

the transverse myelitis association

newsletter

fall 2018



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

- 004** *Why I Still Care*
- 008** *We Care. Do you? Get yourself some CARESOCKS!*
- 009** *2018 Ask the Expert Podcast Series*
- 010** *Upcoming Phase I Remyelination Trial Using Q-cells in Transverse Myelitis*
- 012** *New Research on Epidural Electrical Stimulation in Spinal Cord Injury*
- 014** *Vaccines and the Association with Relapses in Patients with Neuromyelitis Optica Spectrum Disorder*
- 016** *The TMA Registry Partnership with University of Texas Southwestern*
- 017** *James T. Lubin Fellowship Update from Dr. Ohwen Murphy*

- 018** *Notes From Our 2018 Events*
- 030** *Introducing the Care Coordinator at Children's Health CONQUER Clinic, UTSW in Dallas, TX*
- 032** *TMA Volunteer Spotlight*
- 036** *New Hope Ambassador Stories!*
- 037** *Our TMA Website*
- 038** *The TMA Announces its Partnership with The Sumaira Foundation*
- 042** *Clinical Studies & Trials*

Follow The Transverse Myelitis Association on Facebook (facebook.com/myelitis) and Instagram (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.

Why I Still CARE

Pauline died a year ago. The only routine and purpose I had in my life was forced on me by Kazu. Kazu was Pauline's Canine Companions for Independence Service Dog. Kazu gave my life structure and meaning until he died just about three months ago. He was 13 years old. I am retired, so I didn't have a job to go to every day. When Pauline died, my TMA family, with great sensitivity, shielded me from the day to day operations of our organization. They knew I needed time and space. I had the luxury and the burden of being able to devote a year to my personal journey through mourning and grief. As I'm an amazingly neurotic and driven person, I approached this journey with the same energy I attack just about everything else. I hired a fantastic therapist, I surrounded myself with the most supportive and thoughtful family and friends, I immersed myself in the Jewish rituals for mourning, and I filled my calendar with a fitness routine that included tai chi, yoga and Pilates. My heart was broken, my spirit was crushed, my brain was mush, but my core was in great shape for a 66-year-old.

The rituals for mourning in Judaism are well defined for the first year. The process of finding acceptance and peace will go on for the rest of my life. Finding meaning in my life and finding life in my life is a daily endeavor for me.

The work I have done for The Transverse Myelitis Association has been so central to my life and so much a part of my life with Pauline since she was diagnosed in 1994. This next year, I will have been involved in doing this work for 25 years. It just doesn't seem possible that all that time has gone by. In many ways, I feel as though the work over the past 25 years has just happened to me. There was no great plan or strategy for what I was doing. I have absolutely no training to do any of this work. I have no background in physiology or medicine, I have no education or training in social work or counseling. As I often describe to people over the phone, "I'm just some guy in Ohio." I was trained to be a cultural anthropologist. That fourteen years of training didn't include anything about helping people. Honestly. The training honed my fascination with people. I am an exceptional observer of people. The helping part came with my values. Tikkun Olam. The Jewish value to



heal the world has been a part of everything that motivates me. I don't even think about it. I just do what feels right.

There was never any doubt for me why I was doing the work. Pauline was suffering and there was nothing that existed to help her. There were no doctors or researchers in this area of medicine. There were no medical centers specializing in rare neuro-immune disorders. There was no research. There was no education for patients or for doctors. There was no support network. We were in an enormous wasteland to deal with this horrible experience on our own. We were ignorant and there was no reason to hope. The situation was untenable. If it was possible to change it, we were going to try. It was as simple, thoughtless and unplanned as that. I was always motivated in the work by my love for Pauline. I was always driven by my wanting to make a difference in her life.

It was a blessing for me in doing this work that I've never been motivated by money. Working for free was never something I ever thought about. Pauline and I also understood that by having no financial interest in doing this work, we gained significant credibility. No one could ever question our motives for what we were doing or how we were doing it. Money in our culture can bring out the greatest cynicism in people. We were spending our own money, and we were also truly humbled by even the smallest donations. And that has never changed.

It also helped our credibility that I've worked hard to keep my ego out of the work. This work has never been about me. I was surrounded by people who have these horrible disorders, starting with Pauline. What I was doing was about Pauline and the many people in our community who I have come to care for and love. I don't expend time or energy counting coup.

Now what? My involvement in this work is no longer about Pauline's suffering.

I will do this work until the end of my time. I can't imagine my life without it. I will always want to make a difference in this community.

I have learned so much about life from all of you. I have learned so much about myself from all of you. You are amazing at the best and the worst times of your lives. As this is the only life we get, you figure out how to live a life. That's been the greatest lesson for me. You've helped me to be aware of what I have, and you've helped me to be grateful for and appreciate all of it. This has been a labor of love, because I have come to love so many of you. I have been touched by all of you. I have been changed by all of you.

I owe the deepest gratitude to Pauline. Everything I learned and how I learned it has been informed by my experiences with Pauline. It has been painful for me to watch what Pauline went through. There had been triumphs for Pauline, but the overwhelming nature of the experience was challenging. That's just an honest appraisal. The suffering was overwhelming. And the suffering is done, and I am grateful for that.

You know a lot about Pauline's journey, because over the years she courageously and generously allowed me to share her experiences with all of you. She took on the responsibility and the kindness to appreciate that in learning about her experiences, you would also learn something about your own. Almost everyone I'd spoken to wanted to know how Pauline was doing. If they'd been members for a long time, they asked because they cared about her from

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my writings. If they'd been recent members, they asked because they wanted to hear something hopeful about their futures. Pauline had become a perspective through which people thought about their own condition. I reminded people repeatedly that every experience is different, but everyone seeks some frame of reference for thinking about themselves, and often, Pauline served that purpose. And there was something hopeful in the notion that a person who moved nothing below their waist recovered enough motor function to walk after 30 days.

I was only able to do this work because Pauline allowed me to do it. The time I spent working was time I was not spending with Pauline. There wasn't a selfish bone in her body. Pauline was a remarkable person and genuine to the core. We worked as partners to make a difference.

In Judaism, Tzadakah is associated with the ritual of remembering a loved one. The simple meaning of this Hebrew word is charity. The more complex meaning is righteousness or justice. It is customary to give to a charity in the name of your loved one on the anniversary of their death, their Yahrzeit. There's no better way for me to honor Pauline's memory than to give of myself to the cause that was so central to her life, and to support the people from our community who she loved. There would be no organization without Pauline. The Transverse Myelitis Association is her legacy.

I love Pauline. She was my best friend and life partner. How could I not still care?

Sandy



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2018 Ask the Expert Podcast Series

The TMA's Ask the Expert Podcast Series in 2018 included conversations with clinical professionals and experts from our community on a range of topics including diagnostic markers, stem cells, air travel tips, and the recent increase in acute flaccid myelitis cases.

In January, Dr. Jaime Imitola and Dr. Michael Levy discussed **stem cells as a treatment for rare neuro-immune disorders**. They described what stem cells are, their role in the body, what research is being done, and the potential dangers of unapproved stem cell therapies.

In March, Dr. Benjamin Greenberg and Dr. Ben Thrower talked about the role of **alternative therapies in treating the symptoms of rare neuro-immune disorders**. Janet Dean and Dr. Philippines Cabahug also participated in a podcast on **managing spasticity** after a rare neuro-immune disorder diagnosis.

In April, Dr. Cristina Sadowsky and Dr. Tae Hwan Chung spoke with TMA community member Maureen Hallagan about the impacts of **aging in people who have a rare neuro-immune disorder**. They discussed what is currently known about aging in general, and what we know about the effects of aging and neurological conditions.

In May, Dr. Michael Levy and Dr. Carlos Pardo-Villamizar discussed the **diagnostic markers for rare neuro-immune disorders**. They discussed what medical tests are done to determine diagnosis of a rare neuro-immune disorder and whether blood, genes, or other biomarkers can indicate the presence of one of these disorders.

In June, Katherine Treadaway and Sandy Hanebrink gave an important overview of how to **navigate life after a rare neuro-immune disorder**. They discussed **Social Security, state and local benefits, assistive technology, and more**. We also had a special podcast with Dr. Benjamin Greenberg and Dr. Michael Levy on a recently coined neuro-inflammatory condition called **MOG antibody-associated disease** (MOG-Ab disease). Kristina Lefelar from the TMA community co-moderated this podcast.

In July, we had a **conversation with two TMA James T. Lubin Fellows**, Dr. Cynthia Wang and Dr. Olwen Murphy. They discussed their research, clinical experiences, and answered questions from our community.

In August, Samuel Hughes, GG deFiebre, and Tricia Plumb gave us an overview on **how to find, understand, and interpret research** about rare neuro-immune disorders.

In September, Dr. Anjali Forber-Pratt, Kimberly Beer, and Bernadette Mauro discussed **air travel with a disability**. The conversation included information on travelers' rights, best practices, and suggestions, as well as an update on recent legislation.

In October, Cindy Kolbe, Tina Robbins, and Katherine Treadaway discussed **caregiving for someone with a disability**. They discussed their personal experiences and gave some advice for dealing with stress and caregiver burnout. Dr. Carlos Pardo-Villamizar and Dr. Benjamin Greenberg also participated in a podcast on **acute flaccid myelitis and the recent increase in diagnoses**.

All of the podcasts have been recorded and can be found in our resource library (tma.org/podcast-recordings). Many of the podcasts have also been transcribed so that they can be read.

Upcoming Phase I Remyelination trial Using Q-cells in Transverse Myelitis

Who is conducting this study? The University of Texas Southwestern, Q Therapeutics, Inc., and The Transverse Myelitis Association are collaboratively sponsoring the first human safety study to treat central nervous system (CNS) disease. Q Therapeutics is a privately-held biotechnology company founded on the work of Dr. Mahendra Rao during his time at the University of Utah and the National Institutes of Health. The University of Texas Southwestern is a medical education and biomedical research institution in the United States. The Transverse Myelitis Association is a patient advocacy organization for individuals with rare neuro-immune disorders (acute disseminated encephalomyelitis, MOG antibody-associated disease, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, including acute flaccid myelitis).

What are Q-Cells®? 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. In mice born with nerve cells without myelin, Q-Cells have been shown to produce myelin and other factors that restored the mice to normal function.

What is the difference between these cells and stem cells? Stem cells are undifferentiated cells that can turn into other types of cells. Q-cells are not stem cells because they can only turn into oligodendrocytes and astrocytes, the support and repair cells of the CNS.

How is this study being funded and what are these funds going to be used for? The cost of the Phase I study is approximately \$2.5 million. The CONQUER program at The University of Texas Southwestern secured a \$1.5 million gift towards funding of the Phase I trial. The TMA through The Pauline H. Siegel Eclipse Fund and Q Therapeutics, Inc. have committed to raise the remaining funds to cover participant travel expenses, the production and testing of the cells for the trial, and the cost of a contract research organization (CRO) that will manage the clinical trial.

Who can participate, and why were these inclusion criteria picked? This study is enrolling patients diagnosed with transverse myelitis who are between one and ten years from their event and remain unable to walk. These criteria were picked because Phase I studies are focused on safety. Given the surgery that is required to implant these cells, it was decided to start with a patient population with the least potential for harm and simultaneously the greatest need for intervention. There are other inclusion/exclusion criteria that will be reviewed before study entry and will be listed at clinicaltrials.gov.

How can someone sign up to participate? Screening is scheduled to begin by the end of 2018. A link to the website will be provided at that time. We will update our website when this study is open for enrollment. If you have any questions about the study, please email info@myelitis.org.

How many people will participate? The Phase I trial will include nine non-ambulatory adult transverse myelitis patients.

How are the cells being used? 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.

What are the outcomes the study will look at? As a Phase I study, the majority of outcomes in this study are focused on assuring the safety of this treatment modality. We will look for any complications from surgery, evidence of immune rejection of the cells or abnormal growth of cells. In order to assess for clinical benefit, we will do serial physical exams, MRI imaging and electrophysiology studies to determine if the cells are producing new myelin.

Are there any risks to participating? There are always risks to participating in research and those are greatest in Phase I studies, based on our limited experience. In this study there are risks to the surgical procedure, the cell implantation, and the medications used to prevent rejection. All of these elements have been used in other studies and found to be reasonably safe, but they have not been attempted in patients with transverse myelitis. Detailed discussions of risks will occur during the informed consent process.

What would cause the study to end early? Studies can be stopped early for many reasons, including concerns about safety, evidence of harm, or regulatory concerns.

What will it take to get the study to a Phase II or efficacy trial? If successful, the data from the Phase I study will be used to justify raising the funds necessary for a Phase II trial. Sometimes, a second Phase I trial is needed to explore various dosing options or patient selection criteria. Moving forward from the first study is based on the data collected and funding.

Is it possible this might cure TM? After an attack of monophasic transverse myelitis, damage is done to the spinal cord, which causes neurological symptoms, such as weakness, paralysis, sensory changes, bladder, bowel, and/or sexual dysfunction, etc. Therefore, a cure would be a therapy that repairs the damage to the spinal cord, which improves neurological symptoms. This trial is a safety trial, meaning the safety of this therapy is being assessed. This is the first step needed before it moves into an efficacy trial. It is too early to assess whether this cell therapy will repair the damage to the spinal cord, but it is hoped that it will, as this has also been shown in animal models.

Since this study is only in transverse myelitis, how may it help people with neuromyelitis optica spectrum disorder, acute disseminated encephalomyelitis, or multiple sclerosis? If it is shown that this therapy repairs damage to the spinal cord in individuals with transverse myelitis, this therapy may be used to repair damage to the spinal cord from neuromyelitis optica spectrum disorder, acute disseminated encephalomyelitis, multiple sclerosis, or even traumatic spinal cord injuries.

Where can I find a press release about the study? You can find the press release about the study by going to: tma.org/q-cells-press-release.

New Research on Epidural Electrical Stimulation in Spinal Cord Injury

Two research articles were recently published on the use of epidural electrical stimulation (EES) to help paralyzed individuals recover motor function. The first study was conducted by the Frazier Rehabilitation Institute and the Kentucky Spinal Cord Injury Research Center at the University of Louisville. It included four participants who had motor complete spinal cord injuries, meaning no motor function below the level of injury. Two of the participants had lost all sensation below their level of injury in the spinal cord, which is classified as AIS grade A, and the other two participants had retained partial sensory function below their level of injury, which is classified as AIS grade B. This grading system, The American Spinal Injury Association Impairment Scale (AIS), is used to describe and measure the severity and characteristics of a spinal cord injury. The second study was conducted by the Mayo Clinic Rehabilitation Medicine Research Center in Rochester, MN and included one participant who had a motor complete spinal cord injury and had lost all motor function below their level of injury.

In both studies, participants had received clinical rehabilitation after their spinal cord injury and were 2.5 to 3.3 years from when their injury was sustained. All participants received locomotor training at the start of each study, which lasted 8 to 22 weeks depending on the participant. The participants were then implanted with the EES system during a surgical procedure in which a 16-electrode array was implanted on the spinal cord and a spinal cord stimulator was implanted on the abdomen. After participants rested approximately three weeks, the EES system was tested to identify muscle groups in the legs using electromyographic (EMG) recording.

Next, participants in these studies received locomotor training with the aid of electrical stimulation. The participants practiced stepping on a treadmill, stepping over ground, and standing over ground. Participants used a body-weight support system (BWS), trainer assistance, and a walker when needed. They adjusted to not using these aids if progress was shown over the course of the training.

In the Frazier Rehabilitation Institute and the Kentucky Spinal Cord Injury Research Center study, the two AIS grade B participants were able to walk over ground while using assistive devices. The two AIS grade A participants were able to achieve some aspects of stepping on the treadmill with body-weight support, but they were unable to walk over ground. The participant in the Mayo Clinic Rehabilitation Medicine Research Center study was able to achieve stepping on a treadmill, independent standing, and stepping over ground while using a front-wheeled walker and occasional trainer assistance. All four participants were only able to perform these motor functions while the EES system was turned on and when they had the intention to move. The results of these studies suggest that motor functions may be able to be restored in individuals with spinal cord injury with the use of electrical stimulation. The researchers at the Frazier Rehabilitation Institute and the Kentucky Spinal Cord Injury Research Center noted that the difference in outcomes between the two participants who were able to walk over ground and the two participants who were not able to walk over ground may be due to their sensory level below their injury or other factors. The researchers in both studies recommend a follow-up study be conducted with a larger number of participants.

Dr. Cristina Sadowsky, Clinical Director of the International Center for Spinal Cord Injury (ICSCI) at the Kennedy Krieger Institute, shared with us about how the results of these studies may be applicable to those with rare neuro-immune disorders.

“The epidural stimulation case reports prove that some brain-spinal cord connections are dormant post injury and can be activated by ‘raising the excitability level’ of the neurons in the ‘gait center’ in the lumbar spine using the epidural spinal cord stimulator. The stimulator appears to work better in people with (sensory) incomplete injuries, which makes sense, as the number of tracts that connect the brain to the lumbar spine is probably higher than those with motor complete injuries. The stimulation does not work in everyone.

While the case series reports on results in individuals with traumatic spinal cord injury, the results of epidural stimulation could potentially be applied to paralysis related to non-traumatic conditions, like transverse myelitis (TM), neuromyelitis optica spectrum disorder (NMOSD), acute disseminated encephalomyelitis (ADEM), etc., as long as the injury spares the nerves leaving the cord and supplying the muscles in the legs. One way to determine that is to inquire about muscle spasms and reflexes – if they are present, the nerves to the legs are most likely intact.

What would the next steps be to advance this significant research discovery?

1. Making someone’s gait more energy efficient, which would allow for smoother, longer distance ambulation. You would do that by working towards a more “normal” gait, including reducing assistance from other people to stabilize the pelvis, etc.
2. Figuring out the best candidates for the procedure; establishing criteria that would preclude a person from getting the stimulator.
3. Making the process of figuring out the best electrode parameters that give the optimal gait response easier by making this process short, reliable, and clinician friendly.
4. Getting the smallest, safest, most reliable, customizable epidural stimulator.

There are also some concerns:

1. Implanting a stimulator/foreign object leads to the possibility of technological failure.
2. The implant might make it impossible to have an MRI study.
3. The stimulator assisted gait is not independent and certainly not normal/efficient (yet).
4. The hype it creates makes everyone think that they can walk if a stimulator is implanted.
5. It’s still far away from actual use in clinical care. It takes a long time to program, programing is very personalized and requires a lot of knowledge. Dr. Susie Harkema and Dr. Reggie Edgerton, the senior scientists on each paper, have been working in the gait training field for many years!

The case reports are more relevant for the fact that now there is a method to allow for meaningful remaining brain-spinal cord connections to be uncovered and used, and it points out to the absolute NEED to undergo extensive, well designed, meaningful activity based rehabilitative interventions.”

References

Angeli CA, Boakye M, Morton RA et al. Recovery of Over-Ground Walking after Chronic Motor Complete Spinal Cord Injury. *N Engl J Med*. 2018;379(13):1244-1250.

Gill ML, Grahn PJ, Calvert JS et al. Neuromodulation of lumbosacral spinal networks enables independent stepping after complete paraplegia. *Nat Med*. 2018 Sep 24.

Vaccines and the Association with Relapses in Patients with Neuromyelitis Optica Spectrum Disorder

A retrospective study was conducted to determine whether vaccinations were associated with an increased risk of relapse in patients with Neuromyelitis Optica Spectrum Disorder (NMOSD). Patient records were reviewed from three NMOSD centers: the Johns Hopkins NMO Clinic in Baltimore, USA, NeuroCure research Center at Charité University Hospital in Berlin, Germany, and Neuroclinica in Medellín, Colombia. All patients with comprehensive health records related to their NMOSD and who had follow-up information for at least 90 days after their most recent vaccination were included in this analysis.

In order to determine whether there was an increased risk of relapse following a vaccination, the researchers compared relapses that occurred 30, 60, and 90 days after vaccination with relapses that occurred within randomly selected dates. For the purposes of this study, relapses were defined as “a new or worsening acute neurologic symptom lasting 24 hours, associated with a change in exam localizing to the [central nervous system] CNS and not explainable by fever, infection or metabolic condition.” The NMOSD patients were divided into two groups: those who were taking preventative immunotherapy medication such as rituximab, mycophenolate mofetil, azathioprine, methotrexate, or prednisone, and those who were not on a preventative immunotherapy, which included patients who were taking glatiramer acetate and interferon beta, as these medications have been found to worsen or not be effective in NMOSD.

Ninety patients who received a total of 211 vaccinations were included in this study. The median disease course was 6.6 years, and 340 relapses had occurred during this timeframe. Intramuscular influenza was the most common vaccine received (61% of the vaccines received).

The researchers found that vaccines were not significantly associated with relapses among patients on preventative immunotherapy such as rituximab, mycophenolate mofetil, azathioprine, methotrexate, or prednisone. However, the researchers found that vaccines were significantly associated

with relapses in patients who were not on preventative immunotherapy. Also, among patients on preventative immunotherapy, routine vaccinations were associated with lower annualized relapse rates.

There were 7 patients who relapsed within 30 days of a vaccination, 6 patients who relapsed 31-60 days after a vaccination, and 3 patients who relapsed 61-90 days after a vaccination, for a total amount of 16 patients experiencing relapses within 90 days after a vaccination. Five of the inflammatory attacks were at the disease onset and eleven were relapses that occurred later in the course of the disease. The highest proportion of vaccination-associated relapses were after tetanus/diphtheria vaccines, as 15% of patients receiving this vaccination relapsed within 90 days.

118 of the 211 vaccinations in this study were administered to patients who were on immunosuppressive therapy. Most (13 of the 16) patients who experienced relapses were not on immunotherapy, and one patient was on glatiramer acetate, which is not an effective treatment for NMOSD. The remaining two patients were on immunosuppressive treatment for an average duration of 47 months.

As stated above, the researchers found that routine vaccination was associated with an 81% lower risk of relapse in patients who were using preventative immunotherapy than patients who were not vaccinated after their initial disease onset. A possible explanation for this finding is that relapses can be

triggered by immune system activation, and vaccinations help prevent infections that cause immune system activation, which results in fewer relapses.

The researchers suggest that individuals with NMOSD take preventive immunotherapy treatment prior to receiving any future vaccinations.

The authors of the study note several limitations to this study. For example, they did not include patients who received live attenuated vaccines, such as Japanese encephalitis and yellow fever vaccines, which have been associated with relapses in NMOSD. Additionally, few patients had received the HPV vaccine, which has been associated with relapses in case studies of NMOSD patients. The authors also had limited information and could not include data on the adjuvants that were used for each of the vaccines. Also, there were few aquaporin-4 negative patients included in the study, so additional studies should confirm these findings with aquaporin-4 negative patients. Lastly, there are inherent biases in retrospective data analyses, which could have influenced the results of this study. The study also did not look at vaccine-preventable infections, such as the flu, and their potential association with relapses. The results of the study should be understood within the context of these limitations and biases.

To address the issues with this study, the researchers suggest that there should be a comprehensive, well-controlled prospective study that investigates relapses, vaccines, and infections.

Original article: Mealy MA, Cook LJ, Pache F et al. Vaccines and the association with relapses in patients with neuromyelitis optica spectrum disorder. *Mult Scler Relat Disord*. 2018 Jul;23:78-82. doi: 10.1016/j.msard.2018.05.003. Epub 2018 May 7.

The TMA Registry Partnership with University of Texas Southwestern

The TMA Registry is an ongoing research project that collects information from individuals diagnosed with rare neuro-immune disorders. The questions in the survey cover many aspects of the participant's experience with their disorder, including symptoms, diagnosis, treatment, and complications. The goal of the registry is to develop a deeper understanding of rare neuro-immune disorders and to better advocate for those experiencing these conditions. We launched the registry in 2017 and 187 members from our community have participated in the registry to date.

We are happy to announce that Dr. Benjamin Greenberg at the University of Texas Southwestern Medical Center (UTSW) is partnering with the TMA to provide data about registry participants with TM who are willing to share their information. Dr. Greenberg is the Director of UTSW's Transverse Myelitis and Neuromyelitis Optica Program. Dr. Greenberg's Comprehensive Outcomes Registry Exploring Transverse Myelitis Study (CORE TM Study), will create a registry focused on short and long-term outcomes. One of the important results of this work will be the development of outcome measures for the use in clinical trials. The CORE TM Study will collect similar information as the TMA Registry, but will also include a review of medical records.

The TMA Registry was part of the NIH/NCATS Global Rare Diseases Patient Registry Data Repository (GRDR[®]) until it was discontinued in 2017. The TMA has received Institutional Review Board approval through the Institute for Family Health for this registry. We are grateful to be able to continue this work and look forward to sharing the results!

If you are interested in participating, please visit: tma.org/tma-registry

James T. Lubin Fellowship Update from Dr. Olwen Murphy

Dr. Olwen Murphy received her medical degree from University College Dublin in Dublin, Ireland and completed a neurology residency at The Royal College of Physicians in Ireland. She is a James T. Lubin Fellow at The Johns Hopkins Transverse Myelitis Center (JHTMC) in Baltimore, MD, under the mentorship of Dr. Carlos Pardo-Villamizar. Dr. Murphy's research is on predicting outcomes after a diagnosis of a transverse myelitis using current imaging techniques and spinal fluid analysis. The goal of the research project is to identify patterns or biomarkers that can be used in day-to-day clinical practice to identify benefits from therapies and help make better decisions about care. Visit this link for a recent podcast with Dr. Murphy: tma.org/2018-podcast-fellows.

I have just finished my first year of fellowship at Johns Hopkins University supported by the TMA through the James T. Lubin Fellowship. I have gained a huge amount of clinical experience working with patients with transverse myelitis (TM), other types of spinal cord disorders, neuromyelitis optica spectrum disorder (NMOSD), MOG antibody-associated disease (MOG-Ab disease), acute disseminated encephalomyelitis (ADEM), autoimmune encephalitis, neurosarcoidosis and other rare immune-mediated neurological disorders. It has been really rewarding and interesting to follow patients on their journey from experiencing one of these rare disorders throughout the process of diagnosis, treatment and rehabilitation. For example, seeing some patients with spinal cord disorders progress from using a wheelchair to walking over a period of a few months has been fantastic. On the other hand, there have also been cases which have shown me the challenges in dealing with neuro-immune disorders both from the doctor's and patient's perspectives. I look forward to building on this clinical experience in my second year of fellowship and working with patients with rare neuro-immune disorders throughout my future career.

I have also been busy working on research projects at the Johns Hopkins TM center. We are focusing on clinical and imaging biomarkers that may help predict diagnosis, response to treatment, and outcomes in patients with spinal cord disorders. We are finding that the initial suspected diagnosis is not accurate in many patients with spinal cord disorders. We have identified clinical clues that may help distinguish patients with spinal cord strokes or other blood vessel abnormalities from patients with inflammation of the spinal cord. Providing evidence-based analysis to neurologists on these disorders helps ensure that future patients are diagnosed correctly and therefore treated appropriately.

Notes From Our 2018 Events

2018 Central Ohio Walk-Run-N-Roll

By Krissy Dilger

On Sunday, September 23rd, the TMA held a Walk-Run-N-Roll in Dublin, OH. The air was crisp, and the sun shone over Coffman Park as families and friends arrived for the event. Due to the generous work of volunteers, participants were greeted with sandwiches, coffee, and homemade cupcakes! Kids were treated to face-painting by a talented artist. Each participant received a Walk-Run-N-Roll t-shirt to commemorate the event.

As the last of the attendees arrived, everyone gathered in the pavilion to listen to Sandy Siegel speak. As the president of the TMA, Sandy spoke about his motivation for founding this organization: his wife, Pauline, who was diagnosed with transverse myelitis. Sandy and Pauline worked tirelessly for over 20 years to build the organization to what it is today. Sandy explained that even after a year since Pauline's passing, he continues to dedicate his time and energy to the efforts of the TMA. He does this because he cares about the TMA community and is hopeful that research will improve the future for those with rare neuro-immune disorders.

After Sandy's inspiring speech, the entire group gathered to take a photo. We all squeezed in tight so that all 70+ participants could be seen. Then, it was time to walk, run, and roll around the park! All the children were encouraged to lead the pack in the ceremonial trek, and they did so with bright, smiling faces. Their family members and friends followed in a harmonious movement that signified the strength of our community when we come together. Once finished, the attendees were encouraged to mingle with one another and share their stories. By meeting with one another, we spread understanding and support for everyone who has been diagnosed with a rare neuro-immune disorder.

We are thankful for all participants who came to show their support and helped us raise over \$16,000 for research and



education of rare neuro-immune disorders. We are grateful that families came from all over Ohio to join in this event. There is something special about having our community come together and meet others with their same diagnosis. For many, it is the first time meeting someone with their same disorder. We had a wonderful time at this Walk-Run-N-Roll and can't wait for next year!

If you are interested in starting a Walk-Run-N-Roll or other fundraising event in your city, please contact the Community Partnerships Manager, Jeremy Bennett, at jbennett@myelitis.org.





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The View Through My Camera: 2018 Illinois Walk-Run-N-Roll

By Bruce Mondschain, BLM Fineart Portraits

I believe that pictures tell the story of our lives: the moments of elation and those of despondence, those of great achievement and those that set us back. The moments we wish to keep forever because they show the feelings that cannot be uttered by our mouths. They capture the times that we wish to remember forever, some punctuated with salty tears, others with smiles of recollection, of times less complicated. Photographs capture the moments that remind us that we seldom walk the narrow bridge of life alone. Most often we cross that bridge with those we love and who love us. Photos are proof of that journey. So, four years ago, when my dear friend and former colleague, Nancy Hanna Dove, asked if I would be interested in photographing the Illinois TMA Walk-Run-N-Roll, my reply was an enthusiastic, “For Sure!”

Having now been privileged to photograph four such events, I believe in the power of photographs with even greater conviction. You have taught me so much. And, for those insights, I will be forever grateful and in awe of the strength, promise and compassion that I have witnessed.

The TMA Walk-Run-N-Roll taught me that TM and related neuro-immune disorders do not discriminate. The participants in the event represent a blend of all ages, ethnicities, races, forms of mobility, levels of affluence and life situations. The event creates an arena for veterans of TM, as well as those who were only recently diagnosed. It is a place where a common language is spoken. It is the language of neuro-immune diseases accompanied by the language of hope.

Looking through my camera, I was overwhelmed by the welcomes I witnessed. Welcomes that were instantly visible in the hugs, words of enthusiasm, tears of shared loss and the overwhelming feeling of comfort that accompanies being with others whose hopes, dreams and fears mirror your own. There is no room for pretense or haughtiness. Life is far too short and precious for those. The camera tells the truth!

I saw a sense of hope that was, for me, overwhelming. It showed in the eyes that searched other eyes in conversation. It showed in the words of a 16-year-old athlete who now speaks of her dreams of athletic achievement from her wheelchair. Her service dog sat quietly and attentively next to her.

It showed in the memorials for those who joined us in prior years but who lost their noble battles with this mysterious disease. It showed in the mother who talked about the loss of her precious daughter and the prayer of comfort they said together each day. I saw it in the wife sharing her story of her husband’s fight to the end. Her pain and anguish were raw. Her story was a true love story. My camera recorded it in the brother who talked about the fact that he thinks of his departed sister each day. About her smile, her stamina, the lifelong gifts she gave to her family members. Who says big boys don’t cry?

The event is a day when it is okay to be vulnerable. I watched through my lens as a mother spoke about the pain of her daughter losing her battle. She told her story punctuated with gasps for breath, with tears streaming down her face, with a sense of profound appreciation for what family and friends have done to help her deal with her unthinkable loss. At a point when it seemed she could no longer finish her remarks, a strong young man who had been watching her intently made his way to the stage to put his arms around the woman speaking, his mother. He held her and reminded me once more that we needn’t walk the narrow bridge alone.

But, all that said, my tear-filled eyes saw something I never would have anticipated. Unbridled hope! That is what this incredible event is about. Hope. That we can be with others like ourselves. That we can be authentic in our pain and elation. That the TMA is making a difference every day in educating doctors, improving diagnostic accuracy and sharing new treatment and clinical study findings. That we know more today than we did yesterday and that tomorrow, we will know even more. That the TM community will stand



together in victories and in moments of loss. I cannot think of a moment at any of the TMA events I have photographed that was not about hope. It was there in the enthusiasm at the beginning of the Walk-Run-N-Roll where youthful patients held the event banner, and in the sense of accomplishment as people crossed the finish line and posed for a photo. Hope was there as I took photos of people reading the biographies that were strung around the pavilion. Biographies of TM patients. Epic stories of bravery, commitment and accomplishment. And hope was present in the multitude of excited requests from people wanting their picture taken with their “TMA friends and family”.

And, hope was there as people gathered together to take a group photograph of all those at the event. Before I took that final picture of the day, I stood atop the ladder, looking out at the hundreds of mothers, fathers, husband and wives, sisters, brothers, children, grandparents, friends and neighbors. The love, camaraderie and feelings of hope and spirit were overwhelming. I struggled to steady and focus my quivering camera, took the picture and said a silent prayer.

From the deepest part of my heart, I thank you for letting me be a part of the journey across that narrow bridge. Here is to next year.

Thank you to our 2018 Sponsors

Abilities Expo
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 Sheridan Road Charitable Foundation
 Synergy Adaptive Athletics
 Vistage
 Wiener Takes All



The TMA is making a difference every day in educating doctors, improving diagnostic accuracy and sharing new treatment and clinical study findings. We know more today than we did yesterday and tomorrow, we will know even more.



2018 Massachusetts Walk-Run-N-Roll

The 3rd annual Massachusetts Walk-Run-N-Roll took place on Saturday, October 13th at Endicott Park in Danvers, Massachusetts. It was a crisp, wet morning, but that didn't stop the near 100 people who attended from walking, running, and rolling their way around the park to raise awareness for rare neuro-immune disorders.

U.S. Women's National Hockey Team Captain and three-time Olympic medalist, Meghan Duggan, was the featured speaker this year. Meghan talked about her involvement after recently meeting four-year-old Noah Holt, who was diagnosed with AFM when he was six-months-old. Noah's parents, Elisa and Mitch, are the event organizers.

After the talking, walking, running, and rolling, Meghan posed for pictures and let the kids wear her medals. A DJ kept everyone moving and from getting too cold. And Texas Roadhouse provided some much-needed comfort food.

Thank you to the Holts, all the volunteers who braved the weather to set up tables and tents, Meghan Duggan, our sponsors, and our community. Due to your efforts, the 2018 MA Walk-Run-N-Roll raised more than \$21,000!

2018 NORD Rare Summit

The National Organization for Rare Disorders held their annual Rare Summit on Monday, October 15th and Tuesday, October 16th in Washington, D.C.

During the 2018 NORD Rare Summit, more than 800 leaders from FDA, NIH, industry, patient groups, payers, and research institutions addressed the New Era of Patient-Focused Innovation. Attendees explored the new and innovative ways in which patients and caregivers are helping drive progress for the rare disease community.

The TMA was represented in the Patient Advocacy Pavilion by Chitra Krishnan, Executive Director, and Jeremy Bennett, Community Partnerships Manager.

The TMA, and our community, benefits from the advocacy NORD provides at the legislative level. NORD also provides peer-to-peer networking opportunities, educational webinars, and promotion of our events through their platforms.

If you are interested in getting involved in advocacy, please email Jeremy at jbennett@myelitis.org for more information.



MSD101

Multiple Sulfatase Deficiency

WHAT IS IT? MSD is a genetic disease that causes a build up of cellular trash in the body.

ULTRA-RARE than 100,000 people known GLOBALLY

HOWEVER that number will increase with better awareness of the disease and improved access to diagnostic testing.

HOW DOES IT WORK? MSD is caused by a faulty **SUMF1 gene**. Known as the master gene, SUMF1 is responsible for the process of breaking down and getting rid of the cellular trash that builds up in every part of the body during normal function.

FGE SUMF1 ignites Formylglycine-generating enzyme [FGE] is essential for the proper function of 17 other enzymes.

17 sulfatases [enzymes] get to work breaking down the trash that every cell in the body makes everyday. These sulfatases are crucial for life.

Most children with MSD do not live to see their 10th birthday.

By clogging every body system and not working properly, eventually, cell trash builds up and breaks down completely.

We could give a healthy copy of the **SUMF1 gene** with gene therapy. This could **SAVE** their lives.

UNITED MSD FOUNDATION
MULTIPLE SULFATASE DEFICIENCY

MASTERGENE

The Essential SUMF1 Gene

Multiple Sulfatase Deficiency [MSD] is a rare, genetic disease caused by mutations in the SUMF1 gene, which encodes the Formylglycine-Generating Enzyme [FGE].

Therapies designed for MSD may also benefit patients with other **Lysosomal Storage Disorders** lacking in sulfatases activated by FGE.

- Metachromatic Leukodystrophy (MLD)**
Arylsulfatase A
- Maroteaux-Lamy Syndrome (MPS VI)**
Arylsulfatase B
- Morquio A Syndrome (MPS IVA)**
Galactosamine 6 sulfatase
- Sanfilippo D Syndrome (MPS IID)**
Glucosamine 6 sulfatase

ADVOCACY PAVILION ORGANIZATION:
The Transverse Myelitis Association

The Transverse Myelitis Association

ADVOCACY PAVILION

Thank you Pavilion Sponsors:

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Thank you Patient Advocacy Exhibitors:

- AAIDA
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- IWMF
- DF - Definitive Deficiency Foundation
- INCA
- The MSA Coalition
- MLD+
- NF
- NORD
- RARE CANCER COALITION
- Pdco
- The Transverse Myelitis Association
- UNITED MSD FOUNDATION

Together we are strong.

we are rare.

Jeremy Bennett
Transverse Myelitis Association
NORD Member



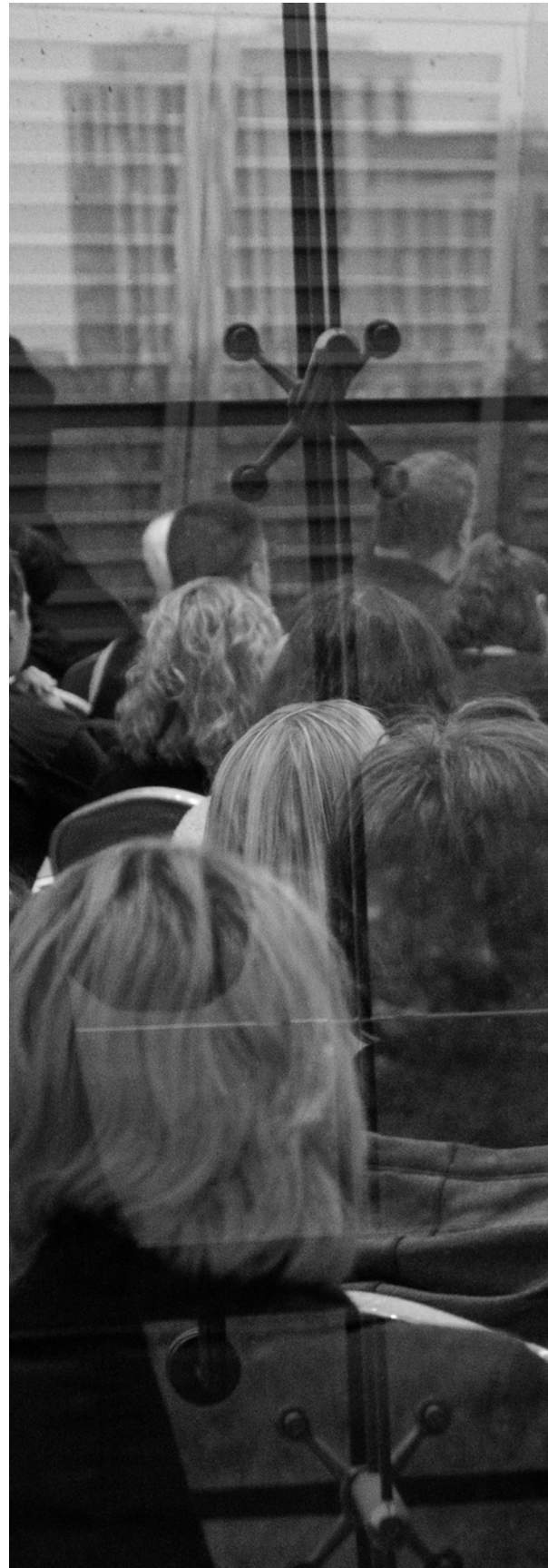
2018 REGIONAL **RNDS**

The 2018 Regional Rare Neuro-immune Disorders Symposium was held on October 27, 2018 in Boston, MA. The TMA partnered with Boston Children's Hospital's Center for Pain and The Brain to host the event. Medical experts gave presentations on a range of topics regarding the rare neuro-immune disorders. The day started with presentations which provided overviews of Transverse Myelitis, Acute Flaccid Myelitis, Neuromyelitis Optica Spectrum Disorder and Optic Neuritis, Acute Disseminated Encephalomyelitis (pediatric and adult), and MOG Antibody-Associated Disease.

Next, GG deFiebre, Associate Director of Research and Education, and Jeremy Bennett, Community Partnerships Manager, talked about Updates from The Transverse Myelitis Association. The presentation explained our ongoing education programs, our outreach and support efforts, our fundraising and advocacy events, and more. Dr. Benjamin Greenberg, Board Member of the TMA, spoke about the importance of community involvement for the future of the TMA, and also announced a generous matching grant of \$250,000 from the Madison Charitable Foundation to further our mission.

A Panel on Symptom Management followed, which included a question-and-answer portion with our medical experts. Next, Jenna Elie, PT, DPT, gave a presentation on Rehabilitation and Recovery. There were then presentations regarding ongoing research in the field of neuro-immunology, including Updates in Remyelination Strategies, Imaging and Rare Neuro-immune Disorders, and Genetics of Familial Transverse Myelitis. Finally, we closed out the day with a question-and-answer session with our medical experts.

We want to thank everyone who attended, as well as the presenters and sponsors. We would not be able to host an event like this without your support and dedication. To all those who attended, we hope you found the event informative and interesting! All of the sessions are available on our YouTube channel, and will soon be in our Resource Library. We will be announcing information about the 2019 Rare Neuro-immune Disorders Symposium in the next few months.





Feeling Good at the TMA Quality of Life Family Camp

By Jeremy Bennett

“CCK! How do you feel?”

If everyone is staring at you now because you just spontaneously yelled, “we feel so good” and started clapping in rhythm, chances are you’ve been to The TMA Quality of Life Family Camp. If you haven’t been to camp at The Center for Courageous Kids and you have a child diagnosed with a rare neuro-immune disorder, keep reading to learn why this is one of our favorite weeks of the year. Please start making plans to join us in 2019!

Last fall, I joined The Transverse Myelitis Association as the Community Partnerships Manager. One of my first weeks on the job was during the Rare Neuro-Immune Disorders Symposium. I met so many members and their families. One of the topics that came up the most that weekend was Family Camp. People wanted to know what it was, when it was, and how they could attend. Everyone (TMA staff included) talked about it with a certain energy that is seldom seen in adults; a throwback to those nights before holidays where the anticipation makes it impossible not to smile.

I spent the next nine months wondering if the actual experience could live up to the expectations. I am happy to report that I was not disappointed. In fact, my five days at camp exceeded everything I had hoped it would be. We often talk about how many of the people diagnosed with these disorders don’t know anyone else diagnosed with their same disorder. It was amazing to watch these thirty-five families interact.

There was a look of recognition and comfort from many of the parents attending for the first time. There was also joy as they watched their kids dance, fish, ride horses, shoot watermelons

with a bow and arrow, and just play. And then there was Messy Games! Remember that energy I mentioned earlier? It was in full force as parents, kids, and staff dumped green oatmeal, chocolate pudding, and other “messy” stuff on each other. A special shout-out to our clinicians and James T. Lubin Fellows for going all-in on the fun. I know there are shirts and shoes that didn’t make it back in the return luggage.

The whole week isn’t just about fun and games. Each day, while the campers were off with the CCK staff, the parents gathered in the dining hall for a two-hour education session with the medical professionals. Experts in the fields of neurology, psychology, disability rights, and rehabilitation answered questions and also learned from the parents.

The beauty of a place like CCK is that there is something for everyone. At times, I sat back and watched as campers participated in arts and crafts, music therapy, and Stage Night (where songs were sung, jokes were told, and princesses were crowned). At other times, I jumped in and played basketball, paddled around the pond in a canoe, and baited fishing hooks (who knew catfish liked hot dogs?). During it all, a strange thing happened. I stopped noticing the wheelchairs, walking aides, and other signs of a disability and started to see the campers as just that...campers. I suppose that’s the point of Family Camp. It’s a place where these kids can go and not have to answer questions about why they are in a chair or have a surgery scar on their arm. It’s a place where they can go bowling, braid a horse’s mane, and most importantly, throw green oatmeal at their parents.

So, when someone says, “CCK! How do you feel?”, we mean it when we say,

“we feel so good.”





Introducing the Care Coordinator at Children's Health CONQUER Clinic, UTSW in Dallas, TX

I graduated from the nursing program at Oklahoma State University in 2012. This is a second career for me, and while I was excited to begin my new journey, I had no idea where to start. There are so many specialties to choose from. The one thing I knew for sure is that pediatrics had my heart. The children are amazing and being a mom myself, I felt a deep connection with the parents and the questions they had as they searched for answers for their sick child. My experience up until now has been in the NICU, neurosurgery, and neurology. While each of these has taught me a great deal, nothing has been more exciting or more fulfilling than working with the neuroimmunology team at our Children's Health CONQUER Clinic (Collaboration on Neuroimmunology: Question, Understand, Educate, Restore). I have seen so many young people, toddlers to young adults, meet their challenges head-on with a smile and a determination that is awe-inspiring. And the parents are engaged and eager to do anything and everything they can to give their child every opportunity to heal or, in some cases, live passionately and fully with their new normal. Many of these moms and dads can spout off tests and talk about MRIs like pros because they have learned that many times, they are the ones educating other medical professionals on these rare diseases. They have certainly taught me!

And our CONQUER team at University of Texas Southwestern is the best! They have taken me in and welcomed me as one of the family. Each time I ask another question (and there are many), there is not one of them that will not stop and explain.

My official title is RN Care Coordinator. When we are in clinic, I direct the "human" traffic! There are potentially 8-10 people that could see each patient. That takes coordination and sometimes a gentle, but firm, nudge to get moving. I also talk with our teens, along with our social worker, about transitioning to adulthood. We want them to be comfortable so that when their friends or other medical professionals ask what's going on, these teens can confidently tell them about their diagnosis. It's also important for them to understand what their medication is, why they are taking it and when to call for help. I do the same education for moms and dads of our younger kiddos. When I am not in clinic I take patient calls, deal (sometimes fight) with insurance, coordinate labs and imaging, write letters of medical necessity and diagnosis letters, and work with the specialty drug companies to make sure medications are getting where they need to go. I encourage patients to call me for anything. If I don't know the answer, it's likely I can figure out who does.

I am incredibly grateful for this opportunity! I have learned a great deal in 5 months and there is so much more to know! I am excited for all that is yet to come!

Denise Maddox, RN

TMA

Volunteer Spotlight

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

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

We are pleased to honor Hannah Stadler. Hannah was a volunteer during the 2018 Quality of Life Family Camp. The event took place between July 22-26, 2018 in Scottsville, KY at The Center for Courageous Kids. Hannah is currently studying neuroscience at Brigham Young University.

“I never considered neuroscience until everything with ADEM happened and then meeting everyone through the TMA. They have definitely been a big source of inspiration for my choice.”

We want to thank Hannah for her hard work and dedication to our mission!



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

I was diagnosed with ADEM in March 2016 and didn't find out about the TMA until September of the same year. The only reason I became aware of the TMA was due to my major jaw surgery that was scheduled for the end of 2016. This jaw surgery had been in the works for years and officially planned for the beginning of June 2016; so, as you can imagine ADEM threw a little kink in the plans. My doctors were debating about whether it was safe or not to do a big surgery on me so soon after a traumatic brain injury, and no one seemed to agree on an answer because I was "one of a kind", in multiple ways apparently :) This answer was not sufficient for my mom, which inspired her to search for a doctor who could give us a better answer, and in doing so she came across the TMA. When she showed me the TMA website for the first time I was beyond excited. I had not known anybody who had experienced ADEM, and suddenly I knew hundreds and was able to read all their stories. I wanted to get involved and have the chance to know people, other than reading their stories, so I decided to become a volunteer. It was, and still is, one of the greatest blessings in my life to be involved in this organization.

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

My advice to any potential volunteers or Support Group Leaders is that you won't regret sacrificing your time to help the TMA. The experience will allow you to become closer with the TMA staff, and the members and their families. It truly has been a rewarding time and I hope to continue to become more deeply involved with this organization in the coming years.

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

The TMA's mission is very important to me. Upon being diagnosed with ADEM, I didn't realize the loneliness that would come along with it. I personally didn't know anyone with this diagnosis for at least six months afterward and it was hard! No one quite knew the pain, fear, disappointment, etc. that I was experiencing. I had many dark days as a result. I think that the mission of advocating, connecting, and spreading the word about these disorders is both necessary and inspiring. Those who are diagnosed with these disorders need to know that there are resources, such as the TMA. They help with information regarding this rare diagnosis, finding doctors, and treatment centers. Most importantly, the

TMA helps us find others who struggle with the same experiences and who can provide companionship in this long journey of living with a neuro-immune disorder. I know that is what the TMA mission has done for me, and I know that it will continue to do so for many more.

What was your favorite part of camp?

I attended camp for the first time in the Summer of 2017, and I didn't realize how amazing it would really be. IT WAS AMAZING, and I would highly recommend that everyone attend if possible. My favorite part of it all is the community that exists there. I was a little nervous to go for the first time, but once there, it felt like I was at home. Everyone there is understanding, willing to help, full of hope and courage, to not only fight this hard thing we call life, but also enjoy it. I loved that I was able to connect with people who had very similar emotions, pains, memories, and trials. It made me feel more whole. I recently attended again this past summer and seriously did not want to leave (it might have been the fact that going home meant going back to school to take a chemistry test, BUT the feelings of joy and relationships formed were definitely the biggest reason why). I think this camp provides a source of healing for the victims of rare neuro-immune disorders, as well as the families, that cannot be found anywhere else. Also, through this camp, I have come to know wonderful people such as Sandy Siegel, Rebecca Whitney, Ashley Harrington and her parents, Bridget Gum and her family (and many, many others!!!), that have inspired me day in and day out. I am grateful for the two camps that I have been to and hope to attend many more in the future.

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



I wanted to get involved and have the chance to know people, other than reading their stories, so I decided to become a volunteer. It was, and still is, one of the greatest blessings in my life to be involved in this organization.

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: Amanda, Scottie, Christina and Karl.



Amanda S.

Diagnosis: TM
Location: Indiana

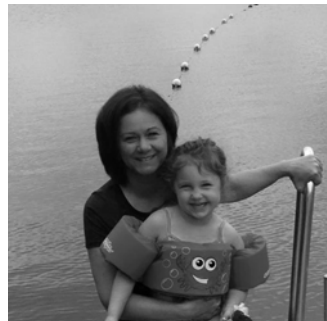
tma.org/amanda



Scottie B.

Diagnosis: TM
Location: United States

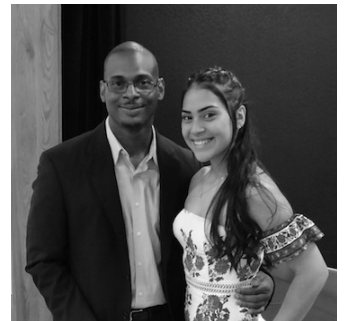
tma.org/scottie



Christina O.

Diagnosis: TM
Location: New Hampshire

tma.org/christina



Karl T.

Diagnosis: TM
Location: Indiana

tma.org/jenny

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

Our TMA Website

We recently re-organized our website (myelitis.org) to make it more intuitive and easier to find information. The top of the website menu includes links to information about the TMA- our mission, staff, Board of Directors, and financial information. At the top of the menu there is a link that allows you to update your information, so you can make sure you are getting communications from us. We also have a link to our blog and our social media channels.

We now have sections on our website for those who were recently diagnosed, a disease information section covering all the disorders we advocate for, and a resource page. Resources include the Myelitis Helpline, the medical professional and support group networks, our resource library, and more. You can also learn more about our programs, like the James T. Lubin Fellowship and our Quality of Life Family Camp, in the Programs dropdown menu. We created an entire section devoted to research, which includes links to studies that you can participate in, as well as research publications that the TMA has funded. Be sure to keep an eye on the events list for any upcoming events near you. There is an entire page devoted to how you can get involved in the TMA's efforts.

We hope that our updated website will make it easy for you to find resources and information. If you have any feedback about the website, please email us at info@myelitis.org.

The TMA Announces its Partnership with The Sumaira Foundation

On October 11, 2018, we announced our partnership with The Sumaira Foundation for NMO (TSF). Both organizations are dedicated to raising awareness for rare neuro-immune disorders while supporting patients and their caregivers. TSF was founded in Massachusetts in 2014 by Sumaira Ahmed, two months after being diagnosed with sero-negative neuromyelitis optica.

“I am hopeful that joining forces with such a prestigious, organized, well-established, and mission-aligned organization like TMA will only fortify our respective efforts, increase the NMOSD footprint, and accelerate progress made towards raising awareness and finding a cure,” Sumaira Ahmed, Executive Director, TSF for NMO.

“We are excited to partner with The Sumaira Foundation and look forward to working together to raise awareness, increase knowledge, and advance research in rare neuro-immune disorders. It has been wonderful getting to know Sumaira and her compelling passion and determination,” Chitra Krishnan Executive Director, TMA.

We look forward to working together to further our common mission.

Sumaira's NMO Story

My name is Sumaira and I am the founder and executive director of The Sumaira Foundation for NMO and Miss Bangladesh-USA 2015. Thank you for taking the time to read my story.

It all started in June 2014. I was a perfectly healthy 25-year-old woman living and working in Boston. At the time, I worked as the Director of Network Development at Boston Laser/Boston Eye Group, a multidisciplinary



ophthalmology group best known in New England for restoring patients' vision through LASIK and/or cataract surgery.

I spent a weekend in New Jersey celebrating the launch of my sister's fashion line when I first noticed the black circle in my right eye. I brushed it off assuming it was a sunspot; summer had just started after all. I returned to the office Monday morning and noticed that the circle was not only still present, but had also increased



in size and, pretty quickly, posed as an obstacle to getting work done. The office was relatively quiet because it was the week of July 4th and most of the doctors and staff were on vacation. I told the outgoing fellow that I was having trouble seeing and was hoping she could take a look. I had my first visual field test, and the doctor was simply startled when she saw the results; there was a significant visual field defect in my right eye. She showed one of the attending physicians who then ordered a full workup. Structurally speaking, there were no remarkable findings, but it was clear that I could not see. The attending physician called

her neuro-ophthalmology friend for advice and an MRI was scheduled at Massachusetts Eye and Ear Infirmary (MEEI) for the following morning.

I went to MEEI the next day with my weekend bag assuming I'd be in and out and would be free to go to my friend's house for the holiday weekend. Gosh, I was so naïve. Long story short, I was in the emergency room for 16 hours having seen five different specialists, who all scratched their heads puzzled by what was going on. It was one in the morning when I came out of my

first-ever MRI in a completely dazed state when the neurology fellows informed me that inflammation on my optic nerves and chiasm had been detected on the scan and that I'd need to spend the weekend at Massachusetts General Hospital to receive a few doses of IV steroids. Truthfully, I was exhausted and disoriented from taking Ativan, so I agreed to everything in order to get some sleep. Three days later, I was diagnosed with idiopathic optic neuritis and discharged with a 16% chance of developing MS and expected full recovery within three months to one year. As instructed, I moved on with my life like nothing had happened. (Side note, I've always thought it was ironic that I got afflicted with a rare eye disease while working in ophthalmology - go figure!)

Three weeks later, I walked into a wall at my office. My skin was flushed, and I was nauseous. I felt a tingling sensation in my hands and feet. Something wasn't right. The ophthalmic technicians reported that I had severe bilateral visual field defect and unable to read the large "E" on the Snellen chart (right eye was 20/600; left eye was 20/120). My boss told me to go straight to the hospital

as he feared it was only going to get worse. At the hospital, I was declared legally blind, got my first lumbar puncture (the worst!), had multiple brain and spine scans, and was discharged six days later. I was diagnosed with sero-negative neuromyelitis optica and began chemotherapy. I left the hospital confused, terrified, and feeling isolated. How did this happen? Did I do something that triggered the onset? What was this disease? I had never heard of it and it didn't seem like anyone around me had either. All I knew is that everything happens for a reason and I was determined to find out why.

After a month of bed rest and acclimating to my ever-changing new normal, I decided it was time to take matters into my own hands. In October 2014, I founded The Sumaira Foundation for NMO to raise awareness. The founding philosophy was that heightened awareness would ideally lead to increased funding for research and development, thereby getting us closer to a cure. I had no idea how to start, let alone run, a nonprofit organization but I was eager to get NMO on the map and have this community's





SARAH HINCHEY

voice be heard. We turned four years old this October and I'm really proud of how this organization has blossomed. Today, our team consists of 17 very talented individuals who volunteer their time, energy, and ideas towards illuminating the darkness of neuromyelitis optica. Our organization weaves light, color, and positivity into virtually everything we do which includes raising awareness, supporting research through our grants program, sharing stories through our "Voices of NMO" campaign, partnering with mission-aligned organizations to widen the reach of our impact, and creating a community for patients and their caregivers.

In terms of my health, while it's not perfect, I've finally reached a point where I've rediscovered happiness, comfort, and peace. In four and a half years, I've had over 400 visual field tests, 100+ infusions comprising of 5 different chemo drugs, 14 MRIs/PET/CT scans, plasmapheresis, 13 visits to the emergency room, 13 specialists, 8 relapses, 6 inpatient hospital visits, 4 months of menopause, 4 eggs harvested, 3 surgical procedures in my bladder, 2 lumbar punctures, 1.5 years of Achilles Tendinitis/Plantar Fasciitis, one

too many battles with insurance companies, and an injection in my right eye (OUCH!). That being said, I wouldn't trade ANY of this! I am the woman I am today because of all my experiences and am truly living my best life. Through illness and the organization, I've met incredible and inspiring people who motivate me to keep pushing the envelope. My heart is so full and there is no greater honor than advocating for this community that deserves attention and representation.

Thank you, Transverse Myelitis Association, for sharing my story!

Sumaira Ahmed
sumaira@sumairafoundation.org



Clinical Studies & Trials

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

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

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

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

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

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

Study Sponsor: AstraZeneca/MedImmune/Vielabio

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

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

5 **A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis**

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

6 **The PREVENT Study**

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

7 **The 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 Neuro-Immune Disorder**

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

12 **Neuromyelitis Optica, Anti-MOG Disease, Transverse Myelitis and Optic Neuritis Biorepository**

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

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

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

14 **Pathology of Idiopathic Transverse Myelitis**

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

15 **Upcoming Phase I human clinical trial using Q-cells in 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 TMA Quality of Life Family Camp: July 27 - July 31, 2019

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