

the transverse myelitis association

newsletter

summer 2018



advocating for those with ADEM, MOG-Ab disease, NMOSD, ON & TM (including AFM)

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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 [facebook.com/myelitis](https://www.facebook.com/myelitis).

From The President

Pauline's diagnosis with transverse myelitis in 1994 was devastating for her and our entire family. The intensity of the experience was magnified by how little anyone understood about what had happened to her. No one could explain the disease process that caused the damage to her spinal cord. The doctors couldn't tell us anything about Pauline's prognosis. We didn't know if this could happen to her again. We didn't know if she would get worse. No one offered anything that could be done to make her better. Our confusion and our ignorance were demoralizing. The confusion and the ignorance we heard from the medical community was way more than demoralizing. There were no specialists in TM. There were no medical centers of excellence. There was no support network. There was no information. It was an entirely frightening and isolating experience.

It was clear to us that this dynamic had to change for people who got a diagnosis of transverse myelitis. The Transverse Myelitis Association grew out of this dire situation and has developed to directly address the issues that contributed to our nightmare in 1994.

Over the years, we have become an umbrella organization for the rare autoimmune disorders that target the central nervous system. In 1994, none of us knew anything at all about acute disseminated encephalomyelitis, neuromyelitis optica spectrum disorder, or optic neuritis. People who were being diagnosed with those disorders came to our organization, in part, because their physicians were describing the inflammatory attack in their





spinal cords as transverse myelitis. They were characterizing the term ‘transverse myelitis’ as a symptom of those other disorders. People often thought that they were being told that they had two different disorders, e.g., NMOSD and TM or ADEM and TM. Going through these experiences taught us about all these rare disorders, and we created a home for these people and their families.

People with optic neuritis and the numerous myelopathies (vascular causes or radiation myelopathy or the neoplastic causes) have come to us primarily because they had nowhere else to go. We have always practiced open arms to people who need support. We’ve come to understand that these disorders are all differential diagnoses, so each of them must be ruled out to arrive at a proper diagnosis. Thus, there is a relationship between all these disorders. Additionally, the symptom management strategies for these disorders overlap, so we’re in a relevant position to offer information and support.

From day one, everyone involved in the TMA understood that we would only move from ignorance to understanding by supporting research. In 1994, we had no idea what that research would entail, and we didn’t know a single scientist interested in doing it. That world has so dramatically changed.

The most substantial research that was done before the TMA was established was the 1981 Israeli study that determined the incidence of transverse myelitis (incidence is the number of new cases per year). This is also the study that arrived at the finding that a third have no recovery, a third have a fair recovery and a third have a good recovery. Most of the studies were small case series from medical centers trying to characterize their patient populations with these rare neuro-immune disorders.

The landscape for research has changed. The TMA has had a significant influence on promoting this research. We were involved in the establishment of the Centers of Excellence at Johns Hopkins and at the University of Texas Southwestern. Under the leadership of Dr. Benjamin Greenberg, we now have a certification for medical professionals in the rare neuro-immune disorders.

To accelerate the development of specialists to improve the quality of care for people in our community and facilitate research, the TMA established the James T. Lubin Clinician-Scientist Fellowship. Through this fellowship, we have been increasing the numbers of specialists and centers of excellence since 2011. We have also worked diligently to expand our network of specialists by developing relationships with other academic medical centers.



These relationships have been nurtured by holding symposia for our community at their centers, through the participation of clinicians and researchers at our Quality of Life Family Camps, and by inviting these specialists to participate as presenters at our education programs and podcasts. As these disorders are rare, most of the research requires the collaboration between medical centers. No one center has a large enough patient population to conduct good research in a reasonable amount of time. We work with our medical professional network to conduct studies that rely on a multi-center collaborative approach, such as the CAPTURE study.

Research is critical to developing an understanding of diagnosis of these disorders. I gave a presentation many years ago at a

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meeting of the Accelerated Cure Project (ACP) for MS in Boston. My presentation was about the diagnostic issues surrounding MS, ADEM, NMOSD, ON and TM. In brief, I characterized the state of affairs as rudimentary and incredibly imprecise. The most significant achievements to date have been the discovery of a biomarker for NMOSD and the recent finding of a biomarker for MOG Antibody-Associated Disease. A biomarker is some biological evidence that can be found in the body, such as in the blood or spinal fluid, that is unique to a person who has one of these disorders. Having a biomarker is a huge deal and looking for them is an expensive and time-consuming process.

Without biomarkers, the diagnosis of all these rare neuro-immune disorders is difficult, imprecise and can take time.

These disorders are diagnoses of exclusion, i.e., the clinician must rule out all of the possibilities or exclude them, before they arrive at the proper diagnosis. If a patient meets all the criteria as seen in blood tests, imaging, spinal fluid exam and other neurological examinations and analyses, then they meet the criteria for a particular diagnosis. A correct diagnosis is so critical because a diagnosis determines treatment. Administering treatment as quickly as possible could impact the outcome for the person diagnosed with one of these conditions.

The development of these criteria is not only important for the purpose of diagnosis, treatment and a possible determination of prognosis, but also for research. A study on transverse myelitis isn't going to create meaningful results if it also includes people

who could have NMO or ADEM or MS. These diagnostic criteria are also inclusion criteria for these studies. Dr. Kerr convened a group in 2001 to develop these criteria for transverse myelitis. Our executive director, Chitra Krishnan, was a researcher at the TM Center at Johns Hopkins at the time and was very much involved in this important work. Dr. Greenberg is currently involved in a process that is being supported by the TMA to revise and update these TM diagnostic criteria.

Our understanding of these rare neuro-immune disorders was accelerated by the development of MRI technology in the 1980s. Before then, the guess work for arriving at a diagnosis was that much less sophisticated than it is today. As we develop better technologies for 'seeing' things in the body, our ability to identify criteria will improve. As we grow our knowledge of these unique characteristics, we will be able to develop better diagnoses. Also, as we find these biomarkers, we will open a window into a much better understanding of the disease process. Once we are able to do that, we will be able to find better and more effective targets for acute treatment. The holy grail to understanding the disease process would be the possibility of shutting down the disease process before it even occurs.

Finding the NMOSD biomarker resulted in a determination that it wasn't a subvariant of MS, and that the treatments for NMOSD are going to be different than those that are administered long term for a person with MS. This biomarker also helped to identify in a much earlier time frame those people who were previously given a TM diagnosis and believed to be at risk for a future inflammatory attack. With the identification of the MOG biomarker, people with this characteristic are now being distinguished as a unique disorder, MOG Antibody-Associated Disease (MOG-Ab disease), which had once been considered NMOSD or ADEM. Dr. Michael Levy is currently engaged in research on MOG. **We recently established the MOG Project at the TMA under the leadership of a few passionate volunteers to offer support, advance research and to develop specific information for this patient group in our community.** A few years ago, we established a subgroup, primarily made up of parents of children with Acute Flaccid Myelitis (AFM) with the purpose of developing specific education materials, offering support and advocating for research.

Until biomarkers are found, it is safe to assume that the possibility that transverse myelitis or acute disseminated encephalomyelitis or multiple sclerosis, for that matter, is more than one disorder, are probably high. As we learn more, as technology becomes more sophisticated, the nomenclature is likely going to change, and we are going to discover different and more specific disorders.

Discovering biomarkers for each of these will facilitate that process. We are currently funding work that is being done by Dr. Carlos Pardo to identify a biomarker for TM. Dr. Pardo is also doing a lot of important work to identify people who are getting a TM diagnosis who have the same or similar symptoms but who have really had a vascular episode, i.e., a spinal stroke or an arterial-venous malformation. We are also currently funding a genetics study by Dr. Michael Levy on TM. All this work is fundamental to a better understanding of these disorders and to improved diagnosis and treatment.

Today, the TMA is an organization that advocates for people with Acute Disseminated Encephalomyelitis, MOG Antibody-Associated Disease, Neuromyelitis Optica Spectrum Disorder, Optic Neuritis and Transverse Myelitis, including Acute Flaccid Myelitis. In the future, it is almost certain that there will be disorders added to this list and the names of the disorders listed above will change. It is also the case that sometime in the future, our organization will be changing our name to represent the inclusion of all these disorders and the recognition that our future will be about the evolution of our knowledge.

The proliferation of research on the rare neuro-immune disorders can be seen at the American Association of Neurology meeting. This year there were two papers on pediatric myelopathies, one on adults, another on vascular causes, three on NMOSD, and one on Chiari Malformation and TM.

Dr. Greenberg is in the process of preparing a cell trial for repairing the spinal cord in transverse myelitis through remyelination. The study has been FDA sanctioned and is being supported in part by the TMA. Through our support of the fellowship program, our fellows participate in a research project on one of the rare neuro-immune disorders. For instance, Dr. Cynthia Wang has been involved in an ADEM study at UTSW and Dr. Jonathan Galli is working on a NMOSD study at the University of Utah.

One of the more exciting developments for me in the way of research has been the work that is being done by the TMA. When we established the organization, we decided to have a membership. As we advocated for a rare disorder, and now a group of rare disorders,



Dr. Benjamin Greenberg at the University of Texas Southwestern Medical Center

we understood that it would be important to be able to maintain contact with a community. Our membership also puts us in a unique position to conduct research. We are also blessed to have staff and volunteers who have the education, training and experience to do this work.

We initiated our first study in 1997. I sent out a survey to our members about their experience with transverse myelitis. We continued to administer the survey until 2004 when we presented preliminary results at a symposium in Baltimore. We had 815 respondents to this survey, which is the largest number of people to participate in a study on transverse myelitis. We are still working on the analysis of this study and hope to have the results completed this year.

We have recently begun a **vaccination study** which was sent to a group of randomly selected members from our community. If you receive this study, please be sure to participate. We will eventually make the survey available to everyone. Understanding the experience people with the rare neuro-immune disorders have with vaccinations is imperative. Vaccinations have been an important topic in our community since our inception. We have the opportunity to get answer to some critical questions. We are depending on you to participate to get those answers.

The TMA has also created a **patient registry**. The purpose of this registry is to help advance research about rare neuro-immune

disorders, collaborate with researchers from around the world and identify participants for clinical trials. The TMA registry has been designed to learn more about the natural history of rare neuro-immune disorders, treatments and outcomes using standardized tools.

There is a lot of research being done on all these rare neuro-immune disorders. It wasn't that long ago that there was no research being conducted and there were no scientists focused on doing this work. **We have come such a long way in a short period of time. There is so much that we don't understand. We are only going to get the answers to critical questions through research.**

We depend on our community to get this research done. First, your experience holds all the answers to our important questions. Without your willingness to participate in studies, we are not going to get those answers. There are studies and clinical trials that require a tremendous amount of consideration because they involve treatments that could have long-term consequences for people. People who participate in these types of studies display great courage and selflessness. Their generosity and bravery should be recognized in this way. Most of the work we are going to ask you to participate in involves answering questions and sharing information. The long-term consequences primarily involve your privacy. We understand our responsibility in that regard and we work diligently to protect our member's anonymity in research.



The National Institutes of Health is the largest source of medical research funding in the United States. We are competing with so many different disease groups to receive any of this money. The diseases that impact the largest portion of our population are going to get the lion's share of this money. The NIH is very good about designating funds for rare diseases, but the unfortunate reality is that there are so many rare diseases. All of them are worthy of funding for research. If we wait for the NIH to fund our studies, we will never get anything done. If we want to learn about the rare neuro-immune disorders, we are going to have to raise the funds from our community to support this work. We need for you to make that difference; you and your family and friends.

After Pauline died last August, the TMA established the Pauline H. Siegel Eclipse Fund. The fund will be used to support and accelerate research. Pauline had so much faith in the physicians in our community and was so hopeful about her future. She

understood the importance of their work and believed that their research would ultimately improve her quality of life. She wanted this for herself and for everyone in our community. To the extent of her ability, she made donations to support this work. She considered it an investment in herself and in the people in our community. Pauline's Eclipse Fund is a wonderful legacy to her hope and her aspirations for a better life. She wanted to make a difference in the world, and she did in such a profound way.

We are asking you to do the same. Please do what you can. Please talk to your family and friends and ask them to do what they can to make a difference for you. We are grateful for your consideration. **Please help us to help you!**

Please take care of yourselves and each other.
Sandy



Introducing The MOG Project at The TMA

As researchers continue to study disorders like neuromyelitis optica spectrum disorder (NMOSD) and multiple sclerosis (MS), we are learning more and more about factors that contribute to the disease processes seen in these conditions. For example, demyelination from MS is thought to be caused by the activation of white blood cells called T cells (and maybe B cells), while most cases of NMOSD involve antibodies to aquaporin-4 (anti-AQP4 or NMO-IgG).

MOG Antibody-Associated Disease (MOG-Ab disease) is a recently coined neuro-inflammatory condition that preferentially causes inflammation in the optic nerve but can also cause inflammation in the spinal cord and brain. Myelin oligodendrocyte glycoprotein (MOG) is a protein that is located on the surface of myelin sheaths in the central nervous system. While the function of this glycoprotein is not exactly known, MOG is a target of the immune system in this disease. The diagnosis is confirmed when MOG antibodies in the blood are found in patients who have repeated inflammatory attacks of the central nervous system.

The TMA recently began working closely with a group of individuals diagnosed with MOG-Ab disease and their family members to add resources and information about this condition to our website. We are happy to introduce them and share their stories with you. We look forward to raising awareness and advancing research on this disorder.

More info about MOG-Ab disease: tma.org/mog

Julia Lefelar was initially diagnosed with NMOSD after a few bouts of optic neuritis (ON). She tested negative for the biomarker of NMO, the aquaporin 4 antibody, but was treated with Rituxan to prevent future attacks of ON. Despite the Rituxan, she still suffered attacks about once a year, either in one eye or the other and once with a small lesion in her spinal cord. Finally, after her last attack, she was tested for the MOG antibody, and it was positive.

"Because of these struggles, my daughter (Kristina Lefelar) and I decided to start the MOG Project. My good friend, also a newly diagnosed MOG patient, as well as my sister (Amy Ednie), happily made the commitment to join us to support the community of those who have nowhere to go and are frightened at the prospect of having a rare disease with no cure. The TMA has graciously taken us in and allowed us to help launch their newest disease advocacy. Things are looking up, and for once, the road ahead seems hopeful."

Julia Lefelar

"We hope to provide MOG patients with everything that my mom did not have. We strive to influence the medical community to maintain a better understanding of this rare auto-immune disease so that they can be prepared for future diagnoses. We hope to push for research funding that will aid in finding a cure through fundraising and donation efforts. We believe that it is our duty to educate new MOG patients on their disease, connect them with a supportive community, and raise awareness to our mission."

Kristina Lefelar, Julia's daughter

"We started the MOG Project to raise awareness, educate and advance research because, as a rare disease, there is a lot of misinformation, lack of education for patients, caregivers and doctors, and not a lot of research addressing MOG-Ab disease. To do this on our own would have been a huge undertaking. Luckily, we were introduced to the TMA by Dr. Michael Levy of Johns Hopkins. MOG-Ab disease falls under the TMA umbrella of diseases and by being connected to this organization it gives us the ability and infrastructure to move forward on this journey. We are working with the TMA to provide vetted research and information on the website, become volunteers and ambassadors, connect to the MOG community through social media, and we recently hosted an informational podcast. Just by widening our reach into the community, it allows us to identify additional needs of the community, provide a sense of hope, and receive direct feedback. As a result, we are building out the MOG Project to address these needs as well as tackle research funding. We are the MOG Squad and we are on a mission to make a difference."

Amy Ednie, Julia's sister





Cynthia Albright was also diagnosed with NMOSD after experiencing several attacks of ON. She also tested negative for the NMO antibody. In February 2018, she was tested for the MOG antibody and it came back positive. She has been on Rituxan to prevent future attacks, and she currently receives four Rituxan treatments a year.

Our mission is to represent MOG patients, their families, and caretakers that are seeking resources to help deal with the ins and outs of this very rare disease. I am proud to be a volunteer for the TMA, and I am grateful that they were able to take us under their wings. I am eager to learn more about Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON), MOG Antibody-Associated Disease (MOG-Ab disease), and Transverse Myelitis (TM, including AFM) so I can pay it forward by helping to spread awareness and raising funds for research with the ultimate goal of finding a cure, as, for many, it is a race against time.

Cynthia Albright



Peter and Pamela Fontanez's daughter Isabel, who is 10 years old, has been dealing with Multiphasic ADEM with recurrent ON for a little over four years. She has had three attacks with multiple lesions and temporary major symptoms ranging from paralysis, inability to speak, seizures, behavioral changes and blindness. She was diagnosed as a MOG positive patient over two years ago and has remained MOG positive. Isabel has had IVIG treatments for the last two years and has made an incredible full recovery with no major lingering symptoms and has no current lesions or scarring.

I would like to help further the information that we have obtained and help other people who are lost in finding a doctor or proper diagnosis. I would also like to help further the research of the illness to help my daughter. The more people that are found to have this the better chance for new treatments and a possible cure. If we are able to help one person have a better outcome with treatment or procedures, we may be able to help my daughter with the same treatments or procedures.

Peter Fontanez

The TMA at The American Academy of Neurology Annual Meeting

One very important part of the TMA's mission is to advance the scientific understanding of and therapy development for ADEM, MOG-Ab disease, NMOSD, ON, and TM (including AFM). We do this by supporting the training of clinician-scientists and by supporting basic and clinical research about these disorders. Part of doing research involves disseminating or sharing research findings with the medical community, and this is often done through peer-reviewed publications, or by presentations at conferences. The TMA is proud to announce that four TMA-funded research posters were presented at the 70th American Academy of Neurology Annual Meeting, which was held from April 21-27, 2018 in Los Angeles, California.

Dr. Olwen Murphy, a current James T. Lubin Fellow, and her colleagues at The Johns Hopkins Hospital presented research on pediatric myelopathies. They conducted a retrospective review of 43 patients who were less than 21 years old who were referred to the Johns Hopkins TM Center with a diagnosis of TM between 2010-2017. They reviewed the temporal profile of symptoms, clinical presentation, cerebrospinal fluid analysis and spinal cord magnetic resonance imaging of the patients. They found that clinical, laboratory and imaging findings were consistent with inflammatory myelopathy in 29 patients (infectious [n=10], idiopathic [n=5], neuromyelitis optica [n=1], neuromyelitis optica spectrum disorder [n=1], clinically isolated syndrome [n=1], other [n=11]) and non-inflammatory myelopathy in 11 patients (SC ischemia [n=9], metabolic [n=2]). In 3 patients, the cause was unclear.

Munoz-Arcos L, Gordon-Lipkin E, Barreras P, Castañeda M, Mealy M, Piedra W, Murphy O, Newsome S, Becker D, Levy M, Pardo C. The spectrum of myelopathies in children: Beyond idiopathic transverse myelitis. Poster presented at: 2018 American Academy of Neurology Annual Meeting; April 2018; Los Angeles, CA.

Maureen Mealy, also from the Johns Hopkins TM and NMO Centers, presented similar research that looked at 1000 patients who were referred to the Johns Hopkins TM Center between 2010 and 2017. They reviewed patients' clinical/temporal profile, their neuroimaging, and laboratory findings to establish a final diagnosis. They found that 62% were confirmed to have an inflammatory cause for their myelopathy, of which 35% was idiopathic.

They found 41% of patients had myelopathy attributable to an underlying disease such as multiple sclerosis or neuromyelitis optica spectrum disorder.

Mealy M, Munoz L, Barreras P, Garcia M, Becker D, Newsome S, Gailloud P, Levy M, Pardo-Villamizar C. It's Not All Transverse Myelitis: The Differential Diagnosis of Spinal Cord Myelopathy. Presented at: 2018 American Academy of Neurology Annual Meeting; April 2018; Los Angeles, CA.

Johns Hopkins' Dr. Olwen Murphy, Dr. Carlos Pardo, and Dr. Phillipe Gailloud also presented research on a group of 100 patients with symptomatic low-flow spinal arteriovenous fistulas (SAVF). Low-flow SAVFs are the most common spinal vascular malformation and they can cause severe disability, including paraparesis, pain, bladder and sexual dysfunction. Most low-flow SAVFs can be treated, but they are frequently misdiagnosed, which can delay treatment. They identified clinical features that may help physicians identify this diagnosis, such as older age, male gender, history of intermittent cramping pain in the legs because of low blood flow during exercise, and risk factors for venous thrombosis.

Murphy O, Pardo C, Gailloud P. Clinical characteristics of 100 patients with angiography-confirmed low-flow spinal arteriovenous fistulas. Poster presented at: 2018 American Academy of Neurology Annual Meeting; April 2018; Los Angeles, CA.

Dr. Stacey L. Clardy at The University of Utah, one of the James T. Lubin Fellowship training sites, also presented research at AAN. Her team's research aimed to determine the rate and characteristics of patients not meeting diagnostic criteria for neuromyelitis optica spectrum disorders who tested positive for

autoantibodies to aquaporin 4 (AQP4). They found 48 patients in the University of Utah medical system who tested positive for AQP4, but only 20 of them met the clinical criteria for NMOSD. They argue that individuals should be tested for AQP4 multiple times to ensure patients do not receive false negative results.

Williams JP, Street M, Badger JK, Peterson LK, Greenlee JE, Carlson NG, Rose JW, Soldan MMP, Clardy SL. Characterization and Alternative Diagnoses in Patients with False-Positive Aquaporin-4 Autoantibody Detection by Enzyme Linked Immunosorbent Assay (ELISA). Poster presented at: 2018 American Academy of Neurology Annual Meeting; April 2018; Los Angeles, CA.

Dr. Jonathan Galli, who started his James T. Lubin Fellowship in July 2018 at University of Utah, worked with Dr. Clardy on another research study that aims to characterize patients with NMOSD in the Department of Defense (DoD) population. They identified 131 patients within the DoD system who had the code for NMOSD documented in their medical record, 39 of whom were service members. Only 17 of this cohort of 39 met the criteria for NMOSD. Their clinical characteristics matched other reports of individuals with NMOSD, except for the distribution between men and women, but this may be because of the characteristics of the DoD population as a whole.

Williams JP, Galli J, Groshans KA, Horvat DE, Austin S, Pittock SJ, Rose JW, Carlson NG, Greenlee JE, Soldan MMP, Tagg NT, Clardy SL. Neuromyelitis Optica Spectrum Disorder in Active Duty Service Members. Poster presented at: 2018 American Academy of Neurology Annual Meeting; April 2018; Los Angeles, CA.

For more research and clinical publications, please visit tma.org/research-summaries

Clinical Biomarkers Differentiate Myelitis from Vascular and Other Causes of Myelopathy

Barerras et al. recently published a study in which they analyzed the clinical presentation, spinal cord MRI findings, and cerebrospinal fluid (CSF) features of patients who were initially diagnosed with transverse myelitis (TM). Their goal was to see how these characteristics may help differentiate inflammatory myelopathy (TM) from other causes of myelopathy.

Myelopathy is a general term used to describe a disease of the spinal cord. Myelopathy can be caused by inflammation, as is the case with transverse myelitis. Myelopathy can also be caused by cancer (neoplastic), vascular issues (related to blood vessels), compression (spondylotic), or metabolic issues (for example, B12 deficiency). In a podcast about the study, Dr. Carlos Pardo expresses the importance of making the distinction between myelopathy versus TM to avoid an incorrect diagnosis of TM resulting in administration of treatments that are not truly indicated.

In order to investigate effective approaches to making a definite TM diagnosis, 457 patients with a newly established diagnosis of TM who were referred to the myelopathy center between 2010 and 2015 were included in the study. 58% were female (n=265), with a median age of 46 years.

First, they looked at how specific characteristics were associated with different myelopathies. These myelopathies were

1. inflammatory myelopathy (IM)
2. vascular myelopathy (VM)
3. spondylotic myelopathy (SM)
4. other causes of myelopathy (OM)

The characteristics they looked at were demographic/medical histories, clinical presentations, neurologic examinations, MRI findings, and CSF findings.

After looking at the clinical, MRI, and CSF characteristics of the participants, 55% of 457 patients (n=247) were classified as true inflammatory myelopathy, 20% (n=92) were reclassified as vascular myelopathy, 8% (n=35) as spondylotic myelopathy, and 18% (n=83) as other myelopathy.

Their analysis showed that a shorter time between symptom onset and when an individual's symptoms were at their worst was associated with different types of myelopathies. IM's temporal profile most often was subacute (between 49 hours and 21 days between onset and symptoms being at their worst), while VM's temporal profile was most often hyperacute (less than 6 hours).

The researchers emphasize the importance of biomarkers and aspects of a patient's medical history, family medical history, and the temporal progression of symptom onset for accurate diagnosis of inflammatory myelopathy. As stated by Dr. Pardo in the podcast, the literal "clinical dissection" of a patient's clinical presentation, combined with past medical history and diagnostic MRI imaging is paramount for successful diagnosis of true myelitis of inflammatory origin.

The study analyzed the inflammatory group as one category, which as the authors state "...may not reflect important differences among specific etiologies within the inflammatory group such as MS vs NMOSD or NMOSD vs sarcoidosis myelopathy..." Also, because the study took place at a referral center for myelopathies, and because the center often receives patients who may be difficult to diagnose, it is possible that these cases may be overrepresented in the study, and that these findings may not be entirely reflective of the larger population of individuals with inflammatory myelopathy.

You can learn more about the study from Dr. Carlos Pardo's presentation at the 2017 Rare Neuro-Immune Disorders Symposium: tma.org/2sXs5Qg.

Article: Barreras P, Fitzgerald KC, Mealy MA et al. Clinical biomarkers differentiate myelitis from vascular and other causes of myelopathy. *Neurology*. 2018 Jan 2;90(1):e12-e21. doi: 10.1212/WNL.0000000000004765. Epub 2017 Dec 1.

Full text: tma.org/2CmUvXU

Podcast featuring an interview with Dr. Pardo about this publication: tma.org/2owdqWK

Announcing the 2018 Regional RNDS

The Transverse Myelitis Association, in partnership with Boston Children's Hospital Center for Pain and The Brain, is excited to host the 2018 Regional Rare Neuro-Immune Disorders Symposium (RNDS) in Boston, MA! The RNDS is an education and advocacy conference for families, caregivers and individuals diagnosed with Acute Disseminated Encephalomyelitis (ADEM), MOG Antibody-Associated Disease (MOG-Ab disease), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON), and Transverse Myelitis (including the subtype Acute Flaccid Myelitis).

The objectives of this event are:

1. Gather an understanding of the knowledge to date on the biology and causes of rare neuro-immune disorders and how they relate to each other.
2. Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic rare neuro-immune disorders.

This conference is a great opportunity for individuals diagnosed with a rare neuro-immune disorder and their families to learn about these disorders and how to better advocate for themselves. Medical experts will be available to answer questions and provide the most up-to-date information regarding these disorders. We also encourage any medical professionals wanting a better understanding of rare neuro-immune disorders to attend.

About The Center for Pain and the Brain

The Center for Pain and the Brain is a multidisciplinary team comprised of leading neurologists, physician-scientists, psychologists, physicists and neurobiologists. Founded and directed by David Borsook, MD, PhD, the Center spans Harvard Medical School, Boston Children's Hospital, Massachusetts General Hospital and McLean Hospital. Their research focuses on the discovery of novel pain pathways, developing novel high-throughput methods for evaluating analgesics, and incorporating results from animal research into human applications. They are one of the few Centers that evaluates both pediatric and adult patient groups. Conducting neuroimaging studies in both acute and chronic pain cohorts as well as experimental pain in healthy volunteers, these researchers seek to transform and improve the field of pain medicine.

Details

Date

October 27, 8:00 a.m. - 5:30 p.m. EDT

Venue

The Joseph B. Martin Conference Center
at Harvard Medical School
77 Avenue Louis Pasteur
Boston, MA 02115

More Information & Online Registration

myelitis.org/2018-rnds

Transverse Myelitis Network Gathering at Spinal Life Australia

By Jeanette Kretschmann

Dr. Cynthia Wang was our guest speaker at our annual event and joined us via video link from Dallas, Texas to present an update to our Transverse Myelitis Network members across Australia and New Zealand.

Dr. Wang is currently a James T. Lubin fellow under the mentorship of Dr. Benjamin Greenberg at the University of Texas Southwestern and Children's Health.

Dr. Wang spoke on:

1. Learning about the disease – What do we now know? An overview of Transverse Myelitis, CAPTURE study, Acute Flaccid Myelitis, MOG antibody syndromes
2. Finding treatments for the disease – What can we now do? NMOSD drugs, Remyelinating drugs, Remyelinating stem cells
3. The Transverse Myelitis Association: Eclipse Fund, Family Camp

Sixteen members and partners attended in-person at our Brisbane office along with five members joining us via their home computers. Dr. Wang explained the nervous system could be quite complicated and gave us an analogy about the spine being a highway connecting the brain to the muscles that control the body and the nerves that produce sensations.

A question and answer session brought some interesting questions from both the in-person audience and the online participants.

We thank Dr. Wang for graciously giving up her Sunday evening to talk to us. Special thanks also go to Jim Lubin whose expertise with linking us all together is fantastic, along with many thanks to The TMA for making this all possible. We received wonderful feedback from people around Australia and New Zealand who shared the day with us. For anyone interested in Dr. Wang's recording of the day, it can be found here: tma.org/2JztLGG.

Lunch and networking were enjoyed by all. Three new members joined us for the first time and were welcomed by long-standing members who attend every year.

Creating Online Worlds is Just a Breath Away for Jim

The following story was recently published in Spinal Life Australia's The Advocate Magazine. Jim Lubin is a member of the TMA Board of Directors and is a TMA Executive Committee Member. Jim was diagnosed with TM in 1989 when he was 21. Jim is a C2 quadriplegic, paralyzed from the neck down and ventilator dependent. In 1996 Jim started the Transverse Myelitis Internet Club email list-group to connect people with TM. Jim was the New Mobility Magazine's 1998 Person of the Year. Jim performed all of the Internet and website work for the TMA prior to 2012. Jim has been written about extensively in books and magazines. He is an inspiration for everyone in the TM community and for everyone who knows him.

Jim Lubin has created websites, hosted online video conferences, chat rooms and forums and enjoys the odd game of Tetris and Angry Birds. Not a particularly remarkable achievement for anyone with a decent understanding of computers, except Jim has done it all using only his breath.

Jim was left paralysed from the neck down by the rare neuro-immune disease Transverse Myelitis when he was 21 and found himself dependent on a ventilator to breathe and unable to use his hands or voice to navigate the computer. Not wanting to give up his life-long passion for technology, Jim took on the arduous task of learning to use Morse code to navigate his computer, using his breath to sip and puff to input dots and dashes.

Now, just by sipping and puffing into a small tube, Jim can create websites and online forums, type at a speed of 18 words a minute (only half the average speed) and even play video games such as Tetris, Chess and Angry Birds. Recently, he helped to host an online video conference for the Spinal Life Australia Transverse Myelitis awareness event in late 2017 for people unable to attend in person.

"I've been using the sip and puff technique since I first became a quadriplegic in 1989," Jim said.

"I had a Morse code chart on the ceiling over my hospital bed that I would memorise."

"In 1994 I acquired a new adaptive keyboard and mouse interface that allowed me to also use a mouse with my computer, using the same sip and puff technique."

Jim has used his computer skills to develop his own disability information and resource site and has worked with Transverse Myelitis Associations all over the world, hosting websites and community discussions through chat rooms and forums.

Spinal Life Australia Transverse Myelitis network facilitator Ross Duncan said Jim had voluntarily assisted in hosting regular online video discussions and communications for the Spinal Life Australia Transverse Myelitis network since 2012.

"We're very appreciative of Jim's support and to think he's made it all possible using only his breath is absolutely remarkable," Ross said.



Notes From Our 2018 Events

2018 Arizona Walk-Run-N-Roll

By Kate Krietor

March 24th was a first for the Arizona TM community. We gathered in Phoenix with our families and friends to show support for the TMA by sharing our stories and flexing our fundraising muscles. The energy and support generated by the 110 participants was gratifying to the volunteer organizers and set the stage for an ongoing Arizona TM community.

We walked and rolled, we ate and we played, but most importantly, we gained strength by sharing our stories.

The youngest was a bouncy three-year-old who got TM when she was just one. Maggie walked at 10 ½ months and had to relearn rolling over and crawling. Her mom wrote, “*Her fight and determination and strength were an inspiration to others, even from someone as young as Maggie.*” Our photographer tried hard to get shy Maggie to smile and it took balloons, wagons, and that blue sea of walkers to get her racing and laughing with her small friends. Her story was shared via a story sheet with her beaming smile.

Brittani, a high school senior and varsity athlete who juggles school, clubs, and a job like many teens, was our keynote speaker. Brittani got TM at 11. She got out of bed one day and landed on the floor unable to walk. Her comments were amazing. Doctors told her she wouldn’t play soccer again, but she was determined,



and a year later was back on the field. She was captain of her varsity team last year. “*I’m resilient,*” she said. “*My Mom reminds me TM takes you two steps forward and one step back.*”

Jason, a local TV reporter, knows how to tell a story. Imagine being on your honeymoon in Hawaii, sitting by a pool and slowly realizing you are becoming paralyzed. His wife came to the walk wearing a T-shirt that said, “*TM ruined our honeymoon but not our lives.*” Jason was able to share a bit of his (and our) story on his stations, Channels 3 and 5.

There were other stories too. Jordan came with his 22 supporters all wearing Team Jordan shirts! His mom



shared his story of playing high school sports when TM upended his life. Jordan is adapting to a wheelchair after having overcome being on a ventilator. He is a fighter.

And then there is our story, the story of five 'newbie' event planners. The idea of putting on a walk was born on October 22, 2017 at the end of the TMA's Rare Neuro Immune Disorders Symposium. We were, for the most part, just meeting each other for the first time and inspired to take hope back to Arizona - to create a community, tell our stories and raise awareness! We inspired each other to organize the walk (in just nine weeks!) and exceed our goals for community building, participation, funds raised and just plain old fun!

Arizona is a big, diverse state. The event was a coming-together facilitated by dedicated volunteers. Thank you, Gail, Kate, Julie, Barb, and Deb, and to the strong support of the TMA staff for their willingness to "seed" the event and for their critical technical support. As a community, we are resilient, we defy the odds and we make things happen. See you all next year in Tucson!

A Day of Awareness: The 2018 Northeast Ohio Walk-Run-N-Roll

By Krissy Dilger

The morning of April 29th, 2018 was sunny and clear, but a strong wind was wreaking havoc on the picnic area in Canton, OH where the TMA's Walk-Run-N-Roll was to take place that afternoon. As paper plates and brochures flew off the tables, the TMA's Community Partnerships Manager, Jeremy Bennett, hopped into his car to purchase tape and thumbtacks for holding down loose materials. Despite this chaotic start, many enthusiastic volunteers stepped in to help, and the event began without a hitch.

As participants arrived at the venue, they were greeted with the smell of delicious Greek food provided by Papa Gyros Greek Grill and pizza provided by Antony's Pizza. Each attendee was offered a t-shirt and was able to peruse prize baskets to bid upon. As more adults and families arrived, the atmosphere became charged with energy and purpose; everyone was united in the mission to bring awareness to rare neuro-immune disorders and to raise funds to support the goals of the TMA.

Before it was time to walk, run, and roll around the park, Jeremy gave an enlightening speech on the research, education, and support provided by the TMA to those in our community. He gave praise to Heidi Bournelis, the organizer of the walk, and her helpers, who were instrumental in the planning and success of the event. After Jeremy finished, Heidi's father also spoke on the importance of raising awareness and funds in support of research and finding a cure for rare neuro-immune disorders. Heidi's daughter, Alexis, was diagnosed with Acute Flaccid Myelitis when she was three years old, so this cause is close to her family's heart.

Finally, it was time for everyone to line up and take off down the path outlined for the Walk-Run-N-Roll. A steady stream of over 100 participants wound its way around the park as talking and laughter filled the air. Although the atmosphere was light, serious conversations were also held. As I walked around the park, I spoke to Heidi about her family's initial struggle to get a

diagnosis for Alexis. Her doctors had first failed to diagnose her and suggested that her symptoms may be psychosomatic, i.e. she was faking her symptoms. However, after many tests and a month of waiting, Alexis was finally diagnosed. Her story served as a reminder to me that the TMA's work to spread awareness is far from over.

As the Walk-Run-N-Roll came to a close, families and friends said goodbye to one another as volunteers cleaned up the picnic area. I was happy to see many new friendships form over the course of the event. I hope that all the participants walked away with a better knowledge of rare neuro-immune disorders and the impact they can make by supporting research and education efforts.



Mother's Day Campaign & 2018 Candles for a Cause

Candles, cards, and camp were all a part of Mother's Day this year. For the second year, we offered our community an opportunity to celebrate all mothers by donating to the Send a Kid to Camp Campaign. For each donation, we sent a Mother's Day card notifying the recipient that a donation had been made in their honor that would help fund the cost of sending a kid to our Annual TMA Quality of Life Family Camp.

In addition to the wonderful photos of flowers taken by our very own Roberta Pesce, we offered cards featuring the artwork of Netta Ganor. Netta was diagnosed with TM in 1994, at the age of 15. She is currently a member of The Association of Mouth & Foot Painting Artists, and paints using her mouth.

This year we added an awareness event to our Mother's Day Campaign. On Friday, May 11, the Candle Lab - Pittsburgh hosted Candles for a Cause and shop owner, Abbey Meyer, donated a percentage of sales from the day to the TMA. Attendees sipped wine from Pittsburgh Winery, ate fancy chocolates from A519, and made candles.

Thanks to Abbey and the Candle Lab - Pittsburgh, Roberta and Netta, and our community, we raised nearly \$3,000 towards our TMA Quality of Life Camp and sent out 49 cards.

2018 Author Night with Margaret Peterson Haddix

Books have the ability to transport readers to a new world, and that's how participants felt at the TMA's Author Night with Margaret Peterson Haddix on March 28th. The event was held in Columbus, OH and benefited the TMA's Pauline H. Siegel Eclipse Fund for Research. Pauline, one of the TMA's founding members, was a teacher in the Worthington School District for 25 years. She was an advocate for learning and loved Margaret Peterson Haddix's books for children and teens. As attendees gathered to listen to the author speak, Pauline's joyful spirit was in our hearts.

The night started with a meet and greet with the author, and refreshments were provided by members of the book club to which Pauline belonged. Attendees munched on cheese and

crackers, grapes, and chocolate buckeyes while mingling with the author and other guests. While some of the attendees were members of the TMA, many attendees had come solely because of their love of Margaret Peterson Haddix's books. We were happy to spread awareness and explain our mission to those who had not known of us prior to the event. Canine Companions for Independence (CCI) was also in attendance with two very special guests: golden retriever puppies in training to become service animals. Pauline's service dog, Kazu, was her constant companion whom she loved, and CCI's attendance was a beautiful tribute to Kazu and Pauline's bond.

When it was time for Ms. Haddix's presentation, everyone piled into the auditorium and seated themselves in anticipation. Ms.



Haddix shared photos from her recent trip to Spain as part of her research for an upcoming book. She also told a fun story about her daughter and a search for the perfect swimsuit when she was a child. But the highlight was the Q&A when several of the young people in the audience got to ask Ms. Haddix about her favorite books and characters. Pauline's granddaughter even asked Ms. Haddix who her favorite Star Wars character was. The answer was Princess Leia, of course!

As the night came to a close, guests were afforded a last chance to speak with the author and get their books signed. Smiles and conversation were exchanged in the joyful atmosphere created by Ms. Haddix's insightful presentation. The members of Pauline's book club organized a successful event that served as a fitting tribute to Pauline's memory, and the TMA is extremely grateful for their work in putting this event together.

We would love for you to hold an event in your area. Please contact Jeremy Bennett for more information at jbennett@myelitis.org.

The Importance of Participation: An Update on Support Groups and How To Get Involved

By Jeremy Bennett

Support groups are often overlooked in the recovery process. Whether it is someone who is newly diagnosed or someone who has had a rare neuro-immune disorder for many years, most people experience some sense of isolation, loss of self, and/or anger. While a support group can't replace a trained therapist, they do offer valuable support. Support groups allow those who share a common diagnosis and their loved ones to come together, share ideas, coping tips, experiences, and, most importantly, to exchange emotional support.

Last year, we began the process of professionalizing and expanding our Support Group Network that continues today. To date in 2018, we've hosted 18 Support Group Meetings and added three new Support Group Leaders, in St. Louis, Denver, and Los Angeles. We expect to add additional Support Group Leaders in the San Antonio, Orlando, San Diego, Tulsa, and Detroit areas by the end of July. Plus, we are adding our first MOG Antibody-Associated Disease Support Group Leader, based in Maryland.

If you are looking for support, please visit the Support Group Network (tma.org/sgn) to locate the nearest Support Group Leader. If there isn't a Support Group Leader in your area, please contact Jeremy Bennett, jbennett@myelitis.org, to learn how you can start a support group. It just takes one person to make a big difference. That one person could be you.

Our support groups are facilitated by leaders who have personal experience (either as someone diagnosed or as a caregiver or relative of someone diagnosed) and became advocates for others. The primary goal of the groups is to ensure that no one with these disorders ever feels alone.

DO SOMETHING GREAT

Upcoming Support Group Meetings

Dallas-Fort Worth Support Group Meeting
10:00 a.m. Saturday, September 22

Scottish Rite Hospital
2222 Welborn St.
Dallas, TX 75219

Contact Barbara Nichols for more information
dfwsupport@myelitis.org



Additional meetings are announced on our site under Upcoming Events, through our social media, and in emails.

TMA Volunteer Spotlight

TMA volunteers are some of the most powerful members of our community. These individuals dedicate their time, energy, and resources towards advancing our mission of supporting individuals and their families diagnosed with rare neuro-immune disorders. Were it not for our volunteers, the TMA would not exist. For almost 20 years, the TMA was an organization operating solely on the hard work of volunteers!

Through our “Volunteer Spotlight” column, we honor and share our gratitude to some of the amazing people in our community who are the fabric of the TMA.

We are pleased to honor Gail Buch. Gail was the lead organizer for the 2018 Arizona Walk-Run-N-Roll. The event took place on March 24, 2018 in Phoenix at Steele Indian School Park. Thanks to Gail’s efforts, the event raised \$16,250! This was the first Walk-Run-N-Roll in Arizona and the first opportunity for many members in the state to meet each other. These opportunities would not be possible without volunteers like Gail.

We want to thank Gail for her hard work and dedication to our mission and increasing awareness about rare neuro-immune disorders!



ARIZONA
Walk-Run-N-Roll
FOR THE TMA
Raising funds and awareness for
rare neuro-immune disorders

Multiple Sclerosis (MS) including Acute Flaccid Myelitis (AFM) | Optic Neuritis (ON)
and Optic Spectrum Disorders (OSD) | Acute Disseminated Encephalomyelitis (ADEM)



How did you get involved in the TMA and what prompted you to become a volunteer?

My sister, Maureen Hallagan, invited me to join her at the 2017 Rare Neuro-Immune Disorders Symposium. Our family had recently participated in a genetic research study with Dr. Michael Levy and he was going to present the results at the symposium. It was very compelling to learn that my sister and I were the first two people who were identified to have familial transverse myelitis. It was at the symposium I had the pleasure of meeting a group of women from Arizona. First, I was amazed to learn that there were other people with rare neuro-immune disorders right in my own backyard. Secondly, that two of the women were TMA board members! In conversations throughout the event we discussed how we could help raise awareness and contribute to research for a cure. On the plane ride back to Arizona, fate happened to have us seated right next to each other, and the plan to have the first Arizona Walk-Run-N-Roll was conceived.

Do you have any advice for those in our community who might be considering becoming a volunteer or Support Group Leader?

Volunteering for the TMA is extremely gratifying for me. Having been diagnosed with TM myself, being able to give back to the organization that's leading the way with medical discoveries is the best I can do.

My suggestion to those considering volunteering is to think about what you like to do. Who in your immediate area could join your team to help put the event together? There are many ways you can positively impact the community. We had tremendous support from the TMA's Community Partnership Manager, Jeremy Bennett. He put us in touch with other volunteers that have held a Walk-Run-N-Roll in their city, so we learned all the do's and don'ts. There is strength in numbers, but it starts with one, and that could be you.

What has your volunteer experience been like?

Getting to know others in the community, especially my new friends from Arizona, was awesome. These women busted their tails to make our event fabulous! We were all very tired afterwards and took a few days to recuperate, but it was well worth it. By hosting public events we are raising awareness in our local communities and we need to continue to do so in the future.

As someone who has been affected by a rare neuro-immune disorder, what does the TMA's mission mean to you?

I am grateful for the commitment made to further educate and support those diagnosed, and for the continued research into rare neuro-immune disorders. It gives those of us with a disorder, and our families, a hope for a better future. And for those who are diagnosed in years to come, let there be more scientists dedicated to finding a cure.

What was your favorite part of the Arizona Walk-Run-N-Roll?

It was when I saw so many smiling faces as walkers exchanged handshakes and introduced themselves. We heard so many folks say, "I have never met ANYONE with transverse myelitis before!" We took a group photo of the 110 participants and another one of just the people with rare neuro-immune disorders (there were 17 of us in the picture). A teenager, Brittani Rusnak, kicked off the walk by sharing her story of TM and how she is not letting it disrupt her soccer career. Then there was a huge group from Casa Grande called Team Jordan. Jordan's mom shared his story of how his diagnosis impacts him and his fight to keep going despite being in a wheelchair. There were many stories shared and every one of them was inspiring to me.

We would never have been able to achieve the level of success we had at the first Arizona Walk-Run-N-Roll event if it had not been for my Phoenix co-organizer Kate Krietor, along with Debbie Capen, Barb Sattler, and Julie Barry. We are already planning for the next event being held in Tucson in 2019! We hope to see you there.

Some advice that I could give to someone thinking of volunteering for the TMA is to just take your time and we are here whenever you are ready to take on a role. You don't have to start big. Maybe just start by going to a support group or just listening to someone who is having a hard time. We all have a part to play in this community. It doesn't matter how big or small that part might be. We are all in this together!

Please visit myelitis.org/events for up-to-date information on all TMA related events. If you'd like to become a volunteer, so you too can one day be featured in our newsletter, contact Jeremy Bennett at jbennett@myelitis.org.



Volunteering for the TMA is extremely gratifying for me. Having been diagnosed with TM myself, being able to give back to the organization that's leading the way with medical discoveries is the best I can do.

New Hope Ambassador Stories!

Our Hope Ambassadors shared their stories of resilience, hope, and strength. As we continue to raise awareness and learn from our community, we are honored to share the stories of six new Hope Ambassadors: Samantha T., Samantha B., Sheila, Jenny, Barb and Sharon.



Samantha T.

Diagnosis: NMOSD
Location: California

tma.org/samantha-true



Samantha B.

Diagnosis: TM
Location: Minnesota

tma.org/samantha-bryce



Sheila

Diagnosis: NMOSD
Location: Oklahoma

tma.org/sheila



Jenny

Diagnosis: TM
Location: Melbourne, Australia

tma.org/jenny



Barb

Diagnosis: TM
Location: Michigan

tma.org/barb



Sharon

Diagnosis: TM
Location: Maryland

tma.org/sharon

To read their full stories and for more information on how to become a Hope Ambassador, visit: tma.org/hope-ambassadors



Clinical Studies & Trials

For detailed information about clinical studies and trials, please visit bitly.com/tma-clinical-trials

1

CAPTURE: Collaborative Assessment of Pediatric Transverse Myelitis; Understand, Reveal, Educate

Principal Investigator: Benjamin Greenberg, MD, MHS
Lead Study Site: University of Texas Southwestern
Online study

2

Efficacy and Safety Study as Monotherapy of SA237 to Treat NMO and NMOSD

Study Sponsor: Chugai Pharmaceuticals
This study is currently not open for recruitment.

3

A Double-masked, Placebo-controlled Study With Open Label Period to Evaluate MEDI-551 in NNMO and NMOSD

Study Sponsor: AstraZeneca/MedImmune/Vielabio

4

Spinal Cord MRI Research Study for Children, Adolescents, and Young Adults with Myelitis

Principal Investigator: Nadia Barakat, PhD
Study Site: Boston Children's Hospital

5

A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

Principal Investigator: Benjamin Greenberg, MD, MHS
Study Site: University of Texas Southwestern

6

The PREVENT Study

Study Sponsor: Alexion Pharmaceuticals
This study is currently not open for recruitment.

7 The Effect of Pregnancy on Neuromyelitis Optica

Principal Investigator: Eric Klawiter, MD
Study Site: Massachusetts General Hospital

8 Neuroimaging and Neurobehavioral Outcomes of Pediatric Neuromyelitis Optica: A Pilot Study

Principal Investigator: Ana Arenivas, PhD
Study Site: Johns Hopkins Medicine

9 Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis

Principal Investigator: Lana Harder, PhD
Study Site: University of Texas Southwestern

10 Assessment of Pediatric and Adult Encephalomyelitis Related Outcomes: Understand, Reveal, Educate or APERTURE

Principal Investigator: Benjamin Greenberg, MD
Study Site: University of Texas Southwestern

11 The TMA Registry**12 Neuromyelitis Optica, Anti-MOG Disease, Transverse Myelitis and Optic Neuritis Biorepository**

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University

13 Phase II, Randomized, Single Blind Sham Controlled Trial Investigating Scrambler Therapy for Neuropathic Pain Caused by Neuromyelitis Optica Spectrum Disorder

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University

14 Pathology of Idiopathic Transverse Myelitis

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University



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Announcements

2018 IL Walk-Run-N-Roll: September 16, 2018

2018 MA Walk-Run-N-Roll: October 13, 2018

2018 Rare Neuro-Immune Disorders Symposium: October 27, 2018

Contact us

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