the transverse myelitis association

newsletter

summer 2016

advocating for those with ADEM, AFM, NMOSD, ON & TM

Find the Transverse Myelitis Association on Facebook! It is a great way to support the TMA and is a wonderful way to network with people in our community. Please take the time to become a fan of our page by clicking "Like," and tell your friends and family about our community's page. Facebook is a great way for us to raise awareness about these disorders and your experiences. Our link is http://www.facebook.com/myelitis.

THE EDITOR'S COLUMN

The Transverse Myelitis Association is embarking on two important studies.

One study is about the relationship between vaccinations and rare neuro-immune disorders, and will be in the form of a survey and potentially a short phone interview. The study will be focused on the experiences people have with vaccination after they have been diagnosed with one of these disorders. Specifically, we will be asking people about whether they have had subsequent inflammatory episodes after receiving a vaccination. We will also be studying whether people's decisions about receiving a vaccination have been influenced by having one of these disorders. The study will offer important insights on all of these subjects, and will offer researchers some directions for future research, as well as some insights that have public health implications.

While we believe the results of this study will be important, it is also essential to understand what this study will not tell us. This study will not in any way determine a causal relationship between vaccinations and an auto-immune episode, and there will be no results which implicate vaccination as a possible cause of ADEM, NMOSD, ON or TM. There is almost nothing understood about the disease process in ADEM, ON or TM. More is understood about NMOSD; but not nearly enough to arrive at any conclusions about environmental factors. Most of the medical world believes that auto-immune disorders result from some combination of a genetic predisposition for auto-immunity in concert with the influences of multiple and likely complex environmental factors. Nothing is understood about either the genetics of these rare disorders or possible environmental factors. Our study could offer some insights that might lead to directions for further research, but that's about as far as the results will go. Nevertheless, it is important for physicians and researchers to understand something about what people have experienced in regard to vaccinations, and as important, what people believe about the role of vaccination in these disorders.

It is important from the outset to recognize that the physicians and researchers on our scientific advisory council encourage people with ADEM, NMOSD, ON and TM to get the recommended vaccinations. There is universal agreement that vaccinations are safe, and that the consequences of being exposed to the diseases to which people are being immunized against are far greater than any risk from an adverse reaction to a vaccination. Those positions have been repeatedly expressed at our symposia and podcasts, and you can find that information in our resource library on our website (*https://myelitis.org/living-with-myelitis/resources/resource-library*).

The TMA is uniquely positioned to perform this study and other studies like it. One of the great problems we have had in our community since the inception of our

Chemistry Lab around 1924

organization is the paucity of information we have about people who have ADEM, NMOSD, ON and TM. There is a critical need for the systematic collection and analysis of information so that physicians and researchers can better understand these disorders. The TMA can play an important role in this information collection and analysis process. While much of our research depends on patient reported information, as opposed to results of imaging, laboratory or other scientific and more objective tests or measures, a lot can be learned from the patient experience. We are well situated to do this type of research and we can often conduct this research at far less cost than a medical or academic institution.

The methodology for this study will be a bit complicated. We are going to take a random sample from our membership and we hope to do so by grouping our members by age. We would like our sample to reflect the relative age categories of our community. From the perspective of a vaccination study, experiences are age-dependent as vaccination recommendations are different for children, than for middle aged adults than they are for the elderly. We are also using a random sample to minimize response bias. By selecting survey participants in a random way, we are hoping to select a group of people that is an accurate representation of our community. We want to minimize the possibility that the people who are most motivated to respond to the vaccination survey might be the people who have the strongest feelings or beliefs about vaccination in regard to all possible positions. We want people who have strong feelings, moderate feelings, as well as people who don't think about vaccinations and have no positions to participate. If you are selected to be a participant in this random sample, please get involved.

In addition to the random sample, we will make the survey available to all of the members of our community who have ADEM, NMOSD, ON or TM, including AFM. The survey will be made available in various ways, including on our website and through social media. I encourage

everyone to fill out the survey. Please only fill out the survey once. If you are part of the random sample, please do not respond to the public survey.

The second study we are launching is a patient registry to collect information about symptoms, treatments, and outcomes. This study is through a collaboration with the National Institute of Health's NCATS Global Rare Disease Registry (GRDR) Program. The purpose of this registry is to help advance research about rare neuro-immune disorders, collaborate with researchers from around the world, and identify participants for clinical trials. De-identified data integration into GRDR will allow query by investigators to accelerate research across many rare diseases, that eventually may lead to the development of novel diagnostics and therapeutics for patient benefit. More information about the GRDR program can be found at *http://www.ncats.nih.gov/grdr*.

For more than twenty years, I've listened to so many people from our community complain about how little information there is about these disorders and how little research is being done. The emotions surrounding this lack of information are very intense and range from sadness to frustration to anger. Pauline and I get it and we share in those emotions. In large part through the efforts of specialists, such as Dr. Ben Greenberg, Dr. Carlos Pardo and Dr. Brenda Banwell and through the opportunities created by the James T. Lubin Fellowship Program, the number of physicians, researchers and centers of excellence are growing. This growth will result in more and more studies being conducted, more results to be analyzed, and a greater understanding of these disorders. There is so much we need to learn.

All of this work and all of these results ultimately depend on your willingness to get involved. I am ready and willing to participate in any research that comes down the pike. Unfortunately, in this regard, and in so many others, I'm totally worthless. I don't have any of these disorders. If our members are willing to participate in research and respond to the call for action when it is made, there will be more and more research. This entire research process all comes down to whether or not we can get the members of our community motivated to participate.

Involvement in many research projects can be very complicated and some very personal decisions need to be made about participation. This is particularly the case where the clinical trials or studies involve a procedure of some sort or the use of a new drug. There are risks involved in these studies, and no one should ever make a judgement about someone's willingness to get involved. Participants in these studies show great courage, and they should be recognized in this way for their role in furthering medical science and the potential for helping countless numbers of people. This is not for everyone; and I would be the last person to make a judgment about a person's willingness to participate.

The more people who respond and participate in research about these disorders, the better our data, the more meaningful our conclusions

I hope we can demonstrate that we can rally our members to participate in studies, i.e., we are a good risk for a government grant, or a pharmaceutical company, or any organization to fund research on one of our disorders, because we are going to produce respondents or participants.

The more people who respond and participate in research about these disorders, the better our data, the more meaningful our conclusions. Please get involved in research if you can, both through the TMA and other institutions. The future of research on these disorders depends on it and our understanding of these disorders depends on it. For more information on clinical trials and research studies, please visit *https://myelitis.org/shaping-the-future/research/clinical-studies-trials*.

Please take care of yourselves and each other,
Sandy

With Gratitude – Evelyn Marks

Evelyn Marks, a member of the TMA, recently passed away and left the TMA a kind and generous donation from her estate. Sadly, we do not know much about Evelyn and have not been able to locate her family to express our gratitude and our condolences. If anyone knew Evelyn, we would greatly appreciate you contacting us at info@myelitis.org so that we can pay our respects to her family and friends and to use her gift to honor her life.

We have grown!

TIMI SCHRUMPF

My path to joining the TMA was certainly different from so many others. I am not affected by a rare neuro-immune disorder nor am I a caregiver. I do, however, know that either of these factors could change in the blink of an eye. I'm a firm believer in living in such a way that you take nothing for granted; you don't have a clue when something could change your whole course. My course changed when what I thought would be a typical 30-minute interview turned into a three-hour conversation with the TMA President, Sandy Siegel. Since that morning, I had a feeling the course I was on was soon going to change, and I was correct!

I've been with the TMA for about a month now, and almost every day I hear a new story involving someone whose life was altered due to the diagnosis of one of these rare disorders. While these accounts are sometimes saddening and often times difficult, they are always inspiring. As Community Partnerships Manager, it is my mission to draw from the sadness, difficulty and other less-than-great feelings that come with a diagnosis and turn them into inspiration and advancement for our community as a whole. One way I will do this is by truly focusing on the central word in my title: partnerships. Whether through the formation of additional support groups, developing relationships with medical establishments or something seemingly as simple as introducing one family to another, I want every member of the TMA to truly feel as though they are in a partnership, working together for the greater good.

There are countless people who diligently try to keep their professional lives and personal lives compartmentalized, never wanting the two areas of life to intersect. I consider myself fortunate that I do not feel this way, instead, it is the complete opposite. This work I am doing is making me a more conscious-minded person, my colleagues are empowering me, and our community is a constant source of motivation. I recently was reminded of a quote from Henry Ford: "coming together is a beginning, keeping together is progress and working together is success." I look forward to great success with each of you!

ERIN CORIELL

In late June, I was contacted by the President of the Transverse Myelitis Association, Sandy Siegel. His email was in response to an application that I had submitted a few weeks prior. Sandy kindly introduced himself and shared that his wife had been diagnosed with TM in 1994. I experienced a special feeling inside after reading that particular line of the email. It

Timi Schrumpf | Community Partnerships Manager

As Community Partnerships Manager, Timi's mission is to build a robust global support network, raise community awareness and engagement, and foster mutually beneficial partnerships. Prior to joining the TMA, Timi worked in several industries including healthcare, economic development and governmental affairs, with a focus on strong relationship management and global client services. Timi is passionate about accessible healthcare, equal rights, and people. She holds a Bachelors in international studies and political science and a Masters in organizational communication with a specialized research focus in cross-cultural communication.

prompted me to visit the TMA website, in order to learn more about Sandy's story and mission.

What struck me the most about the TMA is the heartfelt dedication to provide resources and support for individuals who are newly diagnosed with rare neuro-immune disorders. When you visit the TMA website, you are not just given information and then sent on your way. The love and compassion for each new member is palpable. I immediately wanted to become a part of this extraordinary organization.

While reading a member's story, I was reminded of the first time I saw a neurologist. I was sixteen and a sophomore in high school. I had been experiencing a full body twitch and had undergone several tests for a better understanding of what was causing this involuntary movement. The final diagnosis: a neurological tic.

I felt embarrassed and often isolated because of my tic disorder. I had to accept that I would never be able to carry a full cup of tea without spilling it and that my penmanship would always look like chicken scratch. The acceptance did not come easily or quickly. However, over time I learned to embrace this aspect of my body. I learned to love every involuntary movement.

After interviewing with each staff member of the TMA, I was excited for the possibility to become part of a professional organization that recognizes and embraces these disorders with compassion and empathy. It felt a lot like coming home.

It brings me tremendous joy to share that I have been welcomed into the Transverse Myelitis Association family. As the Education and Digital Media Manager, I am excited to engage with the TMA community, build new education efforts, and increase the awareness of rare neuro-immune disorders. I look forward to growing with the team, as we work together to improve the quality of life for those who are living and affected by rare neuro-immune disorders.

In August, I will be attending the 2016 Regional Rare Neuro-Immune Disorders Symposium. This will be my first event of many to come. I look forward to meeting the community and learning more about these disorders.

I am in deep gratitude for the opportunity to serve in this capacity.

Erin Coriell | Community Education & Digital Media Manager

As the Community Education and Digital Media Manager, Erin's mission is to build new education efforts and to increase the awareness of rare neuro-immune disorders. Erin is passionate about improving quality of life, human rights, and end-of-life care advocacy. She is an optimist with an eclectic background in communications and digital content management. For the last seven years, Erin has contributed her technical skills to an array of non-profit organizations. She copes with a neurological twitch daily and is eager to serve the TMA community.

REFLECTIONS ON THE FIRST TMA MICHIGAN SUPPORT GROUP MEETING

Cynthia Wang, MD | Pediatric neurology resident at Mott Children's Hospital, University of Michigan Health System

Thank you to the individuals who attended the first Michigan TMA support group meeting! It was a pleasure to meet you and learn a little about your initial experiences and ongoing struggles with transverse myelitis.

As a pediatric neurology resident about to embark on my Fellowship training in rare neuro-immune disorders through the generous support of the TMA's James T. Lubin Clinician Scientist Fellowship Award, I was extremely grateful to be able to hear your stories. It reinforced some notions I had about transverse myelitis, but also opened my eyes to lessons linked to firsthand experience of the condition. Several themes emerged during our conversation that left an impression on me.

MISDIAGNOSIS HAPPENS FREQUENTLY

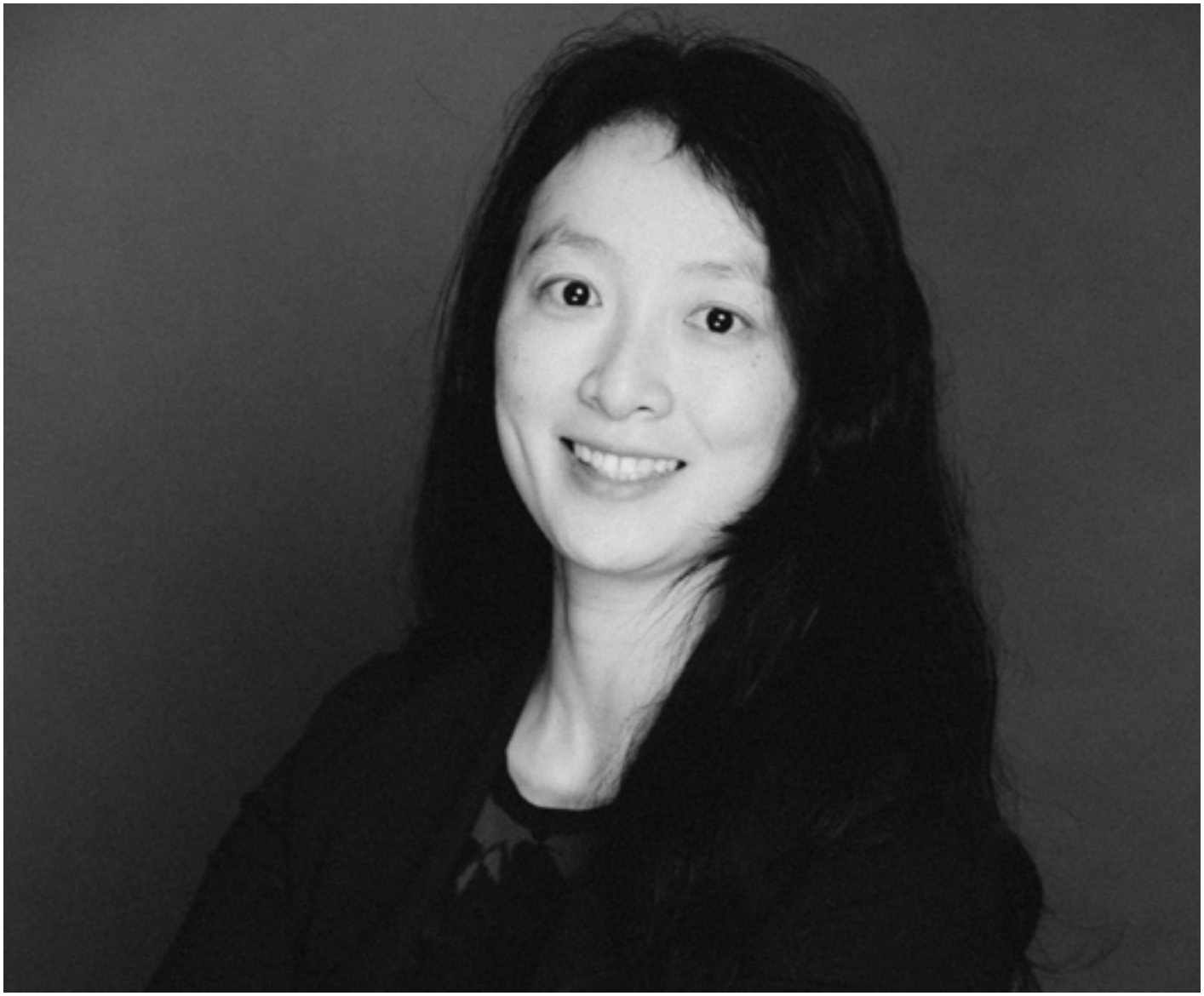
As transverse myelitis is a rare disorder, it was not unexpected that many of our attendees were initially misdiagnosed with more common conditions: muscle strain, a pinched nerve, a viral illness. However, I was surprised that misdiagnosis often occurred multiple times. It did not matter whether individuals lived near a small community hospital or a large academic medical center; it sometimes required a second, third, or fourth opinion before the correct diagnosis was made. Fortunately, many of our attendees continued to press the medical community when things did not add up and advocate for themselves and their loved ones. Later, they spread awareness about the condition to their friends and family in hopes it would benefit others. As a physician, I left with an even stronger commitment to educating my peers, especially those at the frontlines, who may be able to recognize TM faster and provide earlier treatment.

TM STRIKES QUICKLY BUT CAN IMPROVE SLOWLY

Many of the individuals at our meeting described how quickly their symptoms evolved, i.e. what started as a slight backache quickly turned to difficulty walking, numbness below the waist, and paralysis of all four limbs. In contrast to the speed in which their symptoms began, the recovery from TM was often slow and laborious, requiring many hours of intensive inpatient rehabilitation and long regimens of outpatient therapies. The consequences of these efforts may not appear quickly, but their impact becomes clear over time. Even years after their TM diagnosis, some attendees were still finding new ways to improve their function, reduce pain, and better cope with their residual symptoms. As a medical provider, I feel I can sometimes better appreciate the improvement that my patients make with the time that passes between clinic visits, and hope to remind families to keep pushing as their efforts are paying off.

TREATMENTS FOR TM ARE LACKING

How TM is treated can vary greatly. Medications that suppress the immune system such as steroids, IV immunoglobulin and plasmapheresis are frequently used first-line therapies. However, choosing the type, dosing, and duration of treatment currently resembles art more than science. Long-term treatments for the complications



Dr. Cynthia Wang

of TM such as spasticity, bowel and bladder dysfunction are even more variable and less well studied. For many of our group members, finding the right therapy is a trial and error process. Yet, I was pleased to learn that several of our attendees discovered similarities in the types of treatments that worked for them. Some were therapies I knew little about. I believe this collective knowledge is extremely powerful, and could be harnessed through rigorous research studies to see if they have the potential to benefit the greater TMA community.

From this meeting, I take away some of these lessons above and hope to improve the care of those affected by TM and other rare neuro-immune disorders, NMOSD, and ADEM, by educating medical professionals and patients, advocating for long-term therapies, and conducting clinically relevant research on what impacts the outcomes of TM.

I left the meeting reminded of a quote from Margaret Mead,

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

I am so grateful to become a citizen of our small yet mighty community, and hope that together we can make huge strides in improving the quality of life of those affected by TM, NMOSD, ADEM and related conditions.

DR. MICHAEL SWEENEY TMA JAMES T. LUBIN FELLOW COMPLETES HIS TRAINING

Last July, the James T. Lubin Clinician Scientist fellowship was awarded to Dr. Michael Sweeney, at the University of Utah. Thanks to the generous support from our community, this fellowship training has allowed him the opportunity to learn about a wide spectrum of rare neuro-immune disorders from current leaders in the field, including Drs. Stacey Clardy, John Rose, Mateo Paz Soldan, Dana DeWitt at University of Utah. Additionally, he devoted time in the Pediatric Neurology and Rheumatology clinics at Primary Children's Hospital in Utah. Dr. Sweeney had the unique opportunity to learn about clinical tests at ARUP laboratories, a worldwide leader in innovative laboratory research and development. This provided him with exposure to the limitations of tests and to best practices when explaining these complex tests to patients.

Dr. Sweeney spent one month at University of Texas Southwestern as part of his training, under the direct supervision of Dr. Benjamin Greenberg. During this time, he attended the pediatric demyelinating clinic, and saw many patients with TM, NMOSD, and ADEM and gained insight into yet another philosophy on the treatment and paradigm in these patients. This provided him with extremely beneficial insight into how a multidisciplinary clinic can be set up in order to treat pediatric patients with complex neuro-immune disorders. Here, he also gained insight into logistics and research collaboration.

The fellowship provided Dr. Sweeney with a diverse clinical and research training environment. Dr. Sweeney shared that because of this fellowship he has learned important lessons in the establishment and management of clinical trials and first-hand about the challenges of studying rare neuro-immune disorders, as well as effective approaches to overcoming these challenges. Dr. Sweeney has connected with many providers across the country specializing in these rare disorders, and he will continue to work in collaboration with these researchers in his new position at the University of Louisville and Kosair Children's Hospital starting August 2016.

Dr. Sweeney's dedication to the rare-neuro immune disorder community will extend beyond his fellowship time. This fellowship has allowed him to develop his research and become more intimate with the challenges faced when studying these rare-neuro immune disorders.

Thank you Dr. Stacey Clardy and Dr. Michael Sweeney for continuing to support and care for our community.

Dr. Sweeney at the 2015 Annual TMA Quality of Life Camp

Pregnancy outcomes in neuromyelitis optica spectrum disorder

A recently published study looked at pregnancy outcomes in individuals with aquaporin-4-positive (AQP4) neuromyelitis optica spectrum disorder (NMOSD). Studying pregnancy in NMOSD is important because NMOSD is more common in women and often occurs during childbearing years.

60 women with a history of at least one pregnancy who had AQP4-positive NMOSD from three countries (UK, Portugal, and Japan) were enrolled in the study. The researchers looked at pregnancy outcomes, including miscarriage and preeclampsia. Miscarriage was defined as a spontaneous loss of pregnancy during the first 24 weeks of pregnancy. Preeclampsia occurs when there is high blood pressure in pregnancy and protein in urine.

NMOSD disease onset occurred at an average age of 46.4 years. Onset was with optic neuritis in 42% of the women, transverse myelitis in 38% of the women, and brain lesions in 18% of the women.

The study included data from 85 pregnancies from 40 women in the miscarriage part of the study. 71 pregnancies occurred before NMOSD onset and 14 pregnancies occurred after NMOSD onset. Eleven pregnancies in total (12.9%) in 6 women ended in miscarriage, which is not different from the miscarriage rate in the general population.

In this study, the miscarriage rate was found to be higher after the onset of NMOSD (42.9%) than before NMOSD onset (7.04%). There was also an increased odds of miscarriage in pregnancies after or in the three years before the onset of NMOSD, even when controlling for older maternal age and miscarriage in the most recent pregnancy. The miscarriage rate also differed by race: the miscarriage rate after NMOSD onset was 60% in Caucasian women and 0% in Afro-Caribbean women. The NMOSD relapse rate in the

preconception and intrapregnancy period was higher in pregnancies that ended in miscarriage compared with pregnancies that did not end in miscarriage after NMOSD onset. These women were also more likely to be receiving treatment for NMOSD, but the miscarriages were not from the medication. These women had more attacks which made them more likely to be receiving treatment.

The study included data from 113 pregnancies from 57 women in the preeclampsia part of the study. 13 cases (11.5%) of preeclampsia occurred. NMOSD onset was not a risk factor for preeclampsia, although the rate of preeclampsia was higher in the study participants than in the overall population. In particular, the study reported that the odds of preeclampsia were greater in women who had multiple other autoimmune conditions or who had had a miscarriage in their most recent pregnancy.

Annualized relapse rates (ARR) were also calculated. Pregnancies that didn't end in miscarriage were associated with a significantly increased average ARR in the first 3 months after birth compared with the average ARR up to 9 months before conception.

The authors state that it is possible that AQP4 can contribute to miscarriage risk because of the results of this study and other studies done on animals, but they state that further studies are needed in this population. It also appears as though some women were prone to miscarriage in this study. Of note, in this study, the number of women TREATED before and during pregnancy were too small to determine if the rates of miscarriage could be lowered by using treatment. As a result, the data set in this study is too small to base decisions on, but should be taken into account when consulting with a neurologist about pregnancy planning.

Original publication: LNour MM, Nakashima I, Coutinho E et al. Pregnancy outcomes in aquaporin-4-positive neuromyelitis optica spectrum disorder. *Neurology*. 2015;86(1):79-87.

Re-analysis of metagenomic sequences from acute flaccid myelitis patients reveals alternatives to enterovirus D68 infection

A summary of the article by Greninger et al. "A novel outbreak enterovirus D68 strain associated with acute flaccid myelitis cases in the USA (2012–14): a retrospective cohort study" was published on the TMA Blog on November 6, 2015.

Breitweiser, Pardo, and Salzberg recently published an article that re-analyzed data from this study. They used data available from metagenomic shotgun sequencing to re-analyze 31 samples from the prior study published by Greninger et. al. Metagenomic sequencing analysis is when DNA or RNA, the genetic material for organisms, is taken from human samples and analyzed to see if there is DNA from bacterial or viral pathogens. The original study had looked at 48 samples from patients who went to Children's Hospital Colorado or Children's Hospital Los Angeles from November 24, 2013 to October 11, 2014, or individuals who were identified by the California Department of Public Health between January 1, 2012 and October 4, 2014. 25 of them were diagnosed with Acute Flaccid Myelitis (AFM), two with enterovirus-associated encephalitis (inflammation of the brain), five had enterovirus D68-associated upper respiratory illness, and 16 had aseptic meningitis or encephalitis and also tested positive for enterovirus. Breitweiser, Pardo, and Salzberg found in their re-analysis two samples which had more sequences of bacteria than enterovirus D68. One individual without AFM had bacterial sequences from Haemophilus influenza. The other individual did have AFM, and had bacterial sequences from Staphylococcus aureus. Prior studies have shown that S. aureus may be associated with neurological problems like myelitis and meningitis. The authors suggest that while they can't know whether these bacterial infections contributed to the two individuals' symptoms, they argue that they should be considered as a potential factor that led to their symptoms. Furthermore, they found that the data they downloaded had a lot of human DNA in it even though the authors of the original articles stated they removed human DNA. The authors note that this is a common problem in this type of research though. The authors also stated that it is important for researchers to release gene sequencing data so that other researchers can verify the results of studies.

Original Article: Breitwieser FP, Pardo CA and Salzberg SL. Re-analysis of metagenomic sequences from acute flaccid myelitis patients reveals alternatives to enterovirus D68 infection [version 2; referees: 2 approved] ***F1000Research*** **2015, 4:180.**

An update from UTSW's TM and NMO Center

On January 1st, 2016, we had the privilege to award the University of Texas Southwestern's TM and NMO Center a TMA Grant. The one-year grant is being utilized to support the staffing and provide resources for a longitudinal study collecting samples and data from children with rare neuro-immune disorders. The grant provides support to a research nurse within the Children's Hospital who identifies and enrolls these children and a new laboratory technician who manages the sample/data collected. With this grant, since the beginning of the year, 25 children with pediatric rare neuro-immune disorders have been enrolled, growing their database to better understand these rare disorders.

The TMA feels confident that the cutting-edge research being conducted by this grant at this center is both thorough and necessary. Every piece of data provides us with a glimpse into potential treatments and cures for ADEM, NMOSD, ON, and TM, including AFM.

All of the above is made possible through the generosity of our community and their support. Our hope is to continue to fund these incredible research endeavors.

A JOURNEY I NEVER IMAGINED

Lynn Nelson

Six years ago this month I began a journey I never imagined. I was an amateur marathoner who started running at age 49 for a charity in support of a friend who was diagnosed with an incurable form of lymphoma. After I finished my first marathon, I was hooked. I was on my way to completing my goal of 5 full marathons and 10 half marathons by my 55th birthday when I started having health troubles of my own.

Photo taken as I crossed the finish line of the PF Chang Marathon. It was during training for that race that I learned I had TM. Crossing that finish line meant the world to me.

I had been experiencing tingling down my legs intermittently for two years whenever I went for a run. I had consulted a doctor but my symptoms were not significant to arrive at a conclusive diagnosis. One day in July, 2010 I woke up with tingling feeling in both my feet. The feeling was so intense I was unable to sleep at night. I decided it was time to see my doctor again. I learned what I called a weird feeling in my feet had a name: neuropathy. My doctor initially thought I had Lyme disease, but the test results came back negative. She then referred me to a neurologist. It was September and the neuropathy in my feet and legs had lessened. I was training for another marathon and didn't want to take time to see the neurologist. My body had other ideas. As I warmed up for a training run one Saturday morning in November, my legs stopped working. It was as if they were paralyzed (I learned later that these were muscle spasms). The following Monday I scheduled that overdue appointment with the neurologist.

It took several months for me to complete all the tests necessary to diagnose what I had - nerve tests, MRIs, a spinal tap, and lots of blood work. The neurologist explained I had one of three things: transverse myelitis (TM), multiple sclerosis, or cancer, although he was fairly certain that I had TM. While I was undergoing tests, I started reading all the available information that I could find about TM on the TMA and other websites. I have always believed that informaton is power. The more I know, the more I feel like I am in control.

During this period, a friend told me that I would be the one who would find out why I was having episodes of muscle spasms. There wasn't going to be a "Dr. House" who would send a team of doctors to my home to discover some strange chemical there that was causing my symptoms. With this in mind, I started doing my own research. I started keeping a diary of everything I ate, drugs that I took, and shots that I received. I printed out a calendar and noted every day where I experienced muscle spasms; received an allergy shot or a flu shot; or took a drug. I quickly discovered I experienced muscle spasms within 1-2 days of getting an allergy shot. I shared my calendar with my neurologist. We agreed that I would discontinue allergy shots (I only had one more episode of muscle spasms and then they ceased entirely).

When I ultimately received a diagnosis of TM, I decided I was not going to let TM define my life. I was treated with steroids and my symptoms slowly diminished. I wanted to continue running, an activity I enjoyed immensely, but my neurologist was not supportive. He told me to resume running slowly but stop if I saw my symptoms reappear. Memories of my muscle spasms also held me back. It was through a supportive running group that I gained the confidence to run again.

When I ultimately received a diagnosis of TM, I decided I was not going to let TM define my life

I have to take extra precautions when running in hot weather. Overheating can cause my TM symptoms to reappear as they did when I had a fever during a bout of the flu a few years ago (this is called Uhthoff's Phenomenon). I have several methods of coping with the heat including wearing neck gaiter filled with ice cubes to keep my core cool.

I have since completed 12 full marathons and 42 half marathons. I have found that running minimizes my TM symptoms. In fact, I read an article on the TMA website stating "exercise can promote functional recovery." My neurologist who previously was not supportive of my running ambitions now tells me to run every race that I want to run. I have set a new goal of completing a full or half marathon in each of the 50 states (only 17 more states to go).

None of us knows what the future holds for us health wise. TM may rear its ugly head again in my life. That possibility keeps me moving. Through this unexpected journey, I have learned that it is important to be an informed patient and work as a partner with my doctor in managing my care. It is also important to support organizations such as the TMA that are involved in identifying causes of and researching cures for demyelinating conditions.

se join us at t

Wednesday June

from 5–8 PM

e are excited to announce that the Destin, FL Chick-Fil-A will be donating a
ercentage of it's proceeds on Wednesday, June 22 to the Transverse Myelitis
Association for NMO.

Neuromyelitis Optica (NMO) is a rare auto immune disease that attacks the centr
nervous system and can cause paralysis and blindness. The Transverse Myelitis
Association is dedicating to supporting and advocating for individuals and their
families who have been diagnosed with rare demyelinating diseases.

The decision to partner with the Transverse Myelitis Association came from a
personal family crisis. Our daughter was diagnosed with NMO in July 2010. Since
Overnight she lost her sight in one eye and began to lose function in her legs. Since
that time, she has made some recovery but must undergo chemotherapy treatments
every six months. We have met with many clinicians and
researchers in order to understand this disease, but we
have found that one of the most supportive sources was
the Transverse Myelitis Association. In addition, the
Transverse Myelitis Association hosts a summer camp for
children diagnosed with Transverse Myelitis and NMO
that our daughter attends every year. We are very grateful
to have found support and advocates through the
Transverse Myelitis Association!

The Thomas Family

Transverse Myelitis
iation

THE TMA F

A CHANCE TO GIVE BACK

Brooke & Eric Thomas

Dear TMA Families,

In July of 2010 our daughter was diagnosed with neuromyelitis optica spectrum disorder. Since 2008, she has experienced several attacks of the disease and it affected her spinal cord, brain, and vision. The Transverse Myelitis Association graciously took our daughter with NMO under their wing. The TMA hosts a family camp every summer for children that have been diagnosed with TM, NMOSD, ADEM, ON, and AFM. We have attended camp for the last 3 years. Our family loves the TMA camp! Our daughter has had the rare opportunity to meet kids who have similar experiences and diseases, and we have had the chance to meet supportive parents and knowledgeable doctors.

Because the TMA has helped us, we have been looking for a chance to give back. On June 22, 2016 our family hosted a TMA night at our local Chick-Fil-A. Many restaurants have fundraising opportunities and will give a portion of their proceeds to charities. We chose Chick-Fil-A because they donated a percentage of the evening's profit, and customers did not have to say they were there for TMA night. We also asked a local vacation rental business if they would donate anything to be silent auctioned for the TMA. They donated a 2 night stay in a condo. In total we raised $308 for the Transverse Myelitis Association. This isn't a huge amount of money but the thought occurred to me that if several of the families who have been helped by the TMA had their own TMA fundraisers, collectively we could raise a large amount of money.

With your involvement, we can turn a small donation into a huge one. If you are looking for ways to give back to the TMA, the restaurant fundraiser was a great option and was very easy to do.
For those who are thinking about it, here's what we did:

- We went in person to our local Chick-Fil-A and asked to speak with the manager.
- We introduced ourselves and our child and asked if we could do a fundraiser night for our charity. We told them a little about the Transverse Myelitis Association and about our daughter.
- Our Chick-Fil-A gave us a few dates to choose from and we chose an evening that worked best for us.
- We contacted the TMA and let them know about our fundraiser date, and they posted on the TMA website and on Facebook.
- We made a small poster (8x10 inches) in Microsoft Word inviting people to attend our fundraiser. We included the date, time, and a little info about the Transverse Myelitis Association and how NMO has affected our child.
- We brought the poster to Chick-Fil-A a week before the event. Chick-Fil-A displayed it on their bulletin board.
- We advertised the event on our own Facebook pages and invited friends and family.
- On the day of the fundraiser, we brought TMA brochures and donation envelopes with us to the restaurant. Our Chick-Fil-A set up a small table by the entrance and we placed all of the TMA items on it along with another copy of our poster.
- Our fundraiser was from 5-8pm. We enjoyed eating with friends and family that attended!
- The day after the fundraiser, I called Chick-Fil-A and asked them what the total amount donated would be and if they would be sending the check directly to TMA. I made sure that I left a donation envelope from the TMA for them to put the check into. The tax ID# for the TMA is EIN 91-1780467 and it is a 501(c)(3) organization. All of this information is also available on the TMA website.
- After getting the total donation amount, I sent an email to TMA and let them know to expect a donation.

And that's it! **Happy fundraising!**

If you would like to fundraise for the TMA, please email Timi Schrumpf at tschrumpf@myelitis.org with your ideas and share your story. The TMA will work with you in communicating about the event and help organize it with you.

CLINICAL STUDIES & TRIALS

For more information, please visit bitly.com/tma-trials

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

Principal Investigator: Benjamin Greenberg, MD, MHS
Lead Study Site: University of Texas Southwestern
Study includes online and multiple study sites

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

Study Sponsor: Chugai Pharmaceuticals

3 **Safety and Efficacy of Sustained release Dalfampridine in Transverse Myelitis**

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

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

Study Sponsor: Astrazeneca

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

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

6 **A Safety, Tolerability and Efficacy Study of V158866 in Central Neuropathic Pain Following Spinal Cord Injury**

Principal Investigator: Christine N. Sang, MD, MPH
Study Site: Brigham and Women's Hospital

7 A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

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

8 FES Impact on CNS Growth Factors in TM, NMO and other, Neuroinflammatory Disorders

Principal Investigator: Daniel Becker, MD
Study Site: Hugo W. Moser Research Institute

9 The PREVENT Study

Study Sponsor: Alexion Pharmaceuticals

10 The Effect of Pregnancy on Neuromyelitis Optica

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

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

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

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

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

13 Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis

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

1

An innovative, multi-center, pediatric transverse myelitis study led by Dr. Benjamin Greenberg, MD, MHS, Director of the TM and NMO Center at UTSW in Dallas, TX. The study is the first to combine assessments from health care providers and patients relative to pediatric TM outcomes. The collaboration involves multiple health care centers across North America, the Transverse Myelitis Association and most importantly, patients. The study is designed to assess the current state of Pediatric TM (including AFM or Acute Flaccid Myelitis) in terms of diagnosis, treatment and outcomes. Ultimately, it will lead to an improved understanding of the current status of care for individuals afflicted with TM and reveal what are the current best practices. 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 in this study may involve travel to one of the five participating centers, whichever is closest to the patient geographically (or enrollment into the virtual cohort if travel is not possible), at 3 month, 6 month, and 12 month intervals. It will include a review of treatment records, imaging, and an examination by a physician. Internet access is required for completion of questionnaires by the child and/or parents.

2

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

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

3

The goal of this clinical trial is to test the efficacy of dalfampridine in patients diagnosed with Transverse Myelitis. Dalfampridine is a sustained-release potassium channel blocker that has been shown to be effective in improving gait and other neurologic functions in multiple sclerosis. Dalfampridine has the potential to improve gait and neurologic function in patients with transverse myelitis because of a similar pathogenic process with multiple sclerosis.

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

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

4

The main objective of this study is to determine if MEDI-551 can significantly delay the time it takes for a new NMO/NMOSD attack to occur. This is a multinational randomized, double-masked, placebo-controlled study with an open-label period. "Double-masked" means that neither the patient nor the study staff (for example, the doctor/nurse) know the identity of the study drug they are receiving (either MEDI-551 or placebo). Placebo-controlled means that some patients will receive MEDI-551 and some will receive placebo, an inactive substance designed to look like MEDI-551. Eligible NMO/NMOSD patients will be "randomized" in a 3:1 ratio to received either MEDI-551 or placebo. This random selection is made by a computer and will give a 25% (1 in 4) chance of getting placebo and a 75% (3 in 4) chance of getting MEDI-551. "Open label" means a period in the study where there is no placebo arm and all patients receive MEDI-551.

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

5

Our objectives are to better understand pain involvement in children with myelitis and to develop diagnostic imaging techniques to detect different demyelinating stages of myelitis. The study takes place on-site at Boston Children's Hospital and includes pain sensitivity testing and two MRI scans of the spinal cord, without contrast injections. Each study session takes approximately 3.5 hours. Participants will receive a $100 Visa gift card. They will also receive an additional $10 gift card each time they refer a friend who qualifies for the study as a healthy volunteer.

6

V158866 is an active inhibitor of FAAH1, an enzyme that metabolizes the endocannabinoid called Anandamide (AEA). It is hypothesized that inhibition of FAAH1 can decrease pain without generating side effects in non-activated pathways. Therefore, the primary objective of this study is to investigate the safety and tolerability of V158866 in subjects with central neuropathic pain following spinal cord injury (both traumatic and non-traumatic) and evaluate its analgesic and anti-hyperalgesic effect. The study will consist of four overnight visits to the hospital. All travel to and from the hospital will be reimbursed.

7

This observational study seeks to determine the biologic causes of inflammation in patients with Neuromyelitis Optica (NMO), Neuromyelitis Optica Spectrum Disorder, Transverse Myelitis and Optic Neuritis. While patients will be treated according to decisions with their treating physician, this study will collect data and samples from patients prospectively to gain a better understanding of the disease. The study is seeking to understand why some patients respond to medications, while others do not; and what happens biologically, preceding relapses. Gathering these data and samples will allow researchers to identify new ways of diagnosing and treating these diseases. Data and samples will be shared with researchers around the world to support collaborative efforts to treat these conditions.

8

This research is being conducted to evaluate change in function (spasticity, strength, and sensation) in individuals with inflammatory myelopathies in response to functional electrical stimulation (FES) cycling therapy. The study will also evaluate the changes in CSF growth factors, neurotrophins, and inflammatory cytokines in response to FES stimulation.

A correlation between changes in function and changes in the cerebrospinal fluid (CSF) neurotrophic/inflammatory milieu will provide evidence of biochemical changes that may mediate neurological repair following FES cycle therapy. This data will be crucial for the design of a phase 2/3 clinical trial evaluating the efficacy of FES in patients with inflammatory myelopathies.

9

Alexion Pharmaceuticals is conducting a clinical trial called the PREVENT Study. The primary objective of the study is to assess the efficacy and safety of an investigational medicine as a potential treatment to prevent relapses in NMO and NMO Spectrum Disorder (NMOSD). This is a randomized double blind study, where participants will receive investigational medication or placebo and neither the participant nor the study doctor or their staff will know who received the drug or placebo. In this study, 2 out of 3 participants will receive investigational medication and 1 out of 3 participants will receive placebo. The medication is given intravenously at the study doctor's office or infusion center.

10

This research is being conducted to study the effect of pregnancy on Neuromyelitis Optica (NMO). It commonly affects females of childbearing age. To date, women's health issues in NMO have not been studied in detail. Determining the effect of pregnancy on the NMO disease course is of great importance in counseling patients on family planning. Information will also be gathered on the incidence of complications of pregnancy and the incidence of miscarriages.

11

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

12

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

SCI Hard is a mobile game designed to help teens and young adults with spinal cord injury (SCI) and other spinal cord impairments improve their ability to manage their health and interact with others. The game can be downloaded to Apple or Android mobile devices and takes about five hours to complete. The goal of the game is for players to be able to manage their health and prevent complications so they can achieve independence, get out into the community, and save the world.

We are currently recruiting research participants, 13 to 29 years old, with transverse myelitis, SCI, spina bifida, or related impairments of the spinal cord. Participants will complete a set of online surveys three times over three months and will be expected to download and play their assigned mobile game (either SCI Hard or another game). If they complete all parts of the study, they will be eligible to earn up to $100.

13

Based on previous research showing cognitive problems in transverse myelitis, a pilot study was designed to further investigate this observation. This is a study that utilizes brain imaging to understand cognitive dysfunction in transverse myelitis. Data will be acquired through MRI scan of the brain, optical coherence tomography (OCT), and neuropsychological evaluation.

THANK YOU FOR MAKING THE 2016 WALK-RUN-N-ROLL CAMPAIGN A REALITY

_Ohio

The first ever Ohio Walk-Run-Roll for the TMA was held on May 21, 2016. About 70 brave souls from our community came together on a very soggy Saturday morning from across the state of Ohio and from Kentucky. Most of the morning was spent under the shelter of the Coffman Pavilion in Dublin eating breakfast and visiting. For many of the participants, it was a first opportunity to meet another person who had one of the rare neuro-immune disorders. It was a great time for people to share their experiences. And we did have a walk and roll in the rain, led by some of the children. There were many family members and friends who attended the event, and it was great to experience all of the support people were receiving from their loved ones. We raised over $12,000 from the event.

A special thank you to Barbara Ferguson and Mark McCloskey for all of their hard work in planning and organizing the event. The walk wouldn't have been possible without them. We also want to thank our wonderful sponsors!

We are in the process of planning next year's event which will be held on May 13th, 2017 at Coffman Pavilion in Dublin, Ohio. If you are interested in getting involved in the planning process or would like to start a fundraising team, please get in touch with Sandy Siegel at *ssiegel@myelitis.org*. Thank you for your willingness to make a difference!

Sandy Siegel

A special thank you to our sponsors:

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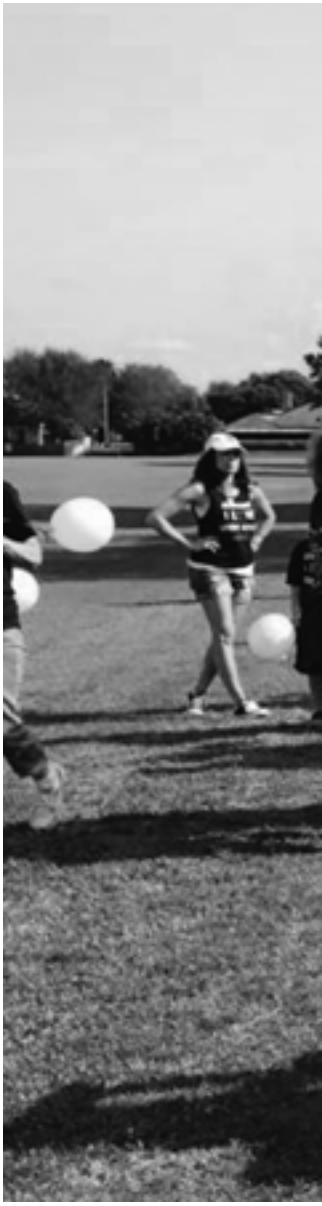
__New Jersey

The 2016 New Jersey Walk-Run-N-Roll took place on Saturday, April 30th at Cooper River Park. It was a beautiful, sunny day. 100 people attended, 15 of whom were people with a diagnosis of a rare neuro-immune disorder. Colleen Spaeth, one of the volunteer leaders of the event shared "the most significant happening to me was the number of TMers that came out...that is of utmost importance, because the more support we have from our community members who understand what we are all going through whether we walk or not...this awful journey...the easier it is ..." The stories of those in attendance were posted on a bulletin board so that the attendees could read and learn about these disorders. Overall, it was a wonderful event, that raised over $14,000 dollars. We thank Colleen Spaeth and Patty Holston for leading the awareness events, their friends and families and the community for supporting our mission and increasing awareness about rare neuro-immune disorders!

GG deFiebre


Myelitis



Florida

I attended the 3rd Annual Central Florida Dinner and Walk hosted by the Robbins Family to support the TMA. Once again the Robbins put on an unforgettable event.

It started on Thursday night when I was invited to dinner at the Robbins home and had a chance to spend time with their family. Sarah is at the heart of the event. I met her last year at the walk and wondered if she remembered me, after all there were a couple hundred people there. When our eyes met she gave me her wonderful smile and a big, long hug. However, Sarah gives almost everyone smiles and hugs. I still think she remembers me.

All the Robbins children are gracious . Their oldest, Zach, 16, is a powerhouse already following in his parents' footprints. He is an actor with an equity card who has been in a Netflix series. Tina cooked a terrific Italian dinner. I don't know how Jason and Tina have the energy to put on this event with all their other responsibilities.

Friday I spent the day on the beach. I love that dogs are allowed. On the Pacific (where I've spent most of my beach time) there are only a few where dogs are not banned. I wished Pauline and Kazu were with me.

Friday night was the dinner and auctions. Chef Beau MacMillan from my home state of Arizona outdid himself. We started with a cauliflower appetizer (I don't like cauliflower and it was delicious), braised beef short ribs and scallops, and indescribable desserts. Lots of wine. There were terrific items to bid on such as trips, time at vacation homes, dinners, and sports memorabilia like a Magic Johnson Laker's jersey. Thanks to Doug Kerr for raising his hand often and buying lots of stuff.

For me the highlight of the event was seeing friends like Chitra Krishnan, Debbie and Michael Capen, Linda Malecky, Sandy Siegel, Doug Kerr and all the Robbins. Again I missed Pauline.

Saturday morning, we gathered at a park for the walk. Krispy Kreme donuts and coffee, and chicken tenders from Chick-Fil-A were all donated. A drone flew overhead taking pictures of the walk.

I loved the bright blue t-shirts from last year and I didn't think they could be better this year, but they were. The shirts were black and in bright blue letters, they read **someone I love needs a cure**.

Barbara Sattler, TMA Board Member

April 28, 2016 marked the 3rd Annual Central Florida Auction and Walk for Transverse Myelitis. I was fortunate to be among over one hundred guests in attendance along with Anjali Forber-Pratt, and we wanted to reflect on what being a part of such an amazing event meant.

As a newcomer to the TMA, I was honored to be invited as a guest after meeting the Robbins family at CCK camp in Kentucky last summer. As a close friend of TMA Board Member Dr. Anjali Forber-Pratt, I had heard nothing but good things about the event in

years past, and couldn't wait to experience it for myself. In Anjali's words, "I was so excited to return to Florida for this event after having attended last year, and was fortunate that Amanda McGrory was able to join me this year! It was wonderful to see how much the event had grown in size just since last year! I predict we're going to need a bigger room for the years to come!"

If one thing is for certain, the Robbins family knows how throw a party! It was truly remarkable to see the sheer number of individuals who came out to support Sarah, the entire Robbins family and the TMA. Some individuals were longtime friends of the Robbins family, some were therapists and professionals who work with Sarah, others were acquaintances just learning about transverse myelitis for the first time that night.

One of the definite highlights of the evening was the video put together by Sarah Robbins' brother and actor, Zach Robbins. It showcased Sarah's story, provided the audience with some educational information about transverse myelitis and helped to gear the audience up for the live auction part of the evening. The room erupted and jumped to their feet for a standing ovation for Sarah Robbins taking center stage. It still gives us goosebumps to think back to this moment and witnessing the entire room rallying to support Sarah and the TMA.

Dr. Doug Kerr spoke about the state of transverse myelitis research and then turned the mic over to me to share a bit about my story and experiences as a Paralympian. Anjali Forber-Pratt also shared a bit of her story with the audience before we enjoyed wonderful dinner prepared by celebrity Chef Beau MacMillan. Anjali explained, "One of the hallmarks of the evening is for attendees to get to meet those of us with transverse myelitis and to hear our stories. It helps donors to better understand how their money is used to support such an amazing organization and the work that the TMA does related to research, advocacy and community building."

After dinner, we all took to the dance floor to dance the rest of the evening away and continue to enjoy everyone's company. Many of us, Anjali and I included, went back

to the hotel for a short night of sleep to wake up early for the Walk-Run- N-Roll that weekend! Sarah Robbins kicked off the walk with both Anjali and I by her side and hundreds of other walkers and rollers following behind. It was a jam packed weekend filled with overwhelming love and support from the community.

Anjali and I would like to extend a huge thank you to the Robbins family, their planning committee and all who attended. In addition to being a ton of fun, the Central Florida Auction and Walk for Transverse Myelitis is one of the TMA's largest annual fundraisers, bringing in revenues close to $60,000, vital to the association's programming. We look forward to next year's event which will be held on Friday, June 2, 2017 at the Radisson at the Port Convention Center at Cape Canaveral, FL.

Amanda McGrory

Save the date! The 4th Annual Central Florida Dinner and Auction will be held on June 2, 2017! Contact Timi Schrumpf at tschrumpf@myelitis.org for early bird sponsorship and tickets!

Thank you to our corporate sponsors:

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Got You Covered, Terri Keeney
And all of our wonderful volunteers and friends

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2016 MASSACHUSETTS WALK-RUN-N-ROLL

Saturday, October 15, 2016 | Endicott Park, Danvers, MA

We are proud to announce the first 2016 Massachusetts Walk-Run-N-Roll benefiting the Transverse Myelitis Association (TMA) on Saturday October 15, 2016 located at Endicott Park, Danvers, Massachusetts in honor of our son Noah Holt. We hope to educate our community on rare neuro-immune disorders and raise funds for research and improve clinical care for patients and their families.

Noah was diagnosed with Acute Flaccid Myelitis (AFM) in October 2014 at 6 months of age. Without the clinical knowledge of how to treat AFM and intensive physical therapy Noah would not be where he is today. We are grateful for the innovative research and clinical care and support of the Transverse Myelitis Association to this rare neuro-immune disorders community.

Unfortunately, there is no way of preventing or early screening for rare neuro-immune disorders. The TMA's research agenda is focused on advancing the scientific understanding of and therapy development for these rare disorders by supporting the training of clinician-scientists dedicated to these rare disorders and by supporting basic and clinical research. The Transverse Myelitis Association is committed to promote awareness and to empower patients, families, clinicians and scientists through education programs and publications. This all ties in to support and advocate for individuals and their families diagnosed with rare neuro-immune disorders of the central nervous system.

We have made it our family's mission to take back Acute Flaccid Myelitis and increase awareness for all the individuals suffering from rare neuro-immune disorders: Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON) and Transverse Myelitis (TM), including Acute Flaccid Myelitis (AFM).

Please join us on Saturday October 15, 2016 at Endicott Park located in Danvers, Massachusetts to raise awareness and funds to continue to support ongoing clinical research needed for these disorders!

2016 MASSACHUSETTS WALK-RUN-N-ROLL FOR TMA COMMITTEE

Gayla Bartlett, Mitch & Elisa Holt
MAWalkRunNRoll.ForTMA@gmail.com
myelitis.org/event/2016-ma-walk-run-n-roll

TRANSVERSE MYELITIS AWARENESS DAY

BRISBANE, AUSTRALIA MAY 16, 2016

Louise Remilton

Spinal Life Australia hosted the seventh annual Transverse Myelitis Awareness Day on May 16, 2016 at our Brisbane office. We were pleased to welcome network members from Queensland, South Australia and New South Wales as well as members from all over Australia who were able to link up live via video to hear our keynote speakers and participate in the question and answer sessions.

Our thanks again to the Transverse Myelitis Association (TMA) for the use of their technology which enables our interactive connection to guest speakers from around the world and especially the patient and invaluable assistance of Jim Lubin.

Our first keynote speaker was Professor Benjamin Greenberg, Director of the Transverse Myelitis and Neuromyelitis Optica Program, University of Texas Southwestern in Dallas. Dr. Greenberg addressed the audience on a number of key issues including outcomes of recent research projects, diagnostic techniques and changes to both the acute and long term treatment of Transverse Myelitis (TM) and related rare neuro-immune disorders. The recording of this compelling presentation is available at *http://bit.ly/2awhYGy* and the power point slides that accompany the address can be obtained by emailing Jeanette Kretschmann at Spinal Life on *jkretschmann@spinal.com.au*.

Australia is in the process of gradually implementing the new National Disability Insurance Scheme (NDIS) which will replace all other public and private sector service and care providers. Renee Chad from Spinal Life Australia gave an interesting address regarding the roll out of the NDIS and how indiviuals can ensure they are ready for the scheme. While some people have found the transition period quite daunting, Renee was able to provide invaluable tips and reassurance that help and support is available to all from the team at Spinal Life Australia.

Sarah Corley and Nathan McCarthy, exercise physiologists from the Sporting Wheelies and Disabled Association Queensland, gave a dynamic and interactive presentation on the fully accessible gymnasium facilities and specialist rehabilitation and recreational activities available through the association. We were pleased to welcome and introduce Lillian Drummond to the event. Lillian is a practicing physiotherapist who has recently joined the Spinal Life team and is working in partnership with Sporting Wheelies to bring a wider range of activities and services to Queensland members.

TM Awareness Day 2016 was a successful event bringing together members from the TM network. The day provided the opportunity to expand member's knowledge of the disease and importantly facilitate informal social networking amongst the attendees. We were able to bring the exciting news that one of our local members has now made the Australian Paralympic swim team and hopes to represent Australia at the upcoming Rio Olympics. Rachael is a little shy but has promised to share some photos and details of her Olympic dream after the games in August. I look forward to sharing this and other stories in our next newsletter. In other network news from Australia, Jeanette Kretschmann and I are pleased to report that our visits to Sydney and Melbourne were well received in both states and brought members together for the very first time. We plan to continue these network events in most states and territories throughout the next year and acknowledge the generous support received from Spinal Life Australia which makes these events possible.

OUR PARALYMPIC EXPERIENCE

Amanda McGrory and Dr. Anjali Forber-Pratt

Photo: 800m at U.S. Paralympic Trials in Charlotte, NC. © Sam Shotick

Amanda McGrory (Beijing ’08, London ’12, Rio de Janeiro ’16) and Dr. Anjali Forber-Pratt (Beijing ’08, London ’12) were diagnosed with transverse myelitis at a young age. Anjali is also a member of the TMA Board of Directors. Olympic and Paralympic fever is upon us, and we wanted to share some of our current and past Paralympic experiences and encourage you to support Amanda McGrory and others from the TM, NMOSD, ADEM community who will be competing on Team USA in the Rio games.

Dr. Anjali Forber-Pratt


U.S. PARALYMPIC
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Forber-Pratt
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GETTING INVOLVED IN COMPETITIVE ATHLETICS

AFP: I got sick with TM as a baby at 4.5 months old in November of 1984. I was first introduced to the world of disabled sports when I was five years old. I was intrigued by seeing wheelchair racers competing in the Boston Marathon and wanted to get involved. I was so blown away by seeing wheelchair racers in the marathon that I dressed up on Halloween as the winner of the Boston Marathon for many consecutive years! There was a weekly Saturday sports clinic for kids with disabilities about 45 minutes away from my parent's house at the Massachusetts Hospital School in Canton, MA. At this clinic, I had the opportunity to try nearly every sport possible and took a strong liking to both track and downhill skiing. By the time I was nine years old, I went to compete at my first Junior Nationals hosted annually by Adaptive Sports USA for youth with disabilities.

AM: I was diagnosed with TM as a kindergartener in 1991. After noticing that I was struggling with my transition from able-bodied kid to wheelchair user, my parents started searching for ways to get me more involved in the disability community. They finally stumbled upon a grassroots wheelchair sports program starting up in Philadelphia, and after one practice, I was hooked. Despite being a scrawny little pipsqueak, "tenacious" is a word that was often used to describe me early in my sports career, and eventually that tenacity paid off, securing me an Athletics Scholarship to the University of Illinois in Urbana-Champaign.

GAMES EXPERIENCES

AFP: I made the decision to attend college at the University of Illinois in Urbana-Champaign, known for its accessibility and disabled sports programs. While there, actually just after I started graduate school, I decided to get more serious about my racing career and made my first national team in 2007 representing the USA at the Parapan American Games in Rio that year. I then was fortunate enough to earn a spot on the Paralympic Games team for Beijing in 2008 where I raced in the 100m, 200m, 400m and

4x100m relay and came home with two bronze medals in the 400m and 4x100m relay team with Amanda McGrory. If you can even imagine walking into a stadium of 91,000 screaming fans are all there to support you, your dream. The experience was incredible. It was literally a longtime childhood dream come true. I also competed on Team USA in London at the 2012 Paralympic Games in the 100m, 200m and 400m. And while London did not go the way I had hoped athletically, I came home with my best finish being 5th in the 200m, one of my most treasured memories from London is that two female athletes in my division (T53), one from Bermuda and one from Ghana, I had helped mentor and to get them involved in sports several years before, and they both were there on the start line for all my races!

AM: Like Anjali, my "competitive sports" career really began at the University of Illinois. Although the scholarship I received was basketball specific, I was able to dedicate my off-season to the wheelchair track team. Frustrated with lack of progress in my racing career, I decided it was time to focus more on basketball. Fast forward two years, lots of long conversations, and one gigantic bribe later, and all of the sudden I was a marathoner. I felt like I had finally found my calling as an athlete, and slowly, basketball, as well as my dreams of becoming a gold medalist sprinter, took a backseat to long distance racing. I qualified in 2008 (with Anjali) for my first Paralympic team, and was 100% pumped to race in Beijing. I returned home with four medals, including a gold in the 5000m (silver in the marathon, bronze in the 800m and bronze in the 4x100m relay). I spent the four years between games traveling the world and racing marathons, which has to be one of the coolest jobs ever. Unfortunately, despite qualifying for the London 2012 Games and feeling strong in the lead up, I came home empty handed - my best finish being 4th place in the marathon. Disappointed as I was in my performance, it gave me a good opportunity to reflect back on my goals, and set new ones for the future.

The experience was incredible. It was literally a longtime childhood dream come true

CHALLENGES IN THE LEAD UP TO 2016 U.S. PARALYMPIC TRIALS

AFP: I shared in a previous TMA Blog (*myelitis.org/blog*) about some of the medical complications I have had since competing in the London 2012 Paralympic Games. The short version is that since September of 2012, I have had five major spinal cord surgeries, and celebrated one year without any surgeries or hospitalizations a few weeks ago at the end of June 2016. That said, I can honestly say that I never in a million years thought that competitive wheelchair racing back at the Paralympic-caliber level was ever going to be a reality again. Having fought hard to simply regain basic life functioning and to have stable health, I was not sure that my body would tolerate the seating position in a racing wheelchair again, or if it would cause spikes in my nerve pain, or increase of spasms or what. Despite all of this uncertainty, once my health did finally stabilize, I began to realize just how much I missed competition and training and being active. I went to see Amanda McGrory and my coach Adam Bleakney at the University of Illinois, also now a Paralympic Training Center, in February to see if I could tolerate just sitting in a racing wheelchair again. I was extremely lucky to find out that I could! When I left Champaign in February, I was thrilled just to have this small piece of my past back again in the forefront. I started training again, not as rigorous as I would have liked, but I was also trying to be cautious to not create more medical problems for myself and to truly ease back into it. I built up my tolerance which started as only being able to sit in the racing chair for no more than 10 minutes at a time and slowly increased to being able to tolerate an hour+. I began pushing regularly about three times a week. In May, I wanted to get a benchmark of where I was at in terms of a time on the track, just for me. I competed in the Dixie Games in Florida, and surprised myself that I ran an entry standard for U.S. Paralympic Track and Field Trials. I knew I was a long way off from a national standard to qualify for Team USA, but considering the years of uphill battles, to simply qualify was an incredible feat to me.

AM: Though not specifically medical in nature, I too had a handful of athletics-related frustrations and setbacks in the lead up to Trials. After my botched performance in London, I had difficulty regaining my stride again. My confidence was shaken, and my performances inconsistent. I felt like I was putting a lot of time and effort into training, and not seeing any results. Conversations with friends (including Anjali) and my coach, finally convinced me that it was time to make some drastic changes. For the first time in almost 10 years I changed up my equipment, adjusted my training plan, gave up on my pescatarian diet, and even applied to graduate school. It was a whole life refresh, and it WORKED. I was training well, putting up some of the fastest times of my career, and for the first time in four years, genuinely excited about racing.

U.S. TRIALS & TEAM SELECTION

AFP: After quite a bit of thought and reflection on whether or not I should go to trials or not, I decided, why not? What did I have to lose? I was grateful for my friends, including Amanda McGrory, and supporters who encouraged me to see it through. The struggle for me was that I did not want to be an athlete showing up at the most important meet in the U.S. this season without having put the work in to get there, or look like I was coming out of the woodwork with expectations of making the Paralympic team without having been at several other key competitions throughout the season and recent years. Thankfully, my friends pointed out to me that the life circumstances and the medical complications I was facing were to blame, and that I had put a lot of work in just to get back into a racing chair and to run an entry time. For me, going to trials was a personal journey and something that I chose to follow through not with expectations of making the team, but rather to prove to myself that I could reclaim my life, finish the race and have fun. I raced in the 100m at trials, and I finished the race and had fun. Even though I did not make the Rio Paralympic team, I hope this is just the beginning of a new athletic chapter for me.

AM: Whoa! Trials time! After a great racing season, I couldn't wait to test my fitness and see how I stacked up against the rest of the American wheelchair racers. For the first time ever, each and every event I competed in had at least five talented athletes competing for only three Paralympic slots. Although this put a little more

pressure on me to perform my best, I was confident that my training and performance from earlier in the season would put me in a position for success. After three super competitive days of racing, the team was announced. My top three finishes from the weekend secured me start rights in the T54 women's 800m, 1500m, and 5K. Add in qualifying times from earlier in the season for the marathon and the 4x400m relay, and that's a pretty full schedule!

LOOKING AHEAD TO RIO

AM: Every Olympic and Paralympic Games is surrounded by its fair share of controversy and media drama - starting from the day the selection is announced, all the way through the closing ceremonies. For anyone who has watched the news or read a newspaper in the past few months, it comes as no surprise that the Rio Games have not been exempted from the trend. Crime, pollution, Zika...and the list goes on. As an athlete, the best thing I can do in this situation is focus on the things within my control, rather than those that are not. For the next two months, I will eat, sleep, and train to be as strong and prepared as possible to face off against the best athletes from around the world.

For the first time ever, NBC has signed on to broadcast a record number of events from the Paralympic Games. Additionally, each and every event in every sport will be live webcast around the globe. If you've never had the opportunity to watch elite adapted sports, I strongly recommend you check it out. I promise, it will be like nothing you've ever seen.

Good Luck to U.S. Paralympic Track & Field Athletes Competing in Rio 2016!

___ **Amanda McGrory | Twitter:** @alittlechipped | **IG:** alittlechipped | **fb:** facebook.com/mcgrory.amanda

Diagnosed with: transverse myelitis
Classification: T54
Rio Events: 800m, 1500m, 5000m, 4x400m relay, marathon

___ **Dr. Cassie Mitchell**

Diagnosed with: neuromyelitis optica
Classification: F51
Rio Events: Club, Discus

___ **Dr. Kerri Morgan**

Diagnosed with: transverse myelitis
Classification: T52
Rio Events: 100m, 400m

___ **Rachel Morrison**

Diagnosed with: transverse myelitis
Classification: F51
Rio Events: discus and club throw

___ **Steven Toyoji | Twitter:** @steventoyoji | **IG:** sstoyoji | **fb:** facebook.com/Team-Toyoji-44477058569434

Diagnosed with: transverse myelitis
Classification: T52
Rio Events: 400m, 1500m

___ **James Senbeta | Twitter:** @SenbetaJ | **IG:** jaklilusenbeta

Diagnosed with: transverse myelitis
Classification: T54
Rio Events: 800m, 5000m, Marathon

___ **Dana Mathewson**

Diagnosed with: transverse myelitis
Classification: T10 Paraplegic
Rio Events: Women's Open Singles and Doubles Tennis

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Announcements

2016 Massachusetts Walk-Run-N-Roll: October 15, 2016

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