



the transverse myelitis association

# newsletter

summer 2019



*advocating for those with ADEM, AFM, MOG-Ab disease, NMOSD, ON & TM*

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Follow The Transverse Myelitis Association on Facebook ([facebook.com/myelitis](https://facebook.com/myelitis)) and Instagram ([instagram.com/myelitis](https://instagram.com/myelitis)) and tell your friends and family to do the same! It is a great way to support the TMA and a wonderful way to network with people in our community. Facebook and Instagram are also great ways for us to raise awareness about these disorders and share your experiences.

# A Note from the President

**The Patient Experience with Transverse Myelitis: An Anthropological Perspective was published in May 2019. It is available on Amazon both as a paperback and for Kindle. If you purchase the paperback, you can download the Kindle version at no cost. The Kindle version alone can be purchased for \$2.85. The paperback is \$18. Please do a Google search for the meaning of the number 18 and Chai in Judaism. The book is self-published.**

I wish we had this book when Pauline was diagnosed with transverse myelitis in July 1994. It would have helped us through this horrible journey.

Over the past 25 years, I've communicated with thousands of people and assisted them with every issue surrounding all the neuroimmune disorders, including MS. Diagnosis, acute treatments, rehabilitation, long-term therapies for recurrent disorders, symptom management, adaptive devices, accessible living spaces, insurance issues, social and behavioral problems, government and social service programs, legal issues, financial issues, service animals. I've helped people through just about everything.

I attended every symposium and sat through every presentation. I've immersed myself in the medical literature. I conducted an open-ended survey in 1997 and was provided with exceptional information from 815 people with transverse myelitis. I have learned a great deal going through this experience.

I am a cultural anthropologist. The primary research method in anthropology is participant observation. Participating and observing is what I've been doing in the TMA community for

25 years. My book attempts to describe and explain the experience for a person who is diagnosed with transverse myelitis, and for their family members.

This is not a medical book. There are no prescriptions for treatments or procedures. It is a book about the experience. It is a book about expectations. Its greatest value is that it will help the reader better understand what they can expect from this experience.

My great hope is that people with all the rare neuroimmune disorders will find the book helpful. The experiences are the same in most areas and similar in the rest.

More than 20 people contributed articles that appear at the end of most of the chapters. These are people with transverse myelitis, parents, and medical professionals. Drs. Douglas Kerr and Benjamin Greenberg co-authored the preface.

Pauline would be so proud and gratified that her story will help others. Pauline's life was hard. She suffered a great deal. She was an amazing and wonderful person.

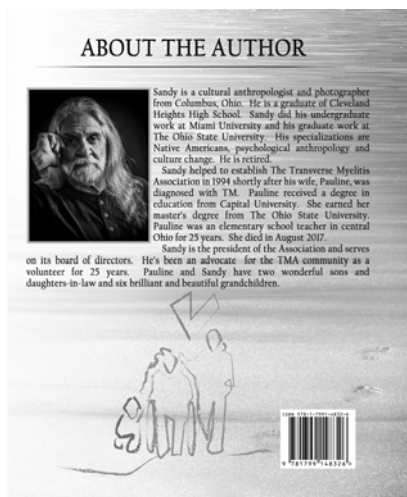
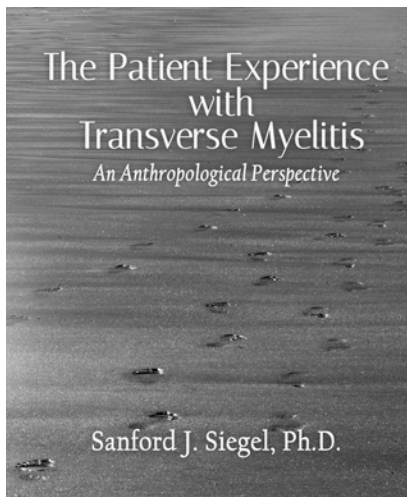
The story I wanted to share about my book is in the forward. An abridged version on the next page.

Please take care of yourselves and each other.

*Sandy*

## Forward

# The Patient Experience with Transverse Myelitis: An Anthropological Perspective



This book is Pauline's story. I was Pauline's friend, husband and caregiver. Pauline was diagnosed with transverse myelitis in the summer of 1994. Shortly thereafter, we helped to establish The Transverse Myelitis Association. Pauline is the reason there is an association dedicated to advocacy for people with rare neuroimmune disorders.

I started writing this book in 2009. For two years, my writing was done exclusively on weekends. I retired from my job with the state of Ohio in April 2011. When I retired, I devoted a tremendous amount of time to researching the regulatory, financial and legal obligations that were entailed in transforming the TMA into a professional organization. At the same time, we began a search to fill our first position. I retired from a full-time job and then worked much more than a forty-hour week to accomplish the tasks that were required to hire Chitra Krishnan as our executive director. We were also laying the foundation for the staff we would hire over the next seven years. My work on this book was done as time allowed.

It wasn't until 2014 that I was able to focus my attention on writing. My purpose for writing the book was to share what I learned through my advocacy work over the past twenty-four years. I have often referred to the writing as a brain dump. To the extent there is value in sharing this experience with the people in our community, I felt obligated to describe the most comprehensive story.

I wrote the entire book without an outline and without any notes. I am a neurotically organized person. It used to make Pauline nuts. Pauline was merely a normal person. I didn't need an outline because, after twenty years of doing this intensely emotional work, the story had an obvious structure. I had so many opportunities to share experiences in my writings for the newsletters and journals, for my presentations at symposia, in conversations with people who called seeking information and support, and from my many discussions with caregivers and medical professionals. I was able to systematically organize the story from these experiences.

I am also a disciplined person. Kazu would wake me up every morning at 6:00 AM to be walked and fed. I would make myself coffee, park myself in front of the computer, and respond to the emails that had arrived since the night before. I would then spend four or five hours writing. I had the first draft of the book completed by the end of 2015.

I didn't want to make a profit from selling this book. Its purpose is to get information into the hands of people who might find it helpful. I couldn't take it to a publishing company, because they wouldn't invest in a book to give it away. The decision to self-publish was an easy one. This is also a personal story for me as Pauline's husband, and as a close friend to so many people in our community. I wanted to have total control over the story.

So much of the book is about Pauline. Pauline carefully reviewed the entire book. She went through every reference to her story. First, she gave me permission to share her experiences. Second, Pauline confirmed that I characterized her experiences accurately. I made the changes she suggested.

I went through the same process with Jim Lubin. There are many experiences in the book about Jim.

Everything I knew about TM began and ended with Pauline. It was important to me that the last words in this book belong to her. Pauline was an elementary school teacher for twenty-five years. She retired at the beginning of the 2016 school year. Shortly after her retirement, I asked her to write the conclusion for the book. She consented and then procrastinated for eight months. I felt horribly about pestering her, because she was so enjoying her first year of retirement. Finally, at the end of June, Pauline handed me the article. She was concerned I wouldn't like what she had written. I loved it. It was perfect. I told Pauline that I wouldn't change a word.

Pauline and I spent the summer planning a three-week vacation to Montana. Pauline's service dog, Kazu, was experiencing complicated health issues, and we were not going to be able to take him. The TMA Family Camp was held in July. Pauline had never missed a camp, but she decided to stay home to be with Kazu. Being at camp for the first time without Pauline was a sad experience for me.

I lived in Montana for two years when I was in my mid-twenties. I did my dissertation research on a reservation and worked in a Catholic mission school as a social studies teacher. The two years on Fort Belknap was a transformative experience. I lived in a community of about 600 people. Many of them became lifelong friends. I also had wonderful friendships with the people I worked with at the mission. I had been back to the reservation and to Montana since I retired and wanted Pauline to finally share in this experience. The beauty of this state is remarkable. I wanted Pauline to meet these important people in my life.

We vacillated all summer long about Pauline being able to make this trip and leave Kazu with our son. A week before we were scheduled to leave, Pauline told me she thought I should make the trip alone. I was disappointed but understood her sense of obligation to Kazu. Over the next couple of days, Kazu started to show some improvement. Pauline made a last-minute decision to make the trip. I was thrilled.

We flew into Billings. We spent two days with Dr. Sara Qureshi. Dr. Qureshi was trained as a specialist in the rare neuroimmune disorders by Dr. Benjamin Greenberg at the University of Texas Southwestern in Dallas. She began a specialization in the rare neuroimmune disorders at the Billings Clinic. We spent two days in the Pryor Mountains and Big Horn Canyon. It was a spectacular trip. On Saturday, Pauline and I participated in an education program at the Billings Clinic, sponsored by the TMA and the Montana Support Group. More than 50 people attended from all over the state. The Montana Support Group held a walk on Sunday morning which Pauline and I attended. It was a wonderful awareness event and we loved being with the people from our community.

The following day, Pauline and I headed to Yellowstone National Park. We spent the summer researching accessibility in the park and devised a plan for getting Pauline out to every waterfall and river rapids possible. Pauline loved the water. We stayed in an accessible cabin in Canyon Village. We were amazed at the places Pauline was able to access. We were out in the most spectacular nature from the crack of dawn until the sun set. We left Yellowstone at the end of the week and headed to Fort Belknap.

We spent two days on the reservation. We visited with friends I had known for over 40 years. We spent those two days attending a pow wow in a beautiful meadow just beyond the canyon in the Little Rocky Mountains. Pauline had never experienced anything like it and was enthralled with the traditional outfits, the music and the dancing. It was wonderful for me to have Pauline finally experience the people and the stunning places that she heard me speak about for so many years.

We left the reservation and headed to Beaver Creek. Our plan was to spend a week with friends who lived in the Bear Paw Mountains just south of Havre. The northcentral region of Montana is the area I was most intimately familiar with and loved. Mike and I worked together at the mission and were friends for more than 40 years.

On Tuesday afternoon, August 15th, Ligia, Mike, Pauline and I made a trip up to the Milk River north of the small town of Gildford. I had been there with Mike four years earlier. It is one of the most beautiful places I've ever seen, and we wanted to share it with Pauline. I knew she would enjoy it because of her love of water.

And then we experienced a total nightmare. Pauline died before we could find our way to the river.

I immediately returned to Columbus with Pauline. Her funeral was held on Monday, August 21st.

Mourning is a process, and the process is unique to each person. We do this grieving based on who we are and based on the relationship we had with the person who we've lost. Pauline and I loved each other to the core. She

was my lifelong partner. Pauline was my reason for being. Now what? This is my process. I am seeking my reasons for being. I am looking for life in my life.

I have been surrounded by the most supportive, caring, loving family and friends, many of whom are people from our TMA community. I am so blessed. So many of you have reached out to me to offer your kind and generous words of compassion, as well as your respect, admiration and love for Pauline. I have no idea how I would have made it this far without your care and love.

I had planned on finishing the book when I returned from Montana. It became the last thing on my mind upon our return. When I did think about the book, I questioned whether I had the emotional and psychological fortitude to even look at it, let alone complete it.

Part of the grieving process for someone who you love so intensely involves wanting to secure their memory and to ensure that the people who knew her appreciate and remember the profound impact she had on people's lives, my life. In time, it became more obvious to me that getting this book published, Pauline's story, was an important way for me to accomplish that end. The book is a testament to this remarkable person's impact on the world. I began the process of getting the book completed and published.

I knew that the most difficult part of this process was going to be reading the words Pauline had written to end the book. I didn't want to start editing from the beginning and work my way through the emotional crescendo of her final words. The intensity of that process felt overwhelming. I instead started reviewing the book by going to the last pages and reading Pauline's words. It was emotional and painful. I also felt such gratitude in thinking about Pauline, what she conveyed in those words and the many blessings we shared in our lives together.

I have not changed Pauline's story in the book to convey that she died. Her story is told as she was when I wrote it, full of life and hope, and filled with love for the people around her.

# TMA-Supported Research at the 2019 American Academy of Neurology Annual Meeting

**The TMA maintains our commitment to advancing the scientific understanding of and therapy development for AFM, ADEM, MOG Antibody-Associated Disease, NMOSD, ON, and TM. We are proud to announce that once again TMA-supported research was presented at the American Academy of Neurology Annual Meeting, which was held from May 4th-10th in Philadelphia, PA.**

Dr. Benjamin Greenberg and colleagues presented about the upcoming study to investigate the safety of the transplantation of human glial restricted progenitor cells into subjects with transverse myelitis (TM). Funding and support for this trial has been provided via the UT Southwestern CONQUER Program, the Transverse Myelitis Association and Q Therapeutics. The primary objective of the study is to evaluate the safety of oligoprogenitor Q-Cells® transplanted into the posterior columns of the spinal cord in patients with TM. A secondary objective of the study is to obtain preliminary data regarding the clinical activity of Q-Cells® in patients with TM. For more information about this study, visit the study page at [tma.org/q-study](http://tma.org/q-study).

Dr. Olwen Murphy, a current James T. Lubin Fellow, and a team at The Johns Hopkins Hospital presented research on sarcoidosis-related myelitis. The research was a retrospective study of patients diagnosed with sarcoidosis-related myelitis at the Johns Hopkins Transverse Myelitis Center. The goal of the study was to identify characteristic clinical, imaging and CSF features of sarcoidosis-related myelitis. They found that distinct imaging patterns occur in sarcoidosis-related myelitis and recognition of these features may aid in coming to a correct diagnosis. Most of the patients in the study had a long symptom evolution (81%), meaning it took more than three weeks from symptom onset to when symptoms were at their worst. Most had sensory symptoms (87%) and motor symptoms (53%). Enhancement patterns suggest that the blood-spinal-cord barrier may play a role in the development of sarcoidosis-related myelitis lesions. Dr. Murphy and colleagues also presented a case report on a 68-year-old man who presented with a 2-year history of severe muscle spasms in the lower back and pelvic region. The patient was ultimately referred to their clinic for evaluation of “treatment-resistant” stiff person syndrome after baclofen and benzodiazepines had no clinical effect. He was correctly diagnosed with an anterior disco-osteo-arterial conflict and underwent surgery to correct the problem. Six months post-surgery he reported marked improvement in his symptoms and increased exercise tolerance.



Dr. Jonathan Galli, another James T. Lubin Fellow, worked with Dr. Clardy on another research study about stiff person syndrome. The goal was to describe epidemiological characteristics, antibody status, and treatment outcomes of stiff person syndrome patients within University of Utah Health. Stiff person syndrome (SPS) is an autoimmune disease that classically causes severe muscle rigidity and spasms. They identified 31 patients with stiff person syndrome. Patients were predominantly female (78%). Some of their cohort had co-existing autoimmune diseases (63%) and malignancy (13%). Diazepam and baclofen was effective in a majority of patients. IVIg was the most commonly utilized immunotherapy (used in 69% of patients) with benefit demonstrated in 41% of patients who received this treatment. Dr. Galli and colleagues also presented a case series with the goal to describe atypical epilepsy presentations in patients with common variable immunodeficiency (CVID) within the University of Utah Healthcare system. Patients with CVID are at increased risk of infection, malignancy, and autoimmune disease. They presented a case series of 5 patients with CVID and

co-existing epilepsy. All patients had atypical seizure symptoms including behavioral arrest, alterations in consciousness, and/or amnesic episodes. Most of the patients had improvement with antiepileptic therapy.

Dr. Cynthia Wang, a former James T. Lubin Fellow, and colleagues presented a case report of a 6-year-old boy with new-onset seizures and altered mental status associated with multifocal right hemispheric lesions resulting from primary CNS vasculitis. Primary CNS vasculitis is a rare vascular inflammatory brain disease. The child was treated with cyclophosphamide with gradual improvement in cerebral edema, and he also underwent cranioplasty four weeks after hemicraniectomy. He improved significantly over one month in inpatient rehabilitation and he regained the ability to ambulate independently. The researchers note that this case demonstrates an unusual presentation of this condition in a child. They also note that hemicraniectomy should be considered in patients with medically refractory increased intracranial pressure.

For more information on other research and clinical publications supported through the generosity of the TMA community, please visit [tma.org/research-publications](https://tma.org/research-publications).

# Announcing Partnership with AFMA

On June 20, 2019, we announced our partnership with the newly formed Acute Flaccid Myelitis Association (AFMA). We are excited to collaborate with the AFMA to advance our joint goals to support families affected by rare neuroimmune disorders, specifically Acute Flaccid Myelitis (AFM). The AFMA was borne from a meeting of parents impacted by AFM and advocates to increase awareness and gain public assistance for this disorder. The AFMA provides support for parents, caregivers, and those with AFM.

Chitra Krishnan, the Executive Director of the TMA, remarked, “By joining forces, and working together, we can achieve so much in raising awareness, improving education, resources, support, and research so we can improve the quality of life of families affected by AFM.”

Director for the AFMA, Katie Bustamante, also noted, “We look forward to this partnership with the hope that our combined efforts will have a growing impact on public awareness, advocacy, and support for those affected by Acute Flaccid Myelitis.”

We at the TMA look forward to partnering with the AFMA to ensure the education, advocacy and research resources we offer meet the needs of the AFM community. We also hope to expand and offer more AFM-specific resources jointly as co-branded documents under this partnership.

As part of our partnership, families and individuals diagnosed with or impacted by AFM can become members of the AFMA and TMA through the TMA membership form by selecting to give permission to share information with both organizations and participate and benefit from programs offered by the TMA and the AFMA.

Should you have any questions at all about our partnership, programs, resources, support, or registry we offer, please reach out to us at [info@myelitis.org](mailto:info@myelitis.org), [tmakids@myelitis.org](mailto:tmakids@myelitis.org), or via phone at (855) 380-3330.

## **About The Acute Flaccid Myelitis Association**

The Acute Flaccid Myelitis Association was born from a meeting of parents impacted by AFM. The AFMA is a resource for those that are personally affected by AFM. We provide shared information based on the experiences and treatments that families have faced as well as grants to patients in need of financial assistance for medical treatment. Additionally, the AFMA works to increase public awareness to this rising public health issue in an effort to promote advocacy for research. The AFMA is a 501(c)(3) registered nonprofit association.

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**Website:** [afmanow.org](http://afmanow.org)

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# Announcing the Acute Flaccid Myelitis (AFM) Physician Consult and Support Portal

**The TMA, in collaboration with CDC, has recently launched the AFM Physician Consult and Support Portal, where clinicians can now access consultation services with AFM experts.**

The goal of the AFM Physician Support Portal is to connect medical professionals and offer 24/7 consultation. If a physician suspects a case of AFM and would like to schedule a consult with neurologists specializing in AFM and other rare neuroimmune disorders, they can complete an online form, and we will set up a peer-to-peer consult for clinical support from physicians at the University of Texas Southwestern Transverse Myelitis Center or Johns Hopkins University Transverse Myelitis Center. We know how important rapid diagnosis and treatment can be for those with AFM, and we hope this portal will connect community neurologists with experts in AFM to ensure quick diagnosis and treatment.

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**Portal:** [tma.org/afm-portal](https://tma.org/afm-portal)

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## Updated AFM Information Sheet

As part of our ongoing effort to keep our community updated on the latest information and research, we have recently updated our Acute Flaccid Myelitis (AFM) disease information sheet so that information on AFM is easily accessible in a concise and helpful manner. The AFM information sheet has sections on Epidemiology, Signs and Symptoms, Diagnosis, Acute Treatments, Prognosis, and Rehabilitation and Symptom Management. You can find the AFM information sheet on our website.

The updated information sheet was published on our website in March of 2019. Our first information sheet was published in 2015, after the term Acute Flaccid Myelitis (AFM) was coined in 2014, formally identifying it as a variant or subtype of myelitis, primarily affecting the gray matter (lower motor neuron) of the spinal cord. AFM may also have white matter (upper motor neuron) involvement. It is likely that many individuals with initial presentation of flaccid limb weakness and/or paralysis were diagnosed as having transverse myelitis or Guillain-Barré Syndrome in years prior to 2014. As more and more families have been impacted and share their experiences, and as scientists and clinicians continue to learn more about this disorder, we will strive to keep our community informed of their findings to provide timely and accurate information and resources.

It is important to familiarize yourself with and share information about AFM. Although it has gained national attention in the recent past, it is still rare and often misdiagnosed. Timing is critical for an accurate diagnosis and for acute treatments to be administered. Please share the information sheet with your clinicians (physicians, therapists, urgent care centers, hospitals), schools, local health departments, and family members. Our information sheet has been updated and reviewed in collaboration with families, physicians and scientists specializing in this rare neuroimmune disorder. As always, if you or someone you know has questions about AFM, please reach out to us at [info@myelitis.org](mailto:info@myelitis.org).

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**Info Sheet:** [tma.org/afm-info-sheet](https://tma.org/afm-info-sheet)

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# Q Study Now Enrolling

A Phase I remyelination trial using Q-Cells in Transverse Myelitis conducted by the University of Texas Southwestern Medical Center (UTSW), Q Therapeutics, and The Transverse Myelitis Association has recently opened enrollment! The trial is designed to study the safety and efficacy of implanting cells that produce myelin into the spinal cord. It is the first study of its kind in transverse myelitis.

Q Therapeutics developed a glial-restricted precursor cell, called a Q-Cell, that develops into oligodendrocytes. Oligodendrocytes produce myelin, the insulation around nerves, and other factors that are necessary for healthy Central Nervous System (CNS) function. The Q-Cells will be surgically implanted into the spinal cord at the level of a lesion. Participants will be followed for both safety assessments and multiple measurements to determine if the cells are inducing any level of repair.

If you are a person diagnosed with transverse myelitis, are between one and ten years from your event, and you remain unable to walk, you may be eligible to participate. To sign up to participate in this trial, please fill out UTSW's survey by visiting [tma.org/enroll-q](https://tma.org/enroll-q). Please note that the study will enroll nine non-ambulatory adult transverse myelitis patients, so filling out the survey does not guarantee enrollment in the study. You can find more information on the study, including inclusion and exclusion criteria for participation, on [clinicaltrials.gov](https://clinicaltrials.gov) or the study page here: [tma.org/q-study](https://tma.org/q-study). If you have any questions about enrollment in the study, please email us at [info@myelitis.org](mailto:info@myelitis.org).

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**More info:** [tma.org/q-study](https://tma.org/q-study)

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# Support Group Updates

Our Support Group Network is growing thanks to the generosity of our members. Generous volunteers continue to step up and take on the role of Support Group Leaders (SGLs), offering invaluable support and information to our community. We are now up to 23 SGLs in North America, seven internationally, and have a few more in the process of completing the application and training requirements.

So far this year, our North American-based SGLs have held more than 30 meetings! That's an average of four to five per month. Some of the meetings can be smaller, with just a few attendees, but some of the meetings, like in Dallas, Los Angeles, and Washington, D.C., can exceed 20 people. No matter the size, the commitment our volunteers make to organizing and running these meetings deserves thanks. We believe these meetings make a difference in the lives of those diagnosed with a rare neuroimmune disorder, along with their friends, family, and caregivers.

Three of our newer Support Groups are organized or co-organized by a friend, family member, or caregiver. Jay Hewelt helps his partner Janelle Healy plan the San Diego Support Group; Kathy Keihl organizes the Ontario Support Group in support of her partner, John; and Peter Fontanez runs the Central Florida Support Group for his daughter, Isabel.

In 2019, we've had six SGLs hold their first meeting. If there isn't a Support Group in your area, you can reach out to Jeremy Bennett at [jbennett@myelitis.org](mailto:jbennett@myelitis.org) to start the process of becoming an SGL.

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**List of Support Group Leaders:** [tma.org/sgn](https://tma.org/sgn)

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# 2019 RNDS

**Thursday - Saturday, September 19 - 21, 2019**

Crowne Plaza, Columbus – Downtown, OH

Since our very beginnings in 1994, we made it our priority to increase education and understanding of rare neuroimmune disorders. Our first symposium took place in August 1999 in Seattle, Washington. It was the first gathering of clinicians, scientists, and people diagnosed with a rare neuroimmune disorder to discuss these disorders and share information. The TMA's symposium has become a regular event, occurring every other year, that brings our community together and fosters the spread of the most up-to-date information about these disorders. It also allows our community to share stories and build connections.

The TMA is excited to announce that our 2019 Rare Neuroimmune Disorders Symposium (RNDS) will take place from September 19-21 in Columbus, OH. Attendees will meet at the Crowne Plaza in downtown Columbus to learn from experts about ADEM, AFM, MOG-Ab disease, NMOSD, ON, and TM. Presentations will include disorder-specific overviews, symptom management strategies, research updates, and more. Individuals who are diagnosed with a rare neuroimmune disorder will also be given the opportunity to meet and participate in community-building and support for one another. The symposium also offers attendees the opportunity to meet the medical experts in the field of rare neuroimmune disorders and to ask questions related to their disorder.

We encourage all our members, their family members, and medical professionals interested in learning about these disorders to attend. You can register for the 2019 RNDS at [tma.org/2019-rnds](http://tma.org/2019-rnds). If you have any questions, please email us at [info@myelitis.org](mailto:info@myelitis.org). We can't wait to see you in Columbus!

**Register:** [tma.org/2019-rnds](http://tma.org/2019-rnds)

## Sponsors

**ALEXION**

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

### 2019 OH Walk-Run-N-Roll

We will be hosting a Walk-Run-N-Roll on Sunday, September 22 to celebrate the end of the RNDS. We hope you will join us!

In 2017, we held a Walk on the Sunday following the RNDS, and over 360 participants attended, one of the most highly-attended Walks we have ever had! This year, we would like to beat our record and bring together as many people as possible to share stories and connect with others.

**More info:** [tma.org/2019-ohio](http://tma.org/2019-ohio)

# CAPTURE: An Update to the Long-Term Study of Pediatric Transverse Myelitis and Acute Flaccid Myelitis

*By Rebecca Whitney, Pediatric Programs Manager*

**In 2014, the Transverse Myelitis Association (TMA) and seven clinics across North America, under the direction of Dr. Benjamin Greenberg at UT Southwestern Medical Center, began a research journey to follow pediatric transverse myelitis diagnoses. I honestly didn't know what to expect from this new venture, having previously only been on the participation end of a research study, but knew in my heart of hearts that this study, CAPTURE, was incredibly valuable and would make an impact in the history of our children and families. I was ready to be a part of it, although it was difficult, often heartbreaking work. But, that's also why I knew I needed to be a part of it. It is a matter of my heart and means something so incredibly personal to me as a parent of a young child diagnosed with transverse myelitis.**

CAPTURE is the first of its kind - a prospective, observational study in pediatric transverse myelitis (TM) and acute flaccid myelitis (AFM). Designed to not only utilize the imaging and clinical diagnosis details from physicians, CAPTURE also collects information from the children and families themselves about their outcomes, relative to the treatments they received. Initially, study criteria required enrollment within three months of diagnosis. After listening to feedback from the TMA and parent community, Dr. Greenberg and his team changed the study's enrollment to include patients who are within six months of diagnosis. Even for the most well-intentioned families vowing to help by participating in a research study, those first three months post-diagnosis are oftentimes so bewildering and surreal. We found we experienced a better enrollment rate and continued participation if we allowed families time to adjust to this new realm of medicine they suddenly found themselves in.

2014 also brought to light a "new variant" of TM that was popping up across the country - Acute Flaccid Myelitis or AFM. Due to the outbreaks of AFM, we found our correspondence with families and enrollment were increasingly with those experiencing AFM rather than TM. Regardless, the study remained open for both diagnoses, and we have continued to learn so much, often debated amongst clinicians and governmental entities, about the acute treatments that might provide the best outcomes for our children. CAPTURE has been and continues to be a critical part of the conversation and debate regarding acute treatments as it is an already established mechanism for collecting essential data and follows children's progress for up to a year after their diagnosis. To date, we have enrolled 140 children into CAPTURE.



CAPTURE, through the work of the TMA and Dr. Greenberg's team in Dallas, has been able to move forward and is still continuing to enroll new participants with TM and AFM within six months of diagnosis through our online cohort. This is incredible considering that when we began, the study was scheduled to end recruitment in 2018. The more information we can obtain, the clearer the way we move forward becomes - how we develop treatments and therapies, engage potential stakeholders, including government officials and entities, and ultimately, provide the best outcomes for children, or better yet, stop TM and AFM from even being a threat to our children. Even more incredible is the fact that recent IRB changes to CAPTURE will allow us to continue to hear from those children and families previously enrolled, should they so choose, through 2026!

Let's think about this for a moment... By following current and future enrollees in CAPTURE through 2026, we will have 10 years - a decade - of real, patient-reported data. For some, this means when they report their recovery and outcomes, we will follow them into adulthood. We all know how quickly children grow and quite frankly, a diagnosis of a rare neuroimmune disorder can be starkly different for a child than an adult, including their recovery. What an excellent opportunity to impact change and the future of medicine related to these disorders! As it stands right now, we can't refer back to medical literature or history books and find what is to be done for a child amid an AFM outbreak. The potential for learning from our heart-wrenching experiences is

astounding. As I sit here and watch my own child recover from major surgery as a result of his TM diagnosis, now almost 12 years out, how he's doing today looks so different than what we thought or imagined 5 or 10 years ago, or even six months post-diagnosis. Since we are forced to face this diagnosis and the ramifications of what it means for his well-being, his growth, his mobility, his quality of life, then we are going to learn and grow from it, and hopefully, we can help other children and families as we do.

CAPTURE must and will continue for our children. We will continue to enroll those newly diagnosed within six months and into the long-term study. Those who were previously enrolled in CAPTURE will be contacted by Tricia Plumb of UTSW to see if they wish to extend their participation. I

hope that each one of the 140 participants to date will consider the impact they may have on our community and future children by continuing to share their stories via the brief surveys. The aim is for each child/family to complete a survey and have a short, secure video chat with the study leader(s) every 4 months. If you or your child has been recently diagnosed or you've participated in CAPTURE and wish to extend your participation, please contact Tricia Plumb or me.

Oftentimes over the last few years, we've been contacted by families further out from six months, even years post-diagnosis, and have heard, "what about my child? What about her experience and her recovery?" If you or your child were diagnosed with TM or AFM before six months ago, your story, your recovery, your outcomes matter, too! A new study called CORE TM is available and currently enrolling participants, and it is similar to CAPTURE. For more information about CORE TM or to enroll, please do so via the TMA Registry. You may also contact Tricia Plumb or me for more information.

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## Study Details

The study is designed to assess the current state of pediatric transverse myelitis (TM) and acute flaccid myelitis (AFM) in terms of diagnosis, treatment, and long-term outcomes. Patients will educate clinicians and the study will educate the broader health care system about what outcomes are important and achievable. It will develop a multi-metric outcome measure based on combined patient generated and provider generated data that can be used in future controlled trials.

**Participation is online only.** It includes a survey at 3 (if able), 6, and 12 months after diagnosis, and continuing long term every 4 months until the year 2026. Accompanying each 4 month survey, a secure telemedicine portal will be utilized to assess the child's mobility, and will also include a short functional survey. The study will also include a review of treatment records, and imaging. Internet access is required for completion of questionnaires, surveys, and the telemedicine portal by the child and/or parents.

**Eligible participants:** children diagnosed with transverse myelitis or acute flaccid myelitis between the ages of 0 to 18 years (or 17 years at onset) within 180 days of the initial onset of symptoms.

For families of children diagnosed with Acute Disseminated Encephalomyelitis (ADEM) or whose diagnosis may have changed from TM to ADEM and are no longer eligible for CAPTURE, there is the possibility for study participation for you, too. APERTURE is currently enrolling and is also an observational study being conducted online. For more information on APERTURE, please contact me, Tricia Plumb, or Dr. Cynthia Wang.

Further to the opportunities noted above, the TMA Registry is always available, and everyone with a rare neuroimmune disorder is invited to participate in the registry.

*This article first appeared on our blog on May 17, 2019. Since that time, multiple families, both new and previous enrollees, have agreed to participate in the long-term study until 2026! Thank you for your thoughtful consideration of this opportunity and volunteering in this manner. Your giving back to the community and furthering of research doesn't go unnoticed!*

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[tma.org/capture](http://tma.org/capture)

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# Introducing the OhioHealth Neuroscience Center

We interviewed Dr. Jacqueline Nicholas and Dr. Aaron Boster about The OhioHealth Neuroscience Center. Jacqueline Nicholas, MD, MPH is a board-certified clinical neuroimmunologist specializing in multiple sclerosis (MS) and spasticity. Dr. Nicholas was inspired by patients she cared for with MS and NMO early in her training to enter the field of neuroimmunology. She is dedicated to providing personalized care to each patient and their family. Dr. Nicholas actively leads several clinical trials to help discover even more advanced treatments to help patients with MS and other neuroimmunological diseases. Aaron Boster, MD, is a board-certified clinical neuroimmunologist specializing in multiple sclerosis (MS). Dr. Boster knew he wanted to become an MS specialist since he was 12 years old when his uncle was diagnosed with the disease. This personal connection and experience inspired him to treat MS patients and their families differently. His relentless focus on not just patients, but also their families, means they receive individualized and longitudinal care. Read more below to learn about this Center.

**What is the Neuroscience Center and what types of services can patients receive at your clinic?**

The OhioHealth Neuroscience Center is a hospital focused exclusively on the needs of neuroscience patients and involves not only high-quality inpatient care for complex neurological diseases, but also comprehensive multidisciplinary subspecialty neurology clinics. It houses the OhioHealth Multiple Sclerosis Center, a comprehensive, interdisciplinary clinic dedicated to providing the highest quality, cutting edge, adult and pediatric patient- and family-centered care to individuals with Multiple Sclerosis and other rare neuroimmune diseases. Our focus is not only on preventing future damage from the underlying disease, but also on symptom management to promote the best quality of life in our patients. In addition, the MS Center houses



the OhioHealth Spasticity Clinic which offers comprehensive care for all degrees of spasticity to our patients including rehabilitation, physical and occupational therapy, oral antispasmodic medications, botulinum toxin injections, and intrathecal baclofen pump management.

**What makes the Neuroscience Center unique in the world of rare neuroimmune disorders?**

We have amassed a team of experts that include fellowship trained neuroimmunologists with extensive experience managing rare neuroimmunological conditions. These expert neurologists are joined by outstanding nurse practitioners dedicated only to the care of neuroimmunologic patients. The team includes expert neurological physical therapists, occupational therapists, a speech pathologist, a dedicated MS/Neuroimmunology social worker, a dietician, RN infusion nurses, and much more, all in the same location. We collaborate with expert urologists, rheumatologists and rehabilitation physicians within our system. Patients are monitored with state-of-the-art neural imaging located on-site including a 3T MRI Scanner with brain volume measurement capabilities.

**What does the future of the Neuroscience Center look like? Are there services or additions you would like to make in the next few years?**

The Neuroscience Center is a modern, state-of-the-art space with the design and décor chosen to promote healing, calmness and wellbeing. Currently, we provide MS Care out of two outreach locations in the region: Delaware and Pickerington, OH. We look forward to continued growth and expansion in the region with a goal of helping more people impacted by neuroimmunological conditions close to home. This is accomplished by creating satellite clinics in infusion centers as well as developing virtual visits in digital ways to interact with patients and their families.

**Are you currently doing research? If not, what type of research most interests you in the world of rare neuroimmune disorders?**

We are currently active in multiple clinical trials studying multiple sclerosis, neuromyelitis optica, and spasticity. We have a busy clinical trials program with many clinical trial options for patients interested in participating.

**What would be the best way for someone reading this to contact your clinic and schedule an appointment?**

Please have your doctor send a referral to our center via phone (614-533-5500) or fax or mail: 3535 Olentangy River Rd., Suite 1501, Columbus, OH 43214.

**Is there anything else you'd like to add?**

We have a strong program dedicated to medical education and medical students, neurology residents, and a fellowship program to help develop new leaders and experts in the field of neuroimmunology and spasticity care. Our goal is to expand care across the country for people affected by these conditions.

# New Hope Ambassador Stories!

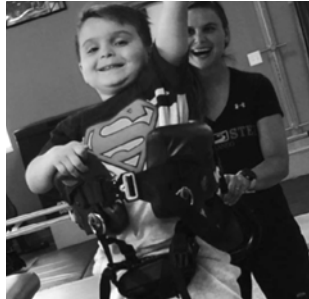
Our Hope Ambassadors shared their stories of resilience, hope, and strength. As we continue to raise awareness and learn from our community, we are honored to share the stories of six new Hope Ambassadors.



*Julie*

**Diagnosis:** MOG-Ab disease  
**Location:** Maryland

[tma.org/julie](http://tma.org/julie)



*John*

**Diagnosis:** TM  
**Location:** Florida

[tma.org/john](http://tma.org/john)



*Maleah*

**Diagnosis:** TM  
**Location:** Wisconsin

[tma.org/maleah](http://tma.org/maleah)



*Janelle*

**Diagnosis:** TM  
**Location:** California

[tma.org/janelle](http://tma.org/janelle)



*Aleena*

**Diagnosis:** MOG-Ab disease  
**Location:** Alabama

[tma.org/aleena](http://tma.org/aleena)



*Tanisha*

**Diagnosis:** NMOSD  
**Location:** Maryland

[tma.org/tanisha](http://tma.org/tanisha)

To read their full stories and for more information on how to become a Hope Ambassador, visit: [tma.org/hope-ambassadors](http://tma.org/hope-ambassadors). Have you been diagnosed with ADEM, AFM, MOG-Ab disease, NMOSD, ON or TM? Become a Hope Ambassador and share your journey with our community. Join our heroes and raise awareness about rare neuroimmune disorders. You can share your story by going to [tma.org/hope-ambassadors](http://tma.org/hope-ambassadors).

# Small Town Big Hearts

*By Julie Lefelar*

**If you decide to take a trip through Southern Maryland down Route 210, also known as Indian Head Highway, you can't help but realize that the further south you go, the more buildings, businesses and signs of the busy Washington DC Metropolitan area that you just came from seem to disappear. If you keep driving, you might just miss the town promised as the destination by its namesake road: Indian Head, Maryland. You would have expected traveling down that route that there would be an explosion of civilization upon your arrival. Instead, you will find a peaceful, unassuming main street, quaint neighborhoods, a beautiful community center called the Pavilion at the Village Green and the Naval Surface Warfare Center lining the Potomac River. It is in this center of town where, if you take a closer look, you will find unmatched generosity and community support. It is here where we experienced the big hearts of Indian Head in planning and holding our TMA Walk-Run-N-Roll.**

It all started when Cynthia Albright, a resident of Indian Head and a MOG Antibody-Associated disease patient of Dr. Michael Levy, ran into Curtis Smith, the Town Councilman. They started talking about her diagnosis of MOG-Ab disease and her involvement with the MOG Project at the TMA. He encouraged her to host a walk at the Village Green. As a co-founder of the MOG Project at the TMA, she contacted me and I was sold on the idea. We brought in Tanisha Willis, an NMOSD patient of Dr. Levy's, who jumped at the chance to help. Amy Ednie and Kristina Lefelar, Co-Founders of the MOG Project decided to make the commitment as well. It wasn't long before Indian Head Mayor Brandon Paulin got involved and the next thing we knew, the town of Indian Head had provided us with a beautiful venue at the Village Green and all the help we would need. Karen Williams, their event guru, pulled in volunteers and ideas for our event that would make it fun for all.

It didn't stop with the town leaders. Cynthia was able to reach out to multiple businesses in the Indian Head area for support and with no second thought, they were all on board to support us. We got free services and donations for raffle items from many businesses interested in our cause and helping Cynthia. Dr. Levy once again demonstrated his generosity and commitment to the community by agreeing to speak at the event. Mayor Paulin and Councilman Smith stepped up to speak as well. It wasn't long before we had a plan for a fun event which included inflatable carnival games, cotton

candy, DJ Rockin' Roger, face painting by Allison Ryan (a Disney face painting artist), an assortment of beautiful raffle and silent auction items like a hand-crocheted afghan by Cynthia's husband Randy, a "MOGarita Basket", a "Bark Basket" and two Mother's Day baskets, among other items. We even planned on having MOG gear for sale, such as T-shirts designed by Allison Ryan and awareness ribbons. Members of the community and family members helped set up a bake sale, "MOGTail" drink station and concessions for the event. We did have a few hiccups along the way, but when an issue arose, Mayor Paulin scrambled to our rescue and, with the help of another local nonprofit, the Indian Head Center for the Arts, all was well. Suddenly, we realized that this little town could make anything happen!

As we continued to plan, other Maryland businesses jumped in to help. We were thankful to have had the support of our friends at Smoker's Delight BBQ, Leverage (a rising technology company), Acker & Sons Plumbing, Gun Monkey's, Firearms Training Incorporated, Blue Dyer Distillery, MoCo Founding Farmers, Target, JDaniels Psychotherapy Services, INC, the LaPlata Green Turtle, Chipotle, and White Plains Golf Course. We also had many other local businesses donate food, drinks and supplies, such as BJ's, Costco, Giant, Safeway, Chick-Fil-A, Walmart and Texas Ribs & BBQ. We can't thank all of our sponsors enough for helping. This event would not be possible without their support. In addition, we had many volunteers who jumped in to make this a success and for that we are grateful.

On the day of the event, clouds loomed overhead, and we were afraid that our Walk would be rained out. We arrived early and diligently set up in preparation for the start of the event. As the time for the event



arrived, suddenly the clouds parted and to our disbelief, the sun came out! What a miracle. People had a wonderful time dancing and playing games. When it was time for the speakers, Cynthia gave a heartfelt speech, telling her story and how supporting rare neuroimmune disorders is important. Mayor Paulin, Councilman Smith, and Dr. Levy all provided inspiring words.

Everyone had fun. Councilman Smith and Mayor Paulin gave life to the party. Everyone chipped in to help, whether to blow up balloons, help put up the welcome sign or excite the masses.



**A huge thank you to our sponsors!**

- Acker & Sons
- Bj's
- Blue Dyer Distilling Company
- Chick-Fil-A
- Chipotle
- Costco
- Firearms Training Incorporated
- Giant Food
- Green Turtle
- Gun Monkeys Armory
- Jdaniels Psychotherapy Services, Inc
- Leverage
- Merle Norman Cosmetic Studio
- Moco Founding Fathers
- Safeway
- Smoker'S Delight
- Target
- Texas Ribs & BBQ

Even the local high schools, Maurice J. McDonough, Loudoun County and Henry E. Lackey sent students eager and excited to volunteer.

While everyone had a great time, we saw the best zest for life from Team Victoria, a group of family and friends from New Jersey whose little girl Victoria had been diagnosed with AFM and is currently doing well. This family seemed to be celebrating her and at the same time showing their solidarity and commitment to keeping her and other children like her well.

When the event came to a close, clearly a success, we started packing up, satisfied

that we had done our jobs. Just as the last box was packed in the car and the cleanup was finalized by the sound of a trunk closing, the rain started. And it really poured.

In retrospect, our hearts were full after this event. The incredible community support was overwhelming, and the town of Indian Head was the driving force for it all. We are thankful for this small town, who saw one of their own in need for a cure of a rare disease and decided to act, putting Indian Head on our map and in our hearts.

# Tucson

## Walk-Run-N-Roll

*By Barbara Sattler*

**Barbara Sattler is on the Board of The Transverse Myelitis Association. While a city court magistrate in Tucson, Arizona, Barbara contracted transverse myelitis. She took four months to recover before returning to work and was later appointed to the superior court bench. Barbara retired in 2008. Since retirement, she has written three novels and has committed all her publications' proceeds to the TMA. Barbara's books are available for purchase on amazon.com. Barbara also has a blog at [barbarasattler.com](http://barbarasattler.com).**

*"We need to have a walk in Tucson,"* Julie says.

*"You guys can do a walk,"* Chitra says.

*"No, no, no,"* says my little voice.

Julie Barry and I met in 2009 and started a support group in Tucson, AZ. At times, we met every month and had 4 or 5 participants.

Times change. Some of our members moved and others weren't able to devote time for a walk, so if there was a walk, Julie and I were the only two people in Tucson willing to plan it. To be fair, Julie was the only one willing. I'm retired, busy as I want to be, and as I grow older, I have less energy. Old age or TM, I can't say for sure.

I had this horrible vision in my head of the walk being a complete flop – only a few people coming, spending more on planning than we took in. Because of the great weather, and caring Tucson community, it seems there are 3 to 4 walks or runs or bike events every weekend. AIDS, Multiple Sclerosis, Multiple Myeloma, Breast Cancer, Diabetes, Muscular Dystrophy, Parkinson's disease, Alzheimer's, and Melanoma to name a few. Nobody has ever heard of TM. Who would show up?

*"We need to have a walk in Tucson. Phoenix had the first Arizona one last year and they'll help."* Julie says.

*"You guys can do a walk,"* Chitra says.

*"No, no, no,"* says my little voice.

Julie and I met a couple times and talked about how, when, and where. She was enthusiastic and I pretended to be. Julie suggested the zoo. I love the Tucson zoo.



It's big enough to have lots of animals to see and small enough to get through it in about an hour and a half. It's not full of bus traffic or extremely crowded. You can get a good view of the animals, and the zoo is pro-conservation and involved in species survival programs.

We arranged to meet Meghan, a zoo employee who was assigned to help with our event and invited Gail Buch and Kate Krieter from Phoenix to join us. They planned the 2018 Phoenix Walk-Run-N-Roll, a tremendous success. Without them we never would have had a successful event.

The walk was planned for March 30, 2019 which turned out to be a beautiful spring day. In Tucson, it can be very hot, but it wasn't.

About 80 people had pre-registered from Tucson, Phoenix, Lake Havasu, Casa Grande, and Eager, Arizona; Modesto, California; and Chicago Illinois.

Julie, Gail, Kate, myself, and our friends and spouses met at 7:00 am at the zoo and got ready putting out food that had been donated, setting up a raffle table and t-shirt table, hanging up enlargements of TMA members' stories explaining how the various neuroimmune disorders the TMA supports impacted them. Every couple of minutes, we'd get an update that more people had shown up. (We believe the final count was 96.)

The event turned out to be a great success. We had inspiring speeches. Jordan, a young man with TM who was diagnosed





incorrectly, and his mom, Kimberly, not only spoke about their situation but brought along about 30 Team Jordan folks. Craig, who had TM and was formerly a pilot, spoke. Ronnie, a mother of four, spoke about her journey with ADEM.

We took group pictures then had the official TMA walk. The zoo turned out to be a great venue. After we completed our program, part of the ticket price allowed participants to remain at the zoo until closing.

We brought in \$11,000 which was \$10,500 more than I expected.

For me, one of the highlights was meeting Kelly from California who had TM for several years but had never met anyone with TM before.

Julie and Chitra Krishnan, Executive Director of the TMA, were right. We could do a walk. Thanks again to Gail and Kate for their enthusiasm and hard work, Debbie Capen for the TMA pins, Jordan and Kimberly for speaking and Team Jordan for coming, and Jeremy Bennett, the TMA Community Partnerships Manager, for all his help in planning and being part of the walk. Thanks to Julie for persuading me to do this, choosing the zoo, and making fabulous pumpkin bread.

If you have thoughts about doing a walk or other event, now is the time.



# Clinical Studies & Trials

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For detailed information about clinical studies and trials, please visit [bitly.com/tma-clinical-trials](https://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 NMO and NMOSD**

Study Sponsor: AstraZeneca/MedImmune/Vielabio  
*This study is currently not open for recruitment.*

## 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 TMA Registry**

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 **Understanding Experiences with Vaccination Before and After a Rare Neuroimmune Disorder**

Principal Investigator: Sanford Siegel, PhD and Gabrielle deFiebre, MPH

12 **Pathology of Idiopathic Transverse Myelitis**

Principal Investigator: Michael Levy, MD, PhD  
Study Site: Massachusetts General Hospital and Harvard Medical School

13 **Study to Investigate the Safety of the Transplantation of Human Glial Restricted Progenitor Cells Into Subjects With Transverse Myelitis**

Principal Investigator: Benjamin M. Greenberg, MD, MHS  
Study Site: University of Texas Southwestern & Children's Medical Center



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## Announcements

**2019 Washington DC Walk-Run-N-Roll:** September 7, 2019  
**2019 Illinois Walk-Run-N-Roll:** September 15, 2019  
**2019 Rare Neuroimmune Disorders Symposium:** September 19 - 21, 2019  
**2019 Ohio Walk-Run-N-Roll:** September 22, 2019  
**2019 Pennsylvania Walk-Run-N-Roll:** October 6, 2019  
**Wisconsin Support Group Meeting:** October 19, 2019

## Contact us

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