISTINCTLY DIFFERENT?**

This is primarily being driven by two factors. First, there are some physicians who want patients with predominantly flaccid weakness to have their own diagnostic category for diagnostic reasons. Yet, categorizing it as a subtype of TM allows for a better understanding of the diversity of injury that can occur. Secondly, AFM may have a viral cause distinct from classic TM but this has not been conclusively proven.

### **HOW IS AFM DIAGNOSED?**

It is diagnosed as TM based on clinical exam, an MRI and a spinal tap or lumbar puncture. Often an EMG is recommended as well. The nerve conduction study/EMG is used to document injury to the lower motor neuron.

**IS AFM STRICTLY RELATED TO A POSITIVE ENTEROVIRUS DIAGNOSIS? WHY IS THE MEDIA CONSISTENTLY REPORTING IT IS RELATED TO ENTEROVIRUS WHEN MOST ARE TESTING NEGATIVE FOR THIS VIRUS BUT HAVE STILL BEEN DIAGNOSED WITH AFM? WHY AREN'T THEY REPORTING IT AS A SUB-GROUP OF TM?**

AFM is not always related or caused by enterovirus. The confusion over enterovirus testing being “negative” in cases is based on a single piece of complicated data. Specifically, we have not been able to isolate the virus from the spinal fluid of patients with AFM. Yet, it is **VERY** difficult to isolate viruses from spinal fluid, so this should not be a surprise. We have isolated the virus from many patients with AFM, but the isolation was from respiratory tract samples. As to why they don't elaborate that it is a sub-group of TM is not clear...perhaps because it is new terminology or because transverse myelitis in and of itself is a rare disease that so many are not aware of, they simply aren't aware of the correlation.

**IS AFM THE SAME AS THE POLIO-LIKE SYNDROME CASES IN CALIFORNIA WE HEARD OF IN THE FALL OF 2014?**

AFM is indeed what we are now calling the polio-like syndrome seen in California and elsewhere. We suspect a link to the enterovirus but again this has not yet been proven. It is possible that multiple viruses could be associated or another trigger could be the cause.

**“MY SON’S NEUROLOGIST AT DAYTON CHILDREN’S SAID THAT ONLY THE WHITE MATTER WAS AFFECTED, HIS NEUROLOGIST AT CINCINNATI CHILDREN’S (WHOM WE ARE CURRENTLY WITH) SAID BOTH THE WHITE AND GRAY MATTER WERE AFFECTED. WHAT IS THE DIFFERENCE? THEY BOTH LOOKED AT THE SAME MRIS.”**

Sometimes neurologists have different interpretations of the same MRI, much like two different individuals may see different aspects in a painting or take away different points from a book. Some may be accustomed to viewing imaging for this type of inflammation while others may not have as much experience. We know this can be very frustrating and confusing. Asking questions of your physicians about these differences will help you understand if, why and how, it may make a difference for your child.

**ARE ORGANIZATIONS LIKE THE CDC FOCUSING ON THESE DISEASES? IS THERE A REQUIREMENT FOR REPORTING TO A CENTRAL GOVERNMENT AGENCY FOR FOLLOWING AFM OR TM?**

The CDC recently became interested in understanding more about AFM. We know we are not finding all cases since reporting is not mandatory. While starting mandatory reporting is not an easy undertaking, there are many who think it should be the rule in this case.

I encourage everyone to inquire of and enroll in the **CAPTURE STUDY** (see page 12) as an alternate way to gather accurate and timely data about AFM, so we can better define and understand it. The study is presently enrolling at various sites as well as online. We will be sure to publish results of this study with the help of the TMA so it will be available to the families affected.

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**“AFM is not always related or caused by enterovirus.”**

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**“THE CDC SAID MY SON’S CASE COULDN’T BE REPORTED BECAUSE HE ONLY MET 3 OF THE 4 REQUIREMENTS. THE 4TH WAS BOTH WHITE AND GRAY MATTER IS AFFECTED. THEY WENT OFF OF THE INITIAL REPORT.”**

We think there could be multiple flaws in the CDC reporting structure. Please report your case to the **CAPTURE STUDY** (see page 12) where we will be able to review the imaging and enroll as AFM into the database. Alternatively, if your child does not qualify for the **CAPTURE**

**STUDY** (see page 12), please contact Patricia Plumb at UT Southwestern to discuss other options (214-456-2464 | [patricia.plumb@utsouthwestern.edu](mailto:patricia.plumb@utsouthwestern.edu)).

**WHAT THERAPIES ARE USED TO TREAT AFM? ARE THE SAME ACUTE TREATMENTS USED AS IN TM?**

We do not have specific interventions for AFM, but since the majority of AFM cases have inflammation similar to classic TM, we use those therapies. More research is definitely needed and is one of the goals of the **CAPTURE STUDY** (see page 12). The goal is the same in that we are attempting to stop the immune system from attacking the body and to reduce the inflammation in the spinal cord. After the initial event, there are alternate treatment strategies that may be useful for recovery. Some patients may be candidates for nerve transplant procedures. These procedures are done in a few centers in the country, including Childrens Health in Dallas.

**IS A FULL RECOVERY MORE LIKELY FOR THOSE WHO EXPERIENCED MILD SYMPTOMS (WEAKNESS) VS. FULL PARALYSIS?**

We think that is the case; however, there is limited data to support this and again, more research and reporting of cases is definitely needed.

**HOW OFTEN ARE MRIS RECOMMENDED? SHOULD A FOLLOW UP MRI BE SCHEDULED FOR PATIENTS WHO HAVE HAD A PREVIOUSLY ALMOST CLEAR OR MUCH IMPROVED MRI?**

This has to be decided on a case-by-case basis. There are no global guidelines that indicate how often and when MRI's should be repeated. I would suggest that families communicate with their child's physician any new or worsening symptoms that don't resolve and discuss with them the risks and benefits of repeated MRI's as you move further out from the diagnosis. Every child's case is unique as to when or if additional imaging is beneficial to long-term treatment and management of symptoms.

**IN TERMS OF REHABILITATION AND RESTORATION OF FUNCTION, ARE THERAPIES LIKE FUNCTIONAL ELECTRICAL STIMULATION BENEFICIAL AND RECOMMENDED WHEN**

**DIAGNOSED WITH AFM? WHAT IF THE EMG HAS SHOWN THAT THE NERVES ARE DEAD?**

If there are muscle contractions with electrical stimulation then we tend to recommend it, but this must be done in collaboration with your treating physician. Be sure to review any articles or information pertaining to FES that may be published. Discuss this information with your physician to determine if it is a course of therapy that may be worth pursuing with your child.

**IS IT NORMAL FOR MY CHILD TO EXPERIENCE INCREASED PAIN AS SHE CONTINUES TO IMPROVE? I'M SEEING HER IMPROVE WITH INCREASED MOVEMENT AND LESS WEAKNESS BUT THE PAIN INCREASES. IS THIS NERVE PAIN? IS IT A GOOD SIGN?**

It is so different for each individual based on severity of damage, weakness, location of pain, etc. and should be addressed by your treating providers. Be sure to let your physician know the level of pain, when and where it seems to originate so together you may determine what type of pain is being experienced by your child and subsequently, the best course of treatment (e.g. will continued therapy/ stretching alleviate pain, or should prescription pain medicines be considered).

**HOW LONG SHOULD ONE WAIT BEFORE PURSUING NERVE GRAFT SURGERY?**

At our clinic in Dallas, we do not pursue transplants within the first 6 months post illness because significant healing is occurring during that time. We usually evaluate patients between 6 and 18 months out from their injury to determine if they are candidates.

**WHEN WILL STEM CELL THERAPIES BE AVAILABLE?**

Scientists and researchers are moving along in this field of treatment possibilities and we along with the TMA are working diligently to advocate for TM and AFM to be a top priority of consideration as the field advances. For current information, please visit <http://myelitis.org> and we will share news as more information becomes available.

**WHY DOESN'T AFM RECEIVE THE SAME ATTENTION AS**

## **EBOLA? ISN'T THIS POTENTIALLY A HUGE PUBLIC HEALTH CONCERN IF THERE IS A VIRAL ETIOLOGY TO AFM?**

It absolutely should receive the same attention! Please write your congressional representative to let them know about your family, your concern, that these cases need and warrant their attention. The main reason why it hasn't received the same attention is the fact that Ebola has a

huge fatality rate, and is easily transmissible. AFM does not have the high fatality rate and is not transmissible. That said we are deeply concerned about the public health implications.

**THANK YOU DR. GREENBERG FOR YOUR TIME AND YOUR DEDICATION TO OUR COMMUNITY.**

THE TRANSVERSE MYELITIS ASSOCIATION IS AN ADVOCACY ORGANIZATION THAT HAS LONG BEEN SUPPORTING AND ADVOCATING FOR INDIVIDUALS AND FAMILIES WITH WHAT HAS BEEN KNOWN AND IS NOW BEING CLASSIFIED AS AFM. THERE IS NO CENTRAL DATA COLLECTION OR COMMUNICATION CENTER WITHIN THE GENERAL HEALTHCARE SYSTEM. WHILE THERE ARE STILL MANY REMAINING QUESTIONS, WE ARE ACTIVELY SEEKING TO UNDERSTAND AND FIND MORE ANSWERS FOR THIS RARE DISEASE AND WILL CONTINUE TO ADVOCATE FOR RESEARCH AND SUPPORT INDIVIDUALS AND FAMILIES AFFECTED BY AFM AND TM.

THE TMA IS HOSTING A SYMPOSIUM IN PARTNERSHIP WITH JOHNS HOPKINS UNIVERSITY AND UNIVERSITY OF TEXAS SOUTH-WESTERN ON OCTOBER 22-23, 2015 ON AFM, TM, NMO, ON AND ADEM. STAY TUNED TO LEARN MORE ABOUT THIS ON [HTTP://MYELITIS.ORG/2015-RNDS](http://myelitis.org/2015-rnds).

## **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 of you who 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.

## **SUBSCRIBE TO THE TMA BLOG!**

Have you read The **TMA BLOG** (<https://myelitis.org/category/resources/tma-blog>) lately? We publish weekly stories and articles written by individuals living with rare neuro-immune diseases, caregivers and families, as well as leading researchers and clinicians. The blog covers a wide variety of relevant topics, including stories about your experiences living with a rare neuro-immune disease, clinical care and management updates, new research studies, TMA awareness and education program announcements.

You don't have to wait for the latest publication of the TMA Newsletter or try to remember to visit the TMA website in order to receive the most up-to-date information on the latest research and findings in the field of rare neuro-immune disorders. It's easy to stay informed about the latest events, programs and activities of The Transverse Myelitis Association. You can have all of this information delivered directly to your inbox so you won't miss a thing! To receive a weekly email with our latest blog posts in your inbox, **please go to** <http://eepurl.com/xuoGr>.





# SECOND ANNUAL GOLF OUTING

## THE TRANSVERSE MYELITIS ASSOCIATION

### *Chippin' in against Transverse Myelitis*

#### WHAT

A four-person, best ball scramble and dinner to benefit The Transverse Myelitis Association (TMA). Greens fees are \$100 per person and include use of the range, 18 holes of golf, including cart, lunch, dinner, and participation in contests for prizes. Dinner-only tickets are available for \$20.

#### WHEN

Saturday, June 13, 2015 | 12:00 Registration | 1:30 Shotgun Start and Lunch | 6:30 Dinner and Awards

#### WHERE

Bent Tree Golf Club, 350 Bent Tree Rd, Sunbury, OH 43074

#### WHY

To raise funds and awareness for The Transverse Myelitis Association. The TMA advocates for and supports people and families affected by rare neuro-immune diseases, including acute disseminated encephalomyelitis (ADEM), neuromyelitis optica (NMO), optic neuritis (ON), transverse myelitis (TM), acute flaccid myelitis (AFM) and recurrent transverse myelitis. These disorders occur when a person experiences an acute inflammatory attack in the spine, brain or optic nerve, causing disability and paralysis, depending on the extent of the injury. These diseases affect children and adults at any age.

#### REGISTER

Please join us by registering online at <https://myelitis.org/register/golf-outing-registration> or by mail using the registration form. Invite your friends and family and you can register for dinner only as well! **THE REGISTRATION DEADLINE IS FRIDAY, MAY 29TH.**

#### HOW TO VOLUNTEER

Contact Sandy Siegel | [ssiegel@myelitis.org](mailto:ssiegel@myelitis.org) | +1 (855) 380-3330

# THE SUCCESS OF OUR SECOND TMA ANNUAL GOLF OUTING IS YOUR SUCCESS!

BE A SPONSOR  
OR ASK YOUR  
COMPANY TO  
SPONSOR YOUR  
CAUSE

BE A PLANNING  
COMMITTEE  
MEMBER OR  
VOLUNTEER ON THE  
DAY OF THE EVENT

PLAY A ROUND  
OF GOLF AS AN  
INDIVIDUAL OR A  
TEAM WITH YOUR  
FRIENDS AND  
FAMILY

JOIN US FOR THE  
DINNER COOKOUT  
AND MEET OTHER  
MEMBERS

HELP US MAKE THIS A SPECIAL EVENT WORTHY OF OUR SPECIAL COMMUNITY

[HTTPS://MYELITIS.ORG/GOLF-OUTING](https://myelitis.org/golf-outing)

# 2015 WALK-RUN-N-ROLL EVENTS Near YOU!



**2014** was a banner year for the TMA Walk-Run-N-Roll Awareness Campaign! We had four alumni states that hosted awareness events in FL, IL, MD, and NJ, and two new states of TX and WI joined the campaign. Each event was uniquely remarkable with family and friends gathering together as a community to raise awareness about Transverse myelitis, Acute Flaccid Myelitis, Neuromyelitis Optica, Optic Neuritis and Acute Disseminated Encephalomyelitis. If you have attended a Walk-Run-N-Roll event, you will likely recall an awesome experience; sharing stories, meeting new friends who know and understand our day-to-day struggles and celebrations, hearing about the future of research and the efforts and goals of the TMA. Every walk and awareness event is deeply meaningful to each of us! The act of coming together as a community to continue to place TM, AFM, NMO, ON and ADEM on the forefront of our individual families and community's minds is significant to our everyday efforts and one of the single most important means to advocate for ourselves and the TMA community as a whole.

**WOULD YOU LIKE TO JOIN THIS AWARENESS CAMPAIGN?** It doesn't matter the size of the venue, the number in attendance, the refreshments available, or even the funds that may be raised – every single event makes an impact, no matter how big or small. We must raise awareness for our communities and families so others understand what it means to live with one of these disorders and how important education and research is to our future.

If you have contemplated a Walk-Run-N-Roll in your state or your neighborhood, but felt overwhelmed to start one, please contact us to help you bring your event to life!

## HERE'S HOW YOU CAN GET INVOLVED:

**JOIN** an upcoming walk – find a walk event in your state and form a walk team.

**VOLUNTEER** to help organize a walk near you – contact one of the walk organizers and find out how you can share your talents!

**START** an event in your area – no matter the size, 20 people or 500 people, an event of any size makes a difference and helps raise awareness.

We are here to help! If you are interested in starting a walk or have any questions, please call or email us at (855) 380-3330 or [info@myelitis.org](mailto:info@myelitis.org).

We need your commitment and your participation in 2015 to continue to be sure TM, AFM, ADEM, ON and NMO are on people's radar. And, we want to help you bring an event to your community or your neighborhood!

[HTTP://MYELITIS.ORG/WALK](http://myelitis.org/walk)

# THANK YOU TO OUR

## 2015 WALK-RUN-N-ROLL TEAMS!

FOR MORE INFORMATION ABOUT THE WALKS IN ILLINOIS, MARYLAND AND MICHIGAN, PLEASE VISIT [HTTP://MYELITIS.ORG/WALK](http://myelitis.org/walk)

### florida - ucf lacrosse

LAKE CLAIRE RECREATIONAL AREA | ORLANDO

*april 18*

### new jersey

COOPER RIVER PARK | PENNSAUKEN TOWNSHIP

*april 25*

### michigan

WAYLAND UNION HIGH SCHOOL | WAYLAND

*august 22*

### maryland

GOUCHER COLLEGE | TOWSON

*october 4*

### illinois

DETAILS

*coming soon!*





# 2015 TMA FAMILY CAMP

TUESDAY, JULY 21 - SATURDAY, JULY 25

**A**s a reminder, the TMA Family Camp will once again be held at The Center for Courageous Kids in Scottsville, KY from Tuesday, July 21 through Saturday, July 25, 2015. Space is limited and applications continue to come into CCK! If you are thinking of attending camp, be sure to get your full (that is BOTH Step 1 and Step 2) application in ASAP! CCK will not review an application for acceptance unless both Step 1 and Step 2 have been completed. Space is filling up quickly! Camp is open to families with children diagnosed with ADEM, NMO, TM, AFM and ON who are between the ages of 5 to 17 years. Please visit our website at <http://bit.ly/1FgapsK> to review the application process, eligibility guidelines and the links to the application. We can't wait to see you and your family in July!

## IN THEIR OWN WORDS ARTICLES

In each issue of the 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 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.

# 2015 ASK THE EXPERT PODCAST SERIES



Thank you to those who joined our podcasts as part of TMA's Ask the Expert podcast series. The podcast sessions provide an avenue for individuals diagnosed with these disorders and their family members to ask questions of experts who specialize in these disorders. The podcast recordings have not only been made available on our website at <https://myelitis.org/education/podcasts>, but you can also find all recordings on iTunes by going to:

[HTTPS://ITUNES.APPLE.COM/US/PODCAST/TMA-ASK-EXPERTS-PODCAST-SERIES/ID893008309?MT=2](https://itunes.apple.com/us/podcast/tma-ask-experts-podcast-series/id893008309?mt=2)

You will be able to listen and download all prior podcasts for free! Don't forget to stay tuned for more TMA podcasts featuring leading medical experts in the field of rare neuro-immune disorders.

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## SPONSORED BY



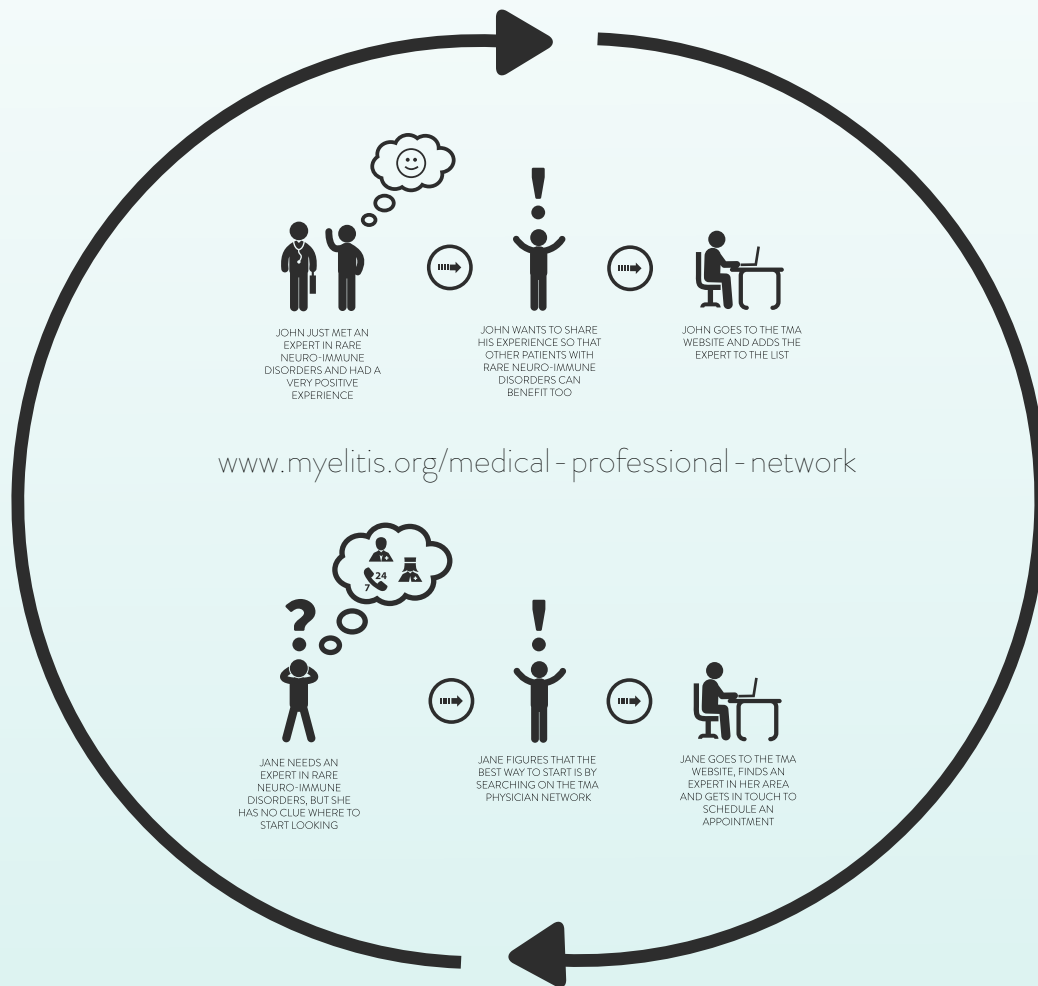
A member of the Roche group

Chugai Pharmaceutical Co, Ltd is conducting clinical studies to create original and innovative drugs, both in the USA and overseas, to address unmet medical needs in neurological disorders, where the level of pharmaceutical contribution and satisfaction concerning patient treatment remains low.

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*\* The Executive Committee of the TMA with the medical and scientific council determines the content and topics of the podcasts. Sponsors are not able to participate in or influence the education program.*

# WE'VE UPDATED OUR MEDICAL PROFESSIONAL NETWORK! REFER YOUR MEDICAL PROFESSIONAL!





In every neurology practice that specializes in MS, there are a considerable number of people who have rarer disorders related to but distinct from MS. These people have one of a spectrum of rare neuroimmunologic diseases that includes transverse myelitis (including acute flaccid myelitis), neuromyelitis optica, optic neuritis, and acute disseminated encephalomyelitis. Those who are educated and aware of the characteristics of these disorders can provide prompt diagnosis and appropriate treatment.

The Consortium of Multiple Sclerosis Centers (<http://www.mscares.org>), under the umbrella of its Multiple Sclerosis Certified Specialist Committee ([http://www.mscares.org/?page=about\\_mscs](http://www.mscares.org/?page=about_mscs)), is proud to announce the development of a certification process for specialists in rare neuroimmunologic disorders, which will provide successful candidates with recognition as a CRND (Certification Exam in Rare Neuroimmunologic Disorders). All licensed health professionals with one year relevant experience in neuro-immunology are eligible to take the certification test. Details on the examination are available at <http://www.ptcny.com/clients/CRND>.

**FOR MORE INFORMATION, GO TO [HTTP://WWW.PTCNY.COM/CLIENTS/CRND](http://www.ptcny.com/clients/CRND)**

“ This certification exam will hopefully increase interest among healthcare providers in North America to learn about the unique needs of patients with rare neuroimmunologic conditions and give patients a means for identifying experts that are nearest to them. ”

*Benjamin M. Greenberg, MD, MHS  
Director, TM, NMO and Pediatric Demyelinating Disease Programs  
Director, Neurosciences Clinical Research Center  
UT Southwestern Medical Center*







**clinical  
studies  
&  
trials**

## 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.

The clinical trial will focus on monophasic Transverse Myelitis (TM) and will evaluate the efficacy of dalfampridine in primary neurologic outcome – 25-foot timed walk, and several secondary outcomes including valid behavioral and neurophysiological measures. To better understand the mechanisms underlying the proposed behavioral gains, the investigators will use Transcranial Magnetic Stimulation as the neurophysiologic measure to identify changes in corticomotor excitability in the spinal cord.

### INVESTIGATOR

Michael Levy, MD, PhD

### STUDY SITE

Johns Hopkins University  
Baltimore, MD

### CONTACT INFO

Maureen Mealy  
[HopkinsTMCenter@jhmi.edu](mailto:HopkinsTMCenter@jhmi.edu)

All study participants will be randomized for the first double-blinded 8-week part of the study with 25-foot timed walking assessments every 2 weeks. At the conclusion of this first 10-week trial, subjects will be crossed over to the other therapy for another 8 weeks and 25-foot timed walking assessments will again be done every 2 weeks.

## ELIGIBLE PARTICIPANTS

Patients (18-70 years) diagnosed with monophasic transverse myelitis confirmed by MRI will be eligible to participate in this study.

Diagnosis of recurrent myelitis or multiple sclerosis is an exclusion criteria for the study; however, patients may have a diagnosis of neuromyelitis optica, lupus, sarcoidosis or other rheumatologic or systemic disorder in the setting of monophasic myelitis.

## OTHER EXCLUSION CRITERIA INCLUDE

HISTORY OF SEIZURES | PREGNANCY OR POSITIVE PREGNANCY TEST (MANDATORY TEST FOR ALL WOMEN AGED 18-55 TO BE DONE AT FIRST SCREENING VISIT) | KNOWN ALLERGY TO DALFAMPRIDINE OR ANY OTHER FORMULATION OF 4-AMINOPYRIDINE | PATIENTS UNABLE TO WALK | PATIENTS WITH HISTORY OF SEVERE ALCOHOL OR DRUG ABUSE, SEVERE PSYCHIATRIC ILLNESS LIKE SEVERE DEPRESSION, POOR MOTIVATIONAL CAPACITY, OR SEVERE LANGUAGE DISTURBANCES, PARTICULARLY OF RECEPTIVE NATURE OR WITH SERIOUS COGNITIVE DEFICITS (DEFINED AS EQUIVALENT TO A MINI-MENTAL STATE EXAM SCORE OF 23 OR LESS) | PATIENTS WITH SEVERE UNCONTROLLED MEDICAL PROBLEMS (E.G. HYPERTENSION, CARDIOVASCULAR | DISEASE, SEVERE RHEUMATOID ARTHRITIS, ACTIVE JOINT DEFORMITY OF ARTHRITIC ORIGIN, ACTIVE | CANCER OR RENAL DISEASE, ANY KIND OF END-STAGE PULMONARY OR CARDIOVASCULAR DISEASE, CLAUDICATION, UNCONTROLLED EPILEPSY OR OTHERS)

### STUDY DETAILS

The primary objective of the study is to assess the efficacy and safety of eculizumab treatment as compared to placebo in relapsing NMO patients using a time to first relapse study design. This is a randomized double blind study, where participants will receive eculizumab or placebo and neither the participant nor the study doctor or their staff will know who received the drug or placebo. In this study participants will have a 67% chance of receiving eculizumab and a 33% chance of receiving placebo. The medication is given intravenously, initially weekly for 5 weeks and then every 2 weeks.

Eculizumab is not approved for treatment of NMO. Eculizumab is a monoclonal antibody that blocks one component of the complement pathway, part of the immune system. Activation of the complement pathway is believed in part to be responsible for relapses in NMO. A pilot study of eculizumab in 14 female NMO patients suggested that eculizumab can reduce the risk of relapse. This study is intended to confirm that finding.

### CONTACT INFORMATION

If you are interested in participating, please contact the sponsor by email at [clinicaltrials@alxn.com](mailto:clinicaltrials@alxn.com) or call 203-272-ALXN

You may also contact:

Robert Glanzman, MD | Executive Director/Neuroscience Lead, Alexion  
Pharmaceuticals Inc. | 203-699-7074

<http://clinicaltrials.gov/ct2/show/study/NCT01892345?term=ALexion&rank=5>

### ELIGIBLE PARTICIPANTS

Participants may be eligible if they are at least 18 years old, have a positive test for the NMO IgG antibody and have experienced 2-3 relapses in the last 2 years with at least one relapse in the last 12 months.

This is an “add on study,” and patients can continue to be on their current NMO medications and receive the study medication. The duration of the study is 2 years. If participants have a relapse, the study will end; however there is a second study participants may be eligible to enroll in where all patients will receive eculizumab.

As with all medications there are potential side effects, which will be discussed prior to enrollment and detailed in the informed consent.

### **STUDY DETAILS**

This research is being conducted to evaluate the efficacy, safety, pharmacodynamic, pharmacokinetic and immunogenic profiles of a humanized anti-human IL-6R neutralizing monoclonal antibody (SA237) in patients with Neuromyelitis Optica (NMO) and Neuromyelitis Optica Spectrum Disorder (NMOSD). This study is being conducted in the US and Canada and will enroll seventy (70) patients to participate in this research.

Mechanism of Action: SA237 is a humanized anti-human IL-6R neutralizing monoclonal antibody that was

designed by applying recycling antibody technology to the approved anti-IL6 receptor antibody, tocilizumab, which is currently marketed as a treatment for rheumatoid arthritis (RA), systemic juvenile idiopathic arthritis, polyarticular juvenile idiopathic arthritis and Castleman's disease. The recycling antibody technology enabled SA237 to bind to IL-6 receptor multiple times and be slowly cleared from plasma, which is expected to contribute to improvement and is convenient with once monthly dosing frequency. The longer plasma half-life of SA237 compared with tocilizumab was confirmed based on the results of a non-clinical study and a Phase 1 study in healthy volunteers.

### **CONTACT INFORMATION**

If you are interested in participating, please contact:

Clinical trials information [clinical-trials@chugai-pharm.co.jp](mailto:clinical-trials@chugai-pharm.co.jp)

SA237 Clinical trial [sa237@chugai-pharm.co.jp](mailto:sa237@chugai-pharm.co.jp)

<http://clinicaltrials.gov/ct2/show/study/NCT02073279?term=SA237&rank=1>

**For more information on the European/Asian trial, please visit:**

<https://www.clinicaltrialsregister.eu/ctr-search/search?query=SA237>

### **ELIGIBLE PARTICIPANTS**

#### **INCLUSION CRITERIA**

1. NMO or NMOSD
2. Age 18 to 74 years, inclusive at the time of informed consent.

#### **EXCLUSION CRITERIA**

PREGNANCY OR LACTATION | EVIDENCE OF OTHER DEMYELINATING DISEASE OR PML | KNOWN ACTIVE INFECTION  
(EXCLUDING FUNGAL INFECTIONS OF NAIL BEDS OR CRIES DENTIUM) WITHIN 4 WEEKS PRIOR TO BASELINE.



# SPINAL CORD MRI RESEARCH STUDY FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH TRANSVERSE MYELITIS

## STUDY DETAILS

The objective of this study is to determine how the structure of the spinal cord in children and young adults with non-traumatic spinal cord injuries with pain involvement, specifically those with Transverse Myelitis, is different from those without back pain or spinal cord injury. More specifically, the study will look to define the relationship between the location of the white matter alterations and the severity of pain in pediatric patients with transverse myelitis compared with otherwise healthy individuals.

The study takes place on-site at Boston Children’s Hospital and includes an evaluation by the study physician, including an assessment of reflexes and the spinal cord injury using an ASIA exam. Once cleared, participants may take part in pain sensitivity testing, which is a safe and accurate way of testing the skin’s sensitivity to stimuli such as temperature and pressure. After the sensory testing, the participant will be asked to lie still in an MRI machine for a 45-minute scan. They will then have a second 45-minute MRI after a break or on a subsequent day. Each study session may take up to 3.5 hours (up to 1 hour for the physician evaluation,

## NEUROIMAGING AND NEUROBEHAVIORAL OUTCOMES OF PEDIATRIC NMO: A PILOT STUDY

### STUDY DETAILS

The primary objective of this study is to determine how well specific neuroimaging modalities detect the different aspects of anomalous white matter development associated with pediatric NMO. Our purpose is to acquire data using neuroimaging obtained at 3.0 Tesla as well as neurobehavioral data to better characterize neuroimaging features and function in this rare population.

This study takes part in two phases. For the first part, participants will undergo neuropsychological (cognitive) testing and have a “mock” or practice magnetic resonance imaging (MRI) scan”. The purpose of this “mock” scan is to improve comfort, decrease potential anxiety, and to train you to lie still while in the scanner. After the “mock”/ practice scan, participants will have the MRI exam. The MRI scan could take up to 1 hour. Participants are in this study for one day for approximately 3-4 hours.

### INVESTIGATOR

Nadia Barakat, PhD

### STUDY SITE

Boston Children’s Hospital  
Boston, MA

### CONTACT INFO

[spineimaging@childrens.harvard.edu](mailto:spineimaging@childrens.harvard.edu)

1 hour for pre-scan sensory testing, and 1.5 hours total for the two 45- minute MRI scans).

Participants will receive a \$50 gift card for each MRI study session they participate in, or \$100 in total. They will also receive an additional \$10 gift check each time they refer a friend who qualifies for the study as a healthy volunteer (limited to three qualifying friends).

### ELIGIBLE PARTICIPANTS

Individuals diagnosed with transverse myelitis between the ages of 7 and 21 years old.

Healthy individuals between the ages of 7 and 21 years old, with no pain are also eligible for the control group of the study.

### INVESTIGATOR

Ana Arenivas, PhD

### STUDY SITE

Johns Hopkins Medicine  
Baltimore, MD

### CONTACT INFO

[Arenivas@kennedykrieger.org](mailto:Arenivas@kennedykrieger.org) | 443-923-4462

### ELIGIBLE PARTICIPANTS

Individuals aged 13-18 years with NMO may join. We will also be enrolling typically developing individuals of the same ages without NMO, to serve as a control group.

# A DOUBLE-MASKED, PLACEBO-CONTROLLED STUDY WITH OPEN LABEL PERIOD TO EVALUATE MEDI-551 IN NMO AND NMOSD | SPONSORED BY ASTRAZENECA

## STUDY DETAILS

The main objective of this study is to determine if MEDI-551 can significantly delay the time it takes for a new NMO/NMOSD attack to occur.

This is a multinational randomized, double-masked, placebo-controlled study with an open-label period. “Double-masked” means that neither the patient nor the study staff (for example, the doctor/nurse) know the identity of the study drug they are receiving (either MEDI-551 or placebo). Placebo-controlled means that some patients will receive MEDI-551 and some will receive placebo, an inactive substance designed to look like MEDI-551. Eligible NMO/NMOSD patients will be “randomized” in a 3:1 ratio to receive either MEDI-551 or placebo. This random selection is made by a computer and will give a 25% (1 in 4) chance of getting placebo and a 75% (3 in 4) chance of getting MEDI-551. “Open label” means

a period in the study where there is no placebo arm and all patients receive MEDI-551.

After being enrolled in the study, patients will be first followed for 28 weeks; this period is called the placebo-controlled treatment period. During the placebo-controlled treatment period, MEDI-551 or placebo will be given in the vein (intravenous infusion) on Day 1 and Day 15. Patients will have the option to enroll into the open-label period if a confirmed NMO/NMOSD attack occurred during the placebo-controlled treatment period. Subjects who complete the placebo-controlled treatment period without experiencing an attack will also be given the option to enroll in the open-label period. During the open-label period, MEDI-551 will be given on Day 1 and Day 15 and then every 6 months thereafter until the end of the study. During the study, the study doctors are allowed to treat NMO/NMOSD attacks with standard rescue medications.

## CONTACT INFORMATION

AstraZeneca Clinical Study Information Center

1-877-240-9479 | [information.center@astrazeneca.com](mailto:information.center@astrazeneca.com)

<https://clinicaltrials.gov/ct2/show/NCT02200770?term=NMO&rank=8>

<http://www.astrazenecaclinicaltrials.com/Submission/View?id=12336>

## ELIGIBLE PARTICIPANTS

### INCLUSION CRITERIA

1. Men and women 18 years or older with diagnosis of NMO/NMOSD
2. AQP4 antibody positive or AQP4 antibody negative NMO/NMOSD subjects with at least one attack requiring rescue therapy in the last year or two attacks requiring rescue therapy in the last 2 years
3. Expanded Disability Status Scale (EDSS)  $\leq$  7.5

### EXCLUSION CRITERIA

LACTATING AND PREGNANT FEMALES | KNOWN HISTORY OF A SEVERE ALLERGIC REACTION OR ANAPHYLAXIS FOLLOWING ANY BIOLOGIC THERAPY | KNOWN ACTIVE SEVERE BACTERIAL, FUNGAL OR VIRAL, OR OTHER INFECTION OR ANY MAJOR EPISODE OF INFECTION REQUIRING HOSPITALIZATION

A cobalt sky slowly lightens above  
the runway of the quiet Spanish airport,  
as an edge of dawn reveals  
the nighthawk silhouette of a Learjet,  
primed on the tarmac  
to receive the stretcher  
supporting my inert form,  
dazed by intravenous Ativan,  
barely aware of the two nurses and EMT—  
angels in flight suits  
who will hover with resuscitation gear,  
in case I “code” on the long flight  
home to Mayo Clinic.

In contrast to most executive jets,  
which are luxurious,  
the Learjet is a spartan hot rod,  
takes off almost straight up if you want,  
rides fast and rough.  
To me, it’s just the ticket  
if you have to get the hell out of Dodge.

It wasn’t supposed to be this way—  
Superman with an autoimmune disease  
that attacks the central nervous system,  
often causing partial paralysis and blindness;  
Superman losing not only his superpowers,  
but possibly needing a nursing home  
for the rest of his days;  
Superman ambushed by kryptonite,  
staring into a chasm of vulnerability  
and humbling dependence on others—  
unable for the moment  
to see that surrender opens  
the door to true love.

There will be time for Superman to see,  
as treatment slowly restores  
blunted mental faculties  
and haywire bodily functions.  
There will be time to reflect  
on the sustaining compassion and generosity  
of family, friends and total strangers  
throughout humbling moments of helplessness.  
There will be time for joy...  
to love and be loved.



**BOB BUCHANAN** writes poetry for fun after retiring as a senior executive with a technology firm in 2005. His first acute attack of NMO was in 2013 while traveling in Spain. It created major dysfunction in his autonomic nervous system (nausea, blood pressure, bladder and bowel, balance, breathing, swallowing, etc.), and was nearly fatal because of misdiagnosis and primitive care. After air ambulance evacuation, he regained almost all of his ability to function at Mayo Clinic. He lives with Robby, his wife of 47 years, and Clovie, their Norwich terrier, in Scottsdale, AZ.



# DATA ARE SHADOWS OF STORIES

I (RONI ZEIGER) HAD THE PRIVILEGE OF SPEAKING AT ROBERT WOOD JOHNSON FOUNDATION'S #DATA4HEALTH CONFERENCE ([HTTP://WWW.RWJF.ORG/EN/BLOGS/CULTURE-OF-HEALTH/2014/11/DATA4HEALTH\\_LIVEFR.HTML](http://www.rwjf.org/en/blogs/culture-of-health/2014/11/data4health_livefr.html)) IN SAN FRANCISCO. HERE I'LL SHARE A WRITTEN VERSION OF MY BRIEF TALK AND MY TWO SLIDES.

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I love data. In some contexts, that might sound like a confession. Obviously not here. I grew up loving math, then science. I decided the most interesting secrets were probably hidden in biology, in particular molecular biology.

I worked in labs in college, learned how to splice DNA, to make antibodies that were part mouse and part human. It was awesome. It was also a little lonely. The lab was a place where I was looking down more than looking up.

I then discovered medicine, and found a place where I could do science and stories at the same time. Data and humanity... but oh man, the data!

My Palm Pilot was always with me, and I learned how to write computer programs. You see, the medical center was producing so much data, we just needed better tools to analyze it. I also ended up getting a degree in medical informatics and cemented my identity.

I still saw patients, something about that kept me grounded, especially when I went to work at Google.

Google... holy cow, best data ever. I analyzed all the health questions people across the globe were putting into the Google search box. Symptoms, diagnoses. Drugs, supplements. Results of a scan. Good news. Bad news.

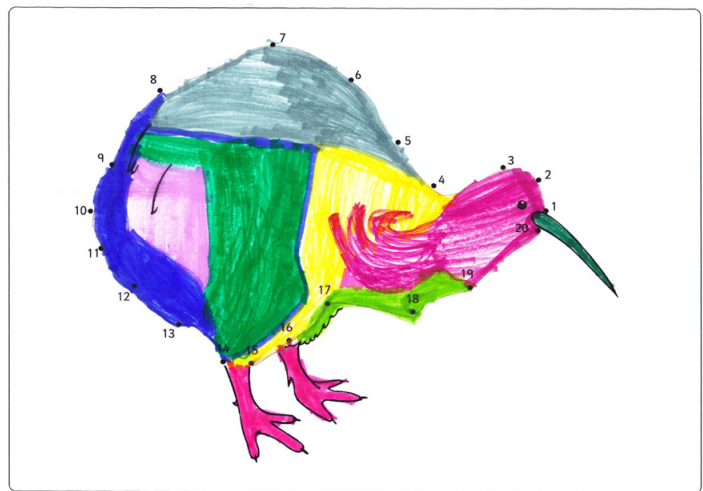
And I started seeing that those searches represent people. Data are tiny shadows, projections of rich complex stories.

Sometimes you can connect the dots, see how a series of searches reveals a new life, or tragedy, hope or fear. And there is SO much more in between those data points. Even a child, perhaps especially a child, can show us that. (In this case, one of my children.)

To be clear: we need more data, and we need better access to data. And we need the stories that bring them to life, that give them color and context.

The data may hold the answers, but stories tell us which questions to ask and stories tell us why the answers matter.

**RONI ZEIGER**



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[HTTPS://WWW.SMARTPATIENTS.COM/BLOG](https://www.smartpatients.com/blog)

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NMO  
NEUROMYELITIS OPTICA  
I have it, but it doesn't have me

NMO  
SCREENWRITER





# NMO WON'T SIDELINE MY WRITING PASSION

**M**y actual diagnosis is NMOSD, since I test NMO IgG antibody negative, and my MRI isn't exactly typical. Leave it to me to be special, even in the rare disease department. The one thing I have learned about NMO/NMOSD, is that it seems to thumb its nose at rules. Nearly every person I talk to who has this disease has a different set of symptoms and response to treatment. We are a unique bunch, aren't we?

My story starts Thanksgiving, 2013 with a bout of optic neuritis. Well, backtracking a bit, in the late 1990's I had what was thought to be a slipped disc in my cervical spine causing numbness, pain, and tingling from my shoulder to my fingers on my left side. As part of the workup, I had an MRI that showed a lesion on my spinal cord. After a few other tests, the neurologist shrugged and said I might have the beginnings of MS, even though I had a negative brain scan, and said we'd just watch and wait. Now, looking back, that might have been my first attack. I was left with permanent weakness in my shoulder and intermittent discomfort. Back to Thanksgiving, I was treated with IV steroids and tapered on oral Prednisone. It was hoped this was an isolated instance, perhaps related to a recent flu shot. I wasn't so lucky. Five months later, I had a second episode of optic neuritis, and in addition to the steroids, was placed on methotrexate to prevent further attacks. My neuro-ophthalmologist now suspected I had

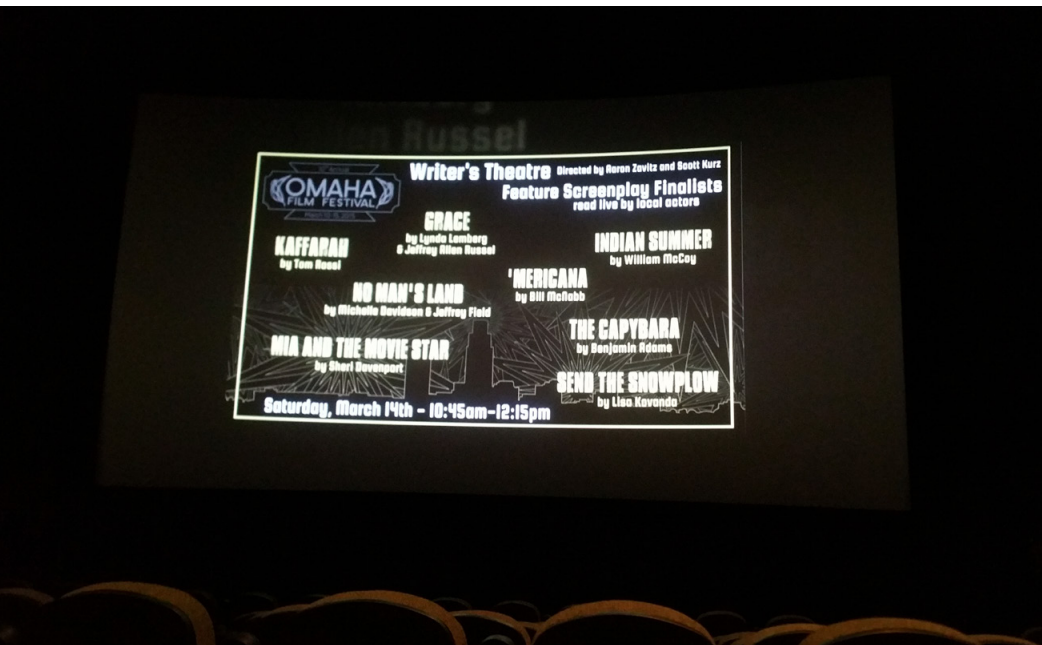
chronic relapsing inflammatory optic neuritis, or CRION.

July 7th, 2014, 6:45 am was when my life changed. I was awakened from a deep sleep with excruciating pain from my hips all the way to my toes, and legs that didn't want to hold me upright. I was scheduled for a test for an upcoming hiatal hernia repair, and also an appointment to see my eye specialist. I managed to make it to both, using a cane to support myself. The appointment with the neuro-ophthalmologist was his last of the day, and he's an eye doctor. Yes, a highly specialized eye doctor, but I could tell by his face that even though he'd had them run the blood test for NMO, he had no idea what to do about the leg symptoms. He suggested I talk to my family doctor the next day. I cried the entire hour drive home from his office. I was terrified, and in so much pain I didn't know what to do. What I should have done was drive straight to the hospital, but I waited until morning and made an appointment to see my doctor for the following day. I did spend a lot of time on the web looking up NMO between excruciating muscle spasms and pain.

My family doctor knew less about NMO than my specialist. Luckily, I'd brought some stuff from the internet with me, and he got busy ordering some tests. They were all outpatient and required insurance approval, so of course that created more delays. And,

he was reluctant to order much for pain, as he was afraid of covering up important symptoms that might help with diagnosis. I'd brought in paperwork for an intermittent leave of absence from work, since there were so many scans and tests scheduled. He filed them—but not for intermittent. He told me I needed to be off work, period. I haven't been able to work since. I was a retail manager at the time, working twelve hour shifts, and averaging about ten miles walking a day. He looked me in the eye and said, "Most people look for a reason to get out of work, but you'd work yourself to death if I let you. You're a writer. I'd tell you to go home and write something happy and fun, but I've read your stuff, so I'm telling you to go home and take a few months to write something dark. Go kill some people."

I also lived in a basement level apartment, and was the President of the Nebraska Writers Guild. In less than a week, I was on an indefinite leave of absence from work, found a new single-level handicapped accessible apartment, resigned my presidency from the Guild, and was terrified of what the next week might bring. One of the tests leading up to my surgery was to have an upper GI endoscopy. That's where they give you some IV sedation and you swallow the tube. I woke up pain free for the first time since July 7th. I told my doctor this, and he started me on baclofen, which while not as effective as the stuff they use for twilight sleep, it did begin the first real steps to controlling



my symptoms. I moved into my new apartment and had the surgery within two weeks. Post op pain meds also did a lot to help with the ever-present leg pain.

The first neurologist I saw spent all of five minutes looking at my brain MRI, and about that long examining me before suggesting I might need to see a psychiatrist. I had a new book and movie release, and other than the stupid pain and vision loss in my right eye, my life was fantastic. I had no problem telling her what I thought of her opinion. She actually told me that some people were so afraid of their own success that they sabotaged themselves. My family doctor was as floored as I was. It's sad that I am no longer shocked when I hear people with TM, NMO, MS, Fibromyalgia, or a myriad of other diseases talk about how many times medical people tell them that their symptoms are all in their heads. This may or may not find its way

into a future story...

Since 2013, I have had six relapses of optic neuritis requiring IV steroids, plasmapheresis, and chemotherapy. I'm currently on Rituximab and oral prednisone. I'm on long-term disability, with social security in the appeals stage. Pain is controlled, but a constant in my life, as is limited mobility. I have both a cane and one of those rolling walkers with a seat. It's been a major life change. But, I took my doctor's words to heart. In between all the medical mayhem, I'm still out there writing. Since my diagnosis, I have had two book releases and two short films sent to pre-production. That puts my book total to six, and my films at one complete, one in post-production, and two in pre-production. To make things even sweeter, while undergoing another round of IV steroids in February for an optic neuritis episode, I got an email notifying me that one of my scripts,

"Send the Snowplow," was selected as one of eight finalists in the Omaha Film Festival.

I didn't win this year, but being a finalist and sitting in a crowded theatre watching trained actors bring my story to life was a high point of the Film Festival. I made some great film industry connections, and overall, had a great time. It's never about the destination, the journey is everything.

The bottom line is this: I don't know what tomorrow will bring. None of us does, really. What I can do is live in this moment now. Like my NMO t-shirt says, "I might have NMO, but NMO doesn't have me."

**LISA KOVANDA**

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# 2015

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**2015 TMA Family Camp:** July 21–25, 2015  
**2015 Rare Neuro-Immune Disorders Symposium:** October 23–24, 2015

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