

the transverse myelitis association

newsletter

spring 2017



advocating for those with ADEM, 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 <https://facebook.com/myelitis>.

THE EDITOR'S COLUMN

The Transverse Myelitis Association will be holding a symposium on October 20th and 21st 2017 in Columbus, Ohio; just miles from the international headquarters of the TMA. We are hosting the education program with The Johns Hopkins Transverse Myelitis Center (JHTMC) and NMO Clinic, The University of Texas Southwestern Medical Center (UTSW) and Children's Medical Center CONQUER Program. The presenters at this two-day program are experts in the rare-neuro-immune disorders, and they are exceptional educators. I've been listening to their presentations for many years – they are incredibly well informed; they are interesting and engaging. If there is any way you can make it, I implore you to attend. How much you understand about your disorder will have a significant impact on the quality of your medical care.

When Pauline was diagnosed with transverse myelitis in 1994, we had never heard of this disorder. We didn't know anyone else in the world who had it. We didn't understand what had happened to Pauline; what caused her to become paralyzed. We had no idea at all what her prognosis was going to be; we didn't know if she was going to get better, if she was going to get worse, if she could possibly die.

When one is diagnosed with a rare disorder, ignorance is a profoundly consequential problem. It is so because one doesn't have any idea whatsoever how to define or even think about expectations, and even more so because it is highly likely that one will be receiving medical care from people who are not experts in the disorder. In fact, in 1994, the people who were providing medical care

to Pauline were general neurologists. Today, we have a pretty good understanding of the training that general neurologists receive on TM and the other rare neuro-immune disorders. Depending on where they receive their training and do their residency, they may see a few cases, or they may not see any at all.

In 1994, there was very little information in the medical literature about TM. There were no studies and there were no clinical trials. All treatment, both acutely and for the long-term management of symptoms, was based on expert judgment. In 1994, there were no experts. Today, there are experts, but there are only a small number, and while they are spread across the country and around the world, they are not likely practicing in your neighborhood.

For the first few years of Pauline's experience with TM, we were entirely passive recipients of her medical care. Doctors made decisions about what they were going to do to Pauline and for Pauline. We heard their pronouncements and prescriptions and nodded our heads like bobble dolls. During an appointment with one of Pauline's physicians, he prescribed a medication that Pauline questioned. She didn't believe that she had the symptoms for which this drug is prescribed. Based on her questioning his judgment, he suggested that Pauline see a psychiatrist, i.e., if you are questioning me, you must have psychological problems. That was our last visit with this physician.

Pauline's status as a patient dramatically changed in 1999; we left the first TMA symposium in Seattle having



taken the first steps and rolls on our journey of becoming educated about transverse myelitis. We listened to presentations about transverse myelitis; what was understood about the disorder. We heard presentations about acute therapies and the many symptom management issues. And Dr. Douglas A. Kerr announced his specialization in TM. The establishment of the TM Center at Johns Hopkins offered the first opportunity for the development of an expert in this disorder, and he began to regularly publish about TM in the medical literature.

Pauline and I have attended almost every symposium since this first meeting. I couldn't tell you how many hours of presentations we've listened to, nor the numbers of medical journal articles we've read. I can say that Pauline and I are about as exceptionally well educated about her disorder as patients and loved ones can be. From our selection of physicians to our decisions about what specializations are involved in her care, to decisions about medications she is taking, to decisions about rehabilitation and exercise, to decisions about adaptive and assistive equipment, to our development of expectations, we are active and informed participants in Pauline's care. The more we learned, the more we understood, the less passive we became in our interactions with physicians and with the medical community.

The TMA has been involved in designing and implementing these education programs for a long time. We've also devoted a lot of time and energy in trying to understand the needs of our community. Thank you to those who shared your feedback about our education programs through our surveys. We believe that the quality of the program this year will reflect these efforts. The agenda for the two-day program, as well as detailed information about the registration and reservation process are on our website myelitis.org/event/2017-rnds. Please review the agenda carefully. There will be presentations that are exclusively focused on each of the disorders. As the groups will be smaller, there will be an opportunity for more interaction with the presenters. The general presentations will cover all the major symptom management issues. There will be small breakout sessions covering important topics. These small groups will encourage discussion and interaction with the presenters. We will also focus an entire afternoon on the latest research and have invited experts from all over the country to come share their work.

I encourage you to register as quickly as possible. This is the first of our symposia that is being held in the Midwest. It is our hope that by offering a location more central in the country, that participation will be more accessible.

Additionally, the costs of just about everything in central Ohio are lower than you generally find on the east and west coasts. If you are flying into the John Glenn International Airport, this is not like LaGuardia or O'Hare; we're sort of like an airport on training wheels.

The symposium will be held at the Hilton Columbus at Easton. Easton is just off the 270-outer belt which will make it easy to get to if you are driving into Columbus. If you are flying, Easton is very close to the airport and is a short freeway drive. The Easton shopping and dining area is an interesting place that includes every retail establishment known to humankind, as well as some exceptional restaurants – in all price ranges.

The symposium will be held during peak tree color season in central Ohio. During this third week of October, it can be spectacularly beautiful with temperatures in the 70s, or it can be rainy and windy and in the 40s. And it can be rainy and windy in the 40s in the morning and sunny and in the 70s in the afternoon.

If you are unable to attend the symposium, all the video presentations will be available on our website. One of the more important aspects of attending our symposia

is the opportunity to interact with the physicians who are experts in our discipline. In addition to the directors of our TM and NMO Centers, all our James T. Lubin Fellows will be attending and presenting. Equally important, the symposia offer the opportunity for people to meet others who have their disorder and their families. These interactions have resulted in lifelong friendships. To facilitate the social support and interaction and to encourage awareness, the Ohio Walk-Run-N-Roll will be held on Sunday morning after the symposium is completed. The details about the walk are also available on our website - myelitis.org/event/2017-ohio-walk-run-n-roll.

Pauline and I will attend every presentation as we know how important it is to learn as much as we possibly can; this education makes us the most effective advocates for Pauline's medical care. And as our discipline grows, and more clinical experience is developed and more research is being done, there is so much more to learn. Pauline and I are looking forward to seeing our dear friends in October; and we are looking forward to meeting as many of you as possible.

Please take good care of yourselves and each other,
Sandy

DR. LANA HARDER JOINS THE TMA BOARD OF DIRECTORS

We are thrilled and honored to welcome Dr. Lana Harder to the Board of Directors of The Transverse Myelitis Association. Dr. Harder is a Pediatric Neuropsychologist at Children's Medical Center of Dallas (CMCD) and Associate Professor with joint faculty appointments in Psychiatry and Neurology at the University of Texas Southwestern (UTSW) Medical Center. Dr. Harder completed her doctoral training at the University of Texas at Austin, pre-doctoral internship at the Kennedy Krieger Institute and Johns Hopkins School of Medicine, and post-doctoral fellowship in Pediatric Neuropsychology at Texas Children's Hospital and Baylor College of Medicine. She is board certified in Clinical Neuropsychology by the American Board of Professional Psychology with subspecialty certification in Pediatric Neuropsychology. Dr. Harder was a founding member and is the Co-Director of the CMCD Pediatric Demyelinating Diseases Program. Dr. Harder specializes in the neuropsychological evaluation of pediatric patients, from infancy to young adults, with disorders of the central nervous system. Research interests include cognitive and psychosocial outcomes for pediatric multiple sclerosis (MS), transverse myelitis (TM), acute disseminated encephalomyelitis (ADEM), optic neuritis (ON), and neuromyelitis optica spectrum disorder (NMOSD).

Thank you Dr. Harder for your commitment to our community.

I am honored to join the TMA Board of Directors. In large part, given my collaboration with and the support of the TMA, my clinical practice and research program is almost exclusively focused on pediatric CNS demyelinating conditions. Consistent with the work of the TMA, I have a long-standing commitment to seeking knowledge about these rare diseases and providing clinical care and education to those affected.

– Dr. Lana Harder



COLLABORATIVE MEETING ON ACUTE FLACCID MYELITIS

On January 23, 2017 the TMA co-sponsored a collaborative meeting on acute flaccid myelitis (AFM) that was hosted by the CONQUER Program of UT Southwestern and Children's Health Dallas. Twenty-four health care providers, researchers, Centers for Disease Control (CDC) representatives, and the TMA participated in this meeting. The purpose of the meeting was to bring stakeholders together to compare data and experiences about AFM, learn about the initiatives led by different stakeholders, review the current case definition and identify research needs and potential collaborations.

Here are the top ten takeaways from the AFM meeting:

1. Dr. Benjamin Greenberg of UT Southwestern started the meeting by giving a background about AFM, including the history of the disorder. He emphasized that AFM has likely been around for many years, but that we are only now aware of it and are describing it as AFM.
2. There remains some ambiguity on the case definition of AFM that gets reported to the CDC, but researchers and medical professionals are working hard to come to a consensus about this. Dr. Sarah Hopkins from the Children's Hospital of Philadelphia shared her experience as a case reviewer for the CDC and at CHOP, and that imaging interpretation continues to be difficult with regard to involvement of gray matter and the timing of the MRI.
3. Dr. Manisha Patel from the CDC discussed the number of AFM cases that have been reported to the CDC. There were fewer cases reported in 2015 than in 2014.
4. Dr. Thomas Briese from Columbia University Medical Center discussed the role of enterovirus D68, a virus that is capable of causing an infection in the central nervous system. Enterovirus D68 may be a factor in recent clusters of AFM.
5. Dr. Carol Glaser from Kaiser Permanente and Dr. Avi Nath from the National Institutes of Health shared their views on whether or not enterovirus D68 could be a cause of AFM, and came to the conclusion that there was significant data linking EVD68 to AFM, but more research would be useful.

Determining the proper diagnostic tests and the correct timing for these tests is critical to improving the care and treatment of people with AFM

6. Dr. Ken Tyler and his team from the University of Colorado have developed an animal model of AFM that will hopefully help researchers better understand the mechanisms behind AFM.
7. Dr. Teri Schreiner from the University of Colorado reported findings from a study on outcomes after pediatric AFM. She found that all the children they followed improved functionally but continue to have limb weakness.
8. Dr. Greenberg reviewed the CAPTURE study which is an ongoing study in pediatric transverse myelitis, including AFM, which will hopefully help us better understand this disorder.
9. While the CDC does not currently recommend IV steroids, IVIG, or plasma exchange (PLEX) in the treatment of AFM, some physicians treating patients with AFM have seen improvement in their patients with these treatments. Currently, there are no data or consensus to systematically guide treatment in AFM. Treatment decisions should be individualized and based on the clinical characteristics of each patient.
10. Determining the proper diagnostic tests and the correct timing for these tests is critical to improving the care and treatment of people with AFM.

Overall, the meeting was an excellent opportunity to learn about what is currently being done to better understand AFM, to improve the case definition, and improve diagnosis and treatment options. It was a great step in building collaborative approaches to addressing this growing public health concern. We look forward to sharing more updates with the community as we learn more.



THE TMA REGISTRY

The TMA registry is a survey that has been designed to learn more about the natural history of rare neuro-immune disorders, treatments and outcomes using standardized tools.

WHO CAN PARTICIPATE

- › Individuals diagnosed with
 - Acute Disseminated Encephalomyelitis
 - Neuromyelitis Optica Spectrum Disorder
 - Optic Neuritis
 - Transverse Myelitis, including Acute Flaccid Myelitis
- › Consent to participate must be provided by an eligible adult participant or a legal guardian, if the participant is under the age of 18 or is an adult who is unable to provide consent for him/herself.
- › Parents or a legally-authorized representative can also enroll on behalf of patients who are deceased. When a legal guardian/representative is completing The TMA Registry, an additional signature is required for participant assent, which is required if an individual is 7 years of age or older and is cognitively able to provide assent.

CONTACT US

For more information and questions about The TMA Registry, please contact The TMA's Associate Director, Research and Education, GG deFiebre, at gdefiebre@myelitis.org.

Join the registry: myelitis.org/shaping-the-future/research/tma-registry

UTSW CENTER GRANT UPDATE

In 2016, Dr. Benjamin Greenberg at The University of Texas Southwestern Medical Center received a TMA Center Grant to help support the TM and NMO Center's Neuro-immunology Biorepository, which was established in 2009. The specimens collected have been critical to many research and biomarker studies. The Center Grant was used to expand the center's staffing and resources of their longitudinal study to collect samples and data from children with rare neuro-immune disorders. With the TMA grant, they have been able to expand the center's laboratory support to handle more samples from children in the hospital in the acute

stage. Since the beginning of 2016, they have enrolled 29 children with ADEM, NMOSD, ON, TM, and autoimmune encephalitis to grow their database and sample repository to better understand these rare disorders. With the additional support, they have been able to follow these cases more closely over time to see how diagnoses change and evolve. To learn more about TMA grants, please visit: myelitis.org/shaping-the-future/research/submit-your-research-idea.

These grants and the critical work that they support are made possible by our community's generosity.



QUEEN'S UNIVERSITY RESEARCHERS MAKE MAJOR MYELIN REPAIR DISCOVERY

Queen's University Belfast scientists have discovered that specific cells from the immune system are key players in repairing myelin in the central nervous system - a fundamental breakthrough that could revolutionise the treatment of debilitating neurological disorders such as multiple sclerosis (MS) and many demyelinating conditions, such as transverse myelitis, neuromyelitis optica spectrum disorder and acute disseminated encephalomyelitis. In all these conditions, the myelin is damaged, and there are immune cells present at many sites of damage in the central nervous system. Myelin is important because without it, nerves are not able to conduct or send signals where they need to go.

The research study, led by Dr Yvonne Dombrowski and Dr Denise Fitzgerald at the Wellcome Wolfson Institute for Experimental Medicine at Queen's University Belfast, is being hailed as a landmark study in unravelling the mysteries of how the brain repairs damage.

The research breakthrough, which was published in Nature Neuroscience (go.nature.com/2nEaJ6Q), shows that a growth regulatory protein made by certain cells within the immune system, called regulatory T cells (Treg), triggers the brain's stem cells to mature into oligodendrocytes, which are cells that repair myelin. What the Fitzgerald group and collaborators have discovered in different settings of myelin damage (including spinal cord and brain tissue), is that this specific immune cell, Treg, is critical for driving efficient repair of myelin. The Tregs accomplish this by producing a protein, CCN3, that triggers immature oligodendrocytes to mature, start producing myelin, and re-wrap nerves.

They studied this using a focal demyelinating mouse model induced by injecting lysolecithin into spinal cord white matter. They confirmed their findings with a second demyelinating model at a different central nervous system site using another drug called cuprizone. Further, in brain slice cultures, they were able to show that Tregs promoted brain tissue myelination and remyelination in the absence of inflammation. The discovery means that researchers can now use this new knowledge to develop medicines which will boost these particular cells and develop an entirely new class of treatments for the future.

Senior author of the study, Dr Denise Fitzgerald from Queen's, was diagnosed with transverse myelitis when she was 21 and had to learn to walk again. Commenting on the findings, Dr Fitzgerald said: "This pioneering research, led by our team at Queen's, is an exciting collaboration of top scientists from different disciplines at Cambridge, San Francisco, Edinburgh and Nice. It is by bringing together these experts from immunology, neuroscience and stem cell biology that we have been able to make this landmark discovery. This is an important step forward in understanding how the brain and spinal cord are naturally repaired and opens up new therapeutic potential for myelin regeneration in patients. We continue to work together to advance knowledge and push the boundaries of scientific knowledge for the benefits of patients and society, in a bid to change lives for the better, across the globe."

This work was supported by a number of funders including the BBSRC, Wellcome Trust and Leverhulme Trust.

Original research: Dombrowski Y, O'Hagan T, Dittmer M et al. Regulatory T cells promote myelin regeneration in the central nervous system. *Nat Neurosci.* 2017 Mar 13.

A GOOD READ AND A GOOD DEED!

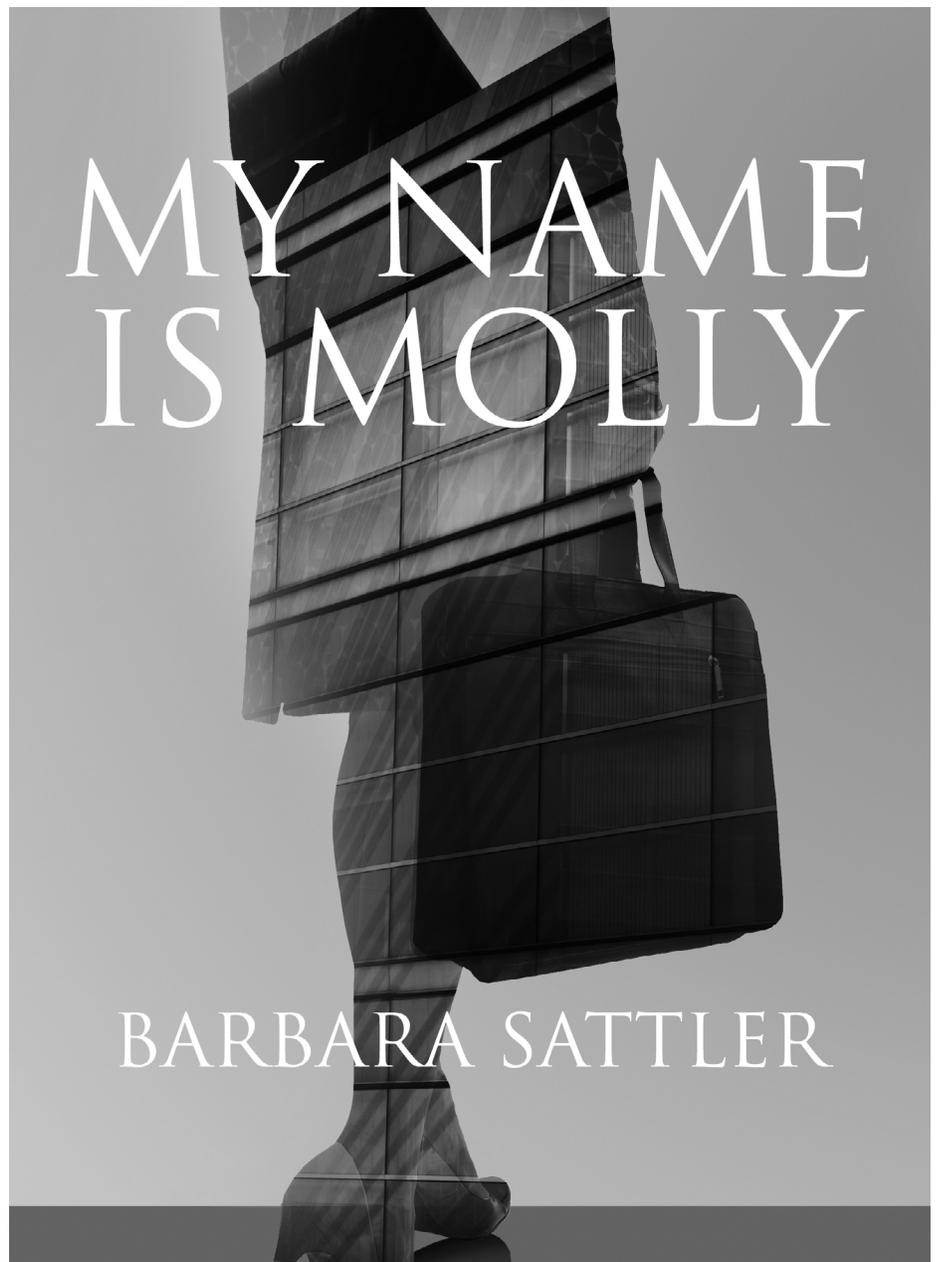
Barbara Sattler's third novel, "My Name is Molly," is available on Amazon (paperback and Kindle).

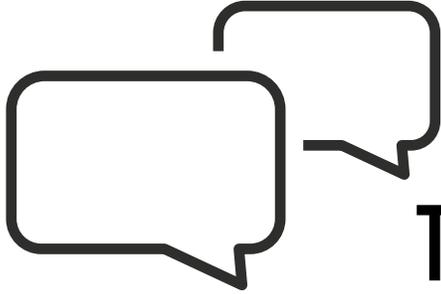
Barbara has been a member of the TMA since 2001. She runs a support group in Tucson and currently serves on The TMA Board of Directors. All profits from the book go to support the programs of the TMA.

Molly a materialistic, ambitious lawyer has everything- a job at a prestigious law firm, a fiancé with a condo in the right postal zone, and looks women covet. But Molly's law firm is hit hard by the recession. She's fired, her fiancé dumps her and evicts her by third-party from his condo. She finds herself jobless and living with her parents. Can it get worse? Finally a job offer. But it's a position at the Public Defender's Office. Molly accepts reluctantly. She believes public defenders are rejects: bad grades, bad interview skills, or bad breath. Their clients all guilty. Will Molly change as she meets her new colleagues, new clients and struggles daily with prosecutors and judges?

Barbara was a defense lawyer for 17 years and a judge for 11 years. Learn what really goes on behind the scenes as Molly represents drug users, a serial rapist and tries a murder case.

Kirkus review said of her second novel, Anne Levy's Last Case, "A highly readable novel of interpersonal and courtroom drama."





THE MYELITIS HELPLINE

Over the last 22 years, we have worked with leading medical professionals and experienced providers to share resources, information, and up-to-date knowledge with our community of individuals diagnosed with ADEM, NMOSD, ON, and TM, including AFM, caregivers, and medical professionals. Based on the questions and feedback from our community, we recently launched a new online tool, the Myelitis Helpline, a collection of frequently asked questions that covers topics from diagnosis to treatments to research to applying for social security disability.

The goal of this online tool is to provide resources, knowledge and help to our community, whether one has been recently diagnosed or has questions several years after onset of a rare neuro-immune disorder. The information provided is for general information purposes and is not a substitute for professional medical advice, care, treatment or for diagnosis.

Please send an email to GG deFiebre at gdefiebre@myelitis.org with additional questions and ideas you would like us to include in the Myelitis Helpline.

myelitis.org/mhl

VISIT OUR RESOURCE LIBRARY

to access over 250 articles, newsletters, videos and podcasts, filtered by disorder and specific topic.

myelitis.org/living-with-myelitis/resources/resource-library

2017 TMA GALA DINNER & AUCTION

in honor of Sarah Robbins

It was November 2011 - our 10-year old daughter, Sarah, walked into our bedroom in the morning after she awoke and within 30 minutes collapsed in front of our eyes. Our already mentally challenged daughter, was now paralyzed and life had forever changed. We were told we were lucky that the acute onset was not in the cervical part of her spine or she may have needed permanent assistance to breathe. We were not feeling lucky. The world for our family changed that day and now we were faced with the everyday challenges of raising our paralyzed daughter. We tried to comprehend the doctor's explanation that currently there is no medicine or treatment plan available to heal this child or anyone else suffering from this disorder. We were told she could possibly walk with constant and consistent physical therapy, or she might not.

Now, our mission has begun. We are asking that you join us on this mission. The 2017 TMA Gala Dinner & Auction is dedicated to raising funds and awareness for the Transverse Myelitis Association (TMA) and helping people with rare neuro-immune disorders and their families meet others for support, sharing and education. For more information, please visit www.myelitis.org.

Dinner & Auction

Friday, June 2, 2017

Radisson Resort Port

8701 Astronaut Blvd
Cape Canaveral, FL 32920

Individual tickets can be purchased for \$125 and opportunities for corporate sponsorship are available

More info: myelitis.org/event/2017-tma-gala-dinner-auction



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 and advocating for individuals and their families diagnosed with rare neuro-immune disorders.

If it were 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! We honor those who work so hard for us to support our mission.

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 Barbara Nichols. Barbara is the TMA support group leader of the Dallas-Fort Worth (DFW) Support Group. She works tirelessly connecting and supporting members, and has also served as chair of the DFW Walk-Run-N-Roll. It is our great pleasure to introduce Barbara to our community!



Barbara, how did you get involved with the TMA and what prompted you to become a volunteer?

After my spinal cord attack, I did some serious surveying of my life. I was working many hours, my mother had just died six months earlier, and I had been her caretaker for the last 10 years, and I was dealing with two teenage sons! Fortunately, I had the blessing of an amazing husband and most important of all, trust in God. I prayed He would show me what to make of this huge change in my life. I committed to do whatever He wanted me to do with this “new normal.”

When I was told it was a Transverse Myelitis attack in 2007, there was very little information available and what we could find was, frankly, quite scary. I started out mostly paralyzed from the mid-chest down. I had already lost vision in one eye five years prior, but no one was connecting the dots yet. A few months later, my blood test was sent to Mayo Clinic for a positive diagnosis of NMOSD. I was very blessed with much more recovery than so many and felt I needed to do something for others. It was two and a half years before I found Dr. Ben Greenberg at The University of Texas Southwestern. He urged me to meet others with

this diagnosis. Frankly, I was glad to know I was not the only one around dealing with this diagnosis. He later asked me to contact the TMA and consider becoming a support group leader. After speaking with Chitra Krishnan at the TMA, I knew I had found my answer and mission.

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

It has been so encouraging to find an organization doing so much to advance the cause of advocacy, education, providing support for the patient community, collecting data for research, and funding fellowships through the James T. Lubin Fellowship Program. The Fellowship trains doctors to specialize in these demyelinating disorders so that others can have access to trained medical professionals that patients have not had access to before.

What has your experience been like as a volunteer, and more specifically, as a support group leader?

Honestly, I thought leading a support group was going to probably consist of a few folks (since it is so rare) getting

I still get the most joy from seeing someone new come into the group and meet someone else with a shared diagnosis for the first time.

together occasionally for dinner or something. I laugh at myself about that theory now! We started the DFW group in 2013 and 27 people attended the first meeting! We meet every other month and have had as few as 5 people attend to as many as 45. I have learned to quit worrying about the numbers, and instead focus on my job to help those there that day. Some of our sweetest times have been with a small group as you really get to know each other. We held a Walk-Run-N-Roll in 2014; 140 people attended and we raised \$25,000 to support TMA programs. Personally, for me, I am always amazed at what God can do if I get out of the way. I have had the privilege of speaking with people from all around the state of Texas and other states as well that don't have support groups in their area. I am the one blessed by the stories and courage shown in the most difficult of situations. It is hard

to hear of the ones who do not have resources on their condition and feel desperate in the fact that they do not have proper medical care and to hear the fear in their voice. There is nothing like talking to someone who has first-hand knowledge of your situation. I still get the most joy from seeing someone new come into the group and meet someone else with a shared diagnosis for the first time. That is why I am so grateful to be a volunteer with the TMA as they provide that education and help to patients, and I have a place to point patients to for valuable help.

Do you have any advice for someone in the TMA community who is considering becoming a volunteer or starting a support group?

If you have ever considered being a support group leader, let me encourage you to not be afraid to step out there.

There is plenty of support from the TMA through our new Community Partnerships Manager, Timi Schrupf, to help you with the details. You just need a willingness to help others through a situation that you have experienced. All of us working together can make a difference!

BUILDING STRONGER SUPPORT GROUP LEADERS

In January, the TMA officially launched a new support group leader process. This multi-step process, which includes a virtual training course, is designed to give all our support group leaders the tools and knowledge necessary to lead an effective and engaged group, and to provide the support that our community needs.

As one of our support group leaders pointed out, a support group can only be as strong as its leader. This belief seems to be a common one; we are happy to report that several support group leaders have completed the entire process, and many are working to complete it.

Once leaders successfully complete the training, they will become official TMA Support Group Leaders, and be given the honor and responsibility of connecting community members, holding meetings, and serving as ambassadors for the TMA. Please take a look at the map (<https://myelitis.org/living-with-myelitis/resources/support-group-network>) to see who the support group leaders are in your area. If there is not a support group in your area, please consider starting one! Contact Timi Schrumppf at tschrumppf@myelitis.org for more information on how to get started.



**I feel I am a better leader
because of the new support
group leader training process!
It has given me the strength,
the tools, and the confidence
to step up and bring everyone
who's affected together! Not to
mention the amazing people I
have been able to meet and get
to know during the process.
All thanks to The Transverse
Myelitis Association!**

Heather Reynolds
Central Texas Support Group Leader

2017 RARE NEURO-IMMUNE DISORDERS SYMPOSIUM



OCTOBER 20-21, 2017
HILTON COLUMBUS AT EASTON
COLUMBUS, OH

On October 20-21, 2017, the TMA along with The Johns Hopkins Transverse Myelitis Center (JHTMC) and NMO Clinic, The University of Texas Southwestern Medical Center (UTSW) and Children's Medical Center CONQUER Program, will be hosting the 2017 Rare Neuro-Immune Disorders Symposium. This conference, held at the Hilton Columbus at Easton in Columbus, Ohio, is dedicated to the exchange of information regarding diagnosis, treatment strategies, and research. The goal is also to bring together individuals diagnosed with these rare neuro-immune disorders, their families, caregivers, and the medical professionals who are specializing in these disorders.

We are excited to announce that the agenda has been finalized and registration is now open! Please visit myelitis.org/event/2017-rnds to register. TMA members can register as a participant for \$45.00 while non-members may register for \$70.00.



2017 RND\$ Registration Fees

TMA MEMBERS

REGISTRATION DEADLINES

	Early Bird - By June 1 st	Regular Fee
Conference Participant	\$ 45	\$ 65
Additional Participant	\$ 35	\$ 55
Children (12 - 18 years)	\$ 15	\$ 25

NON-MEMBERS

REGISTRATION DEADLINES

	Early Bird - By June 1 st	Regular Fee
Conference Participant	\$ 70	\$ 90
Additional Participant	\$ 55	\$ 75
Children (12 - 18 years)	\$ 20	\$ 30

If you would also like to reserve a room at the Hilton Columbus at Easton, we have a limited block of accessible and regular rooms available until September 19, 2017 at a nightly rate of \$189 plus 17.5% taxes. To make your reservations by phone, please call the hotel directly at 614-414-5000 and ask for the “TMA Symposium” room block rate, or you can make reservations online through the online group reservations link (<http://bit.ly/2oAZc5g>). For more hotel information, please visit myelitis.org/event/2017-rnds/#tab-id-2.

Please remember that the 2017 Ohio Walk-Run-N-Roll will be held on Sunday, October 22nd at Coffman Park Pavilion in Dublin, OH, after the symposium. The event is an opportunity for our community to come together to share stories, experiences, and form lasting relationships all while increasing awareness of these rare neuro-immune disorders and raising funds that will allow the TMA to continue providing much needed educational programs like the RND Symposium and supporting research. More information can be found at myelitis.org/event/2017-ohio-walk-run-n-roll.

For any questions, please contact Timi Schrupf at tschrumpf@myelitis.org.

Register today: myelitis.org/event/2017-rnds



CLINICAL STUDIES & TRIALS

For more information, 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
Study includes online and multiple study sites

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

Study Sponsor: Chugai Pharmaceuticals

3 Safety and Efficacy of Sustained release Dalfampridine in Transverse Myelitis

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

This study is currently not open for recruitment. Participants currently enrolled are being followed.

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

Study Sponsor: Astrazeneca

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

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

6 A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

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



7 **The PREVENT Study**

Study Sponsor: Alexion Pharmaceuticals

8 **The Effect of Pregnancy on Neuromyelitis Optica**

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

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

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

10 **SCI-Hard: Evaluating the Effectiveness of a Mobile Game to Improve Self-Management Skills of Teens and Young Adults with SCI and other Spinal Cord Impairments**

Principal Investigator: Michelle A. Meade, PhD
Study Site: University of Michigan

11 **Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis**

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

12 **The TMA Registry**

NIH/NCATS GRDR® Program

For detailed information about clinical studies and trials please visit myelitis.org/shaping-the-future/research/clinical-studies-trials

2017 WALK-RUN-N-ROLLS

We are excited to announce that the TMA is making great progress towards our goal of having ten Walk-Run-N-Roll campaigns across the country in 2017!

A Walk-Run-N-Roll serves as a great community-building event to raise awareness for rare neuro-immune disorders. These events also help the TMA reach our goal of increasing awareness, developing and strengthening our community, and raising funds for research, education and support.

There are other walks being planned, and we will be releasing details as they are finalized. Please visit our website to join a walk near you!

If you would like to help organize a Walk-Run-N-Roll in your area, please contact Timi Schrupf at tschrumpf@myelitis.org.

Upcoming Walk-Run-N-Rolls

2017 NJ Walk-Run-N-Roll

Saturday, April 29, 2017

Cooper River Park

5300 N Park Dr
Pennsauken Township, NJ 08109

More info: myelitis.org/event/2017-nj-walk-run-n-roll

2017 TX Walk-Run-N-Roll

Saturday, October 7, 2017

Cottonwood Creek Park

4051 N Story Rd
Irving, TX 75038

More info: myelitis.org/event/2017-tx-walk-run-n-roll

2017 FL Walk Run-N-Roll

Saturday, September 23, 2017

Lake Eola Park

512 E Washington St
Orlando, FL 32801

More info: myelitis.org/event/2017-fl-walk-run-n-roll

2017 OH Walk Run-N-Roll

Sunday, October 22, 2017

Coffman Park Pavilion

5200 Emerald Parkway
Dublin, OH 43017

More info: myelitis.org/event/2017-ohio-walk-run-n-roll



ASK THE EXPERT PODCAST SERIES

Every month the TMA holds a podcast on a topic that affects those with rare neuro-immune disorders. Experts in the field share the latest knowledge and answer questions from our community. Podcasts have covered topics, such as vaccinations and rare neuro-immune disorders, rehabilitation, and clinical trials.

So far this year our Experts have answered questions about building multidisciplinary teams for complex care, vaccinations, and about managing care with a rare neuro-immune disorder. We are very excited about our upcoming podcasts on nutrition and rare neuro-immune disorders, open forums on each of these disorders, secondary complications of these disorders, and the role of rehabilitation and exercise. We hope you can join us!

Listen and subscribe to our podcast via iTunes today. You can find all past recordings in our resource library: <https://bit.ly/tma-podcasts>.

OUR ADDRESS HAS CHANGED!

Please send all communications and donations to our new bank lockbox address:

**The Transverse
Myelitis Association**
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Philadelphia PA 19182-6962



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Announcements

- 2017 NJ Walk-Run-N-Roll: April 29, 2017
- 2017 TMA Gala Auction & Dinner: June 2, 2017
- 2017 TMA Quality of Life Family Camp: July 15-19, 2017
- 2017 FL Walk-Run-N-Roll: September 23, 2017
- 2017 TX Walk-Run-N-Roll: October 7, 2017
- 2017 Rare Neuro-Immune Disorders Symposium: October 20-21, 2017
- 2017 OH Walk-Run-N-Roll: October 22, 2017

Contact us

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