the transverse myelitis association

newsletter

winter 2018

advocating for those with ADEM, NMOSD, ON & TM (including AFM)

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

EDITOR'S COLUMN

Pauline died five months ago. August 15, 2017. The tragic accident in Montana remains entirely surreal to me. It happened toward the end of what was a remarkable vacation. We spent a few days with Dr. Sara Qureshi exploring the Big Horn and Pryor Mountains. Dr. Qureshi is a rare neuro-immune specialist who has a clinical practice at the Billings Clinic. She is an excellent clinician and a good friend. We participated in a Montana TMA support group education program and walk in Billings. Then Pauline and I had a weeklong adventure in Yellowstone National Park. We stayed in an accessible cabin and explored everywhere we could venture with a wheelchair, and a bunch of places we probably didn't belong. Pauline got to enjoy every magnificent waterfall and rapids we could access. We had a spectacular time. We then spent two days on the Ft. Belknap Reservation. I lived in Hays for two years during the 1970s while I was working on my degree in cultural anthropology. I was also a teacher at a mission school in Hays and taught college courses in this small community. We spent two days visiting friends and also attended a pow wow. We then headed up to the Bear Paw Mountains to spend a week visiting friends. It was such a great vacation. During this trip Pauline and I decided that we would devote the rest of our lives to having these adventures, spending all our money, and not leave anything to our children.

And then we experienced a total nightmare.

I say Kaddish for Pauline three times each day while looking at one of my favorite photographs of her. I often have to shake myself to realize that this really happened. It feels as though it occurred five minutes ago and it feels like it was five years ago.

I have been asked repeatedly whether Pauline died from transverse myelitis. It is too difficult for me to talk about the details of what happened that afternoon, so I usually offer the simplest response, which is no. No, however, is not the most accurate response. The more honest and more complicated response is that our friends who were with Pauline, and could walk, were able to escape. Because Pauline was paralyzed from transverse myelitis, she was not.

Mourning is a process, and the process is unique to each person. We do this grieving based on who we are and based on the relationship we had with the person who we've lost. Pauline and I loved each other to the core. She was my lifelong partner. We had a complicated relationship. Relationships are complicated. Caregiver relationships are more complicated. Pauline was my reason for being. Now what? This is my process. I am seeking my reasons for being. I am looking for life in my life.

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

So many of you know Kazu, Pauline's Canine Companions for Independence Service Dog. When Pauline died, CCI retired Kazu and they offered me the opportunity to adopt him, which I, of course, did. Kazu is going to be 13 years old this May, and he has developed some significant

health issues. And he so misses Pauline; his reason for being. We are both living from day to day, and we support each other the best we can. His companionship and love have helped me tremendously. Kazu is doing okay. His health is stable, and he is adjusting, because dogs appear to be more flexible and adaptable than humans.

Pauline was just 58 years old and she was so filled with life. My mind has been almost entirely filled with the events of that day and the cosmic injustice of Pauline's death. I am not likely going to find meaning in what transpired on that horrible day. I am not going to find meaning in Pauline's loss.

There was, however, profound purpose in Pauline's life. Pauline was so genuine and real in who she was and how she lived her life. She lived her values. Without any self-congratulations or need for recognition, she lived her life devoted to helping others. Her entire life was dedicated to enhancing the lives of the people she cared for, improving their quality of life, and helping to make them better people. She was an elementary teacher for 25 years, and most of those years were while she had transverse myelitis. In spite of the constant pain, the fatigue, the loss of motor function, and all the other problems she had, she gave the best of herself to her students. She loved being a teacher and she loved her students. After we established The Transverse Myelitis Association, shortly after Pauline's diagnosis, Pauline devoted so much of her time, energy and intellect to serving our community. She made herself available to speak to people on the phone, she was a wonderful mentor to the children at camp, and she allowed herself to serve as a role model for so many people who were seeking a better quality of life for themselves and strategies for managing all of the challenges in their lives. Pauline was so generous in all of what she offered to our community. She was first and foremost devoted to her family. She was a sweet, kind, supportive and loving partner to me. She was a wonderful daughter and mother, and she was the greatest Sitte (grandmother) to her five beautiful grandchildren. They love and miss her.

During the service for Pauline, the rabbi and our sons talked about the importance of the sun in Pauline's and my relationship. At our wedding, our son played 'Here Comes the Sun' as we walked up the aisle. During our honeymoon on St. Croix, Pauline and I watched a solar eclipse. And then at the cemetery, as Pauline was laid to rest, we again experienced a total solar eclipse. Shortly after the funeral, our family and some close friends made the decision to honor Pauline by establishing a fund dedicated to research on the rare neuro-immune disorders. They named it The Eclipse Fund in Memory of Pauline H. Siegel. I was so grateful and was thrilled when the TMA Board unanimously adopted Pauline's Eclipse Fund as the research platform for our organization. It is such an appropriate way to recognize the contributions Pauline made to people in her life, and it is the perfect legacy to remember her greatest value, to heal the world. Her devotion to our community, to improving the quality of life for the people she cared for and wanting to find cures for these disorders are memorialized through this fund.

From the time we established the TMA, we knew that research needed to be a cornerstone of our work. We recognized that with research came hope. In those early days, we didn't have a grasp on what the research needed to be and we sure didn't have any researchers focused on our disorders. Both of those pieces of the research puzzle have been solved. In part through our James T. Lubin Fellowship Program, we are growing the rare neuroimmunology discipline and significantly expanding the number of researchers interested in these disorders. And not only do we have a clear understanding of the priorities for research, the TMA is currently involved in funding a number of critical research projects. We are partnering to fund the first Phase one cell trial for the repair of myelin in transverse myelitis. We are funding a genetics study in transverse myelitis that is producing some very interesting results that show promise for better understanding the disease process. We have been funding a biomarker study to facilitate diagnosis and treatment. We are also trying to initiate a study that will produce a mouse model which would open opportunities for testing existing FDA approved drugs. There are currently so many rich opportunities for research. The gap between what we are currently able to accomplish and what really needs to be done is money.

The Eclipse Fund in Memory of Pauline H. Siegel was established and initiated shortly after Pauline's death. Both the Montana Walk and the Ohio Walk dedicated their proceeds to Pauline's Eclipse Fund. Many of Pauline's friends and family began making donations to the fund early on. The TMA received a very generous $150,000 contribution from an anonymous donor to be used as a matching fund for the Eclipse Fund. As of the

I have such a personal stake in the success of The Eclipse Fund in Memory of Pauline H. Siegel. I want it to succeed because raising the money means getting the research done, and getting the research done means hope for our community. This is what Pauline so desperately wanted for the people she cared for in our community and for herself.

time of this publication, we have received a total of 714 contributions from 562 donors that amounted to a total of $205,919. This amount does not include the $150,000 matching fund, and we are so grateful that this goal was achieved, doubling all of your contributions. Half of the contributions came from new donors.

I have such a personal stake in the success of The Eclipse Fund in Memory of Pauline H. Siegel. I want it to succeed because raising the money means getting the research done, and getting the research done means hope for our community. This is what Pauline so desperately wanted for the people she cared for in our community and for herself. And I want for this Eclipse Fund to succeed so that Pauline's memory and her legacy are kept alive. The work that we did since 1994 was so important to her. I want her memory to live on in this community and I want for her cause to remain alive and supported as her legacy; a way to honor her memory.

For The Eclipse Fund to succeed, our base of support is going to need to expand. In a membership of more than 12,000 people, around 10% of our members participate in financially supporting the organization. Those numbers won't sustain Pauline's fund. The horrible reality is that those numbers won't keep The Transverse Myelitis Association existing in the future. We need for everyone to participate in supporting our organization. For those of you who are unable to give because of your financial situations, we are urging you to get your family and your friends involved. It is possible and it is critical for everyone to participate in supporting our organization. Getting more of our members, most of our members, involved in contributing will ensure the success of our research efforts and it will also ensure a future for the TMA.

Over the years, Pauline and I have asked our family and our friends to support the TMA, and we have gone to just about everyone in our lives, from our car dealership, to

our plumber and electrician, to our veterinarian, to our grocery store and anyone else we can get to listen to us for longer than five minutes to support our organization. We've done this for ourselves, and we've made this effort for our community. Pauline and I have never asked anything of our community that we haven't delivered on ourselves.

For 17 years, we had almost no administrative costs because we were an entirely volunteer organization and all of the volunteers paid their own expenses. Through the hiring of Chitra as our executive director, and by hiring staff, we've put the people in place to expand the work that we do for our community and we've been able to accomplish much more complicated programs and projects. While we were an entirely volunteer organization, it would have been impossible for us to partner in or support the kinds of research projects that we are currently engaged in, nor manage the James T. Lubin Fellowship Program. We've created a more professional support group network and we're expanding our support programs in more responsive ways. We've expanded our education programs by adding blogs and podcasts and by making more creative use of social media. And perhaps as importantly, by professionalizing the organization, we've given the TMA a future. Hitching the TMA wagon to Jim, Debbie and I was no guarantee of a future. It was something of a miracle that we were able to make a go of this for 17 years.

In professionalizing the organization, we've also had to accept that we are going to have administrative costs. Not-for-profits are held to an incredibly high standard when it comes to financial accountability. I am so acutely aware of that from my more than two decades of experience doing this work. In some ways, I believe we are held to an even higher standard than the government because your contributions to us are voluntary.

Pauline would be so gratified and proud that her name and her memory will drive the future of research for our organization and community. It is such a fitting legacy for this remarkable person. My love for Pauline and my respect and admiration for the person she was will continue to fuel my passion. I am driven by wanting to keep her memory alive in our community. I would like for her lifetime of work and achievements to be remembered. But most importantly, I want for her values and her character to be recognized and remembered. Kazu and I miss Pauline every day. I have been on the most amazing journey with Pauline. If I wrote the autobiography, no one would believe the story. Half of the time, it doesn't feel real to me. But my life with this most genuine, kind, and loving person was about as real as it gets. While I suffer with the loss, I also never forget that I was so blessed to have this person in my life in just the way we shared this incredible journey together.

Please take care of yourselves and each other.

Sandy

May her memory be a blessing.


Pauline Siegel
Powell, OH

INTRODUCING JEREMY BENNETT

Last year was a year of firsts for me. In 2017, I met someone with transverse myelitis for the first time since my diagnosis five years prior, held my first support group, attended my first Walk-Run-N-Roll event, experienced my first Rare Neuro-Immune Disorders Symposium (RNDS), and started working full-time for the first time since 2012.

When I was diagnosed with transverse myelitis I had to reevaluate my life. I was no longer able to work or do many of the things that brought me joy. I couldn't (poorly) play guitar, play table tennis (better than average), or (expertly) drive a car with manual transmission. Fortunately, I found new passions to replace the old ones. I dedicated my time to volunteerism and school, earning a master's degree in museum studies with an emphasis on volunteer management.

I began working part-time at an art museum. I loved going to work every day in a place full of Monet's, but I became focused on doing more for underserved populations. Luckily, I was introduced to Sandy, and he encouraged me to get involved with the TMA by starting a support group. I knew that I would eventually work for the TMA, but I couldn't have predicted it would happen so soon.

I became the Community Partnerships Manager for the Transverse Myelitis Association in October, during a busy and exciting time for the organization. My first week on the job I headed to Dallas, Texas to attend a Walk-Run-N-Roll. I met volunteers, members, medical professionals from UTSW, the Chick-fil-A mascot, and witnessed just how dedicated our community is to supporting the mission of the TMA.

The TMA was also only two weeks away from holding its biennial RNDS, and it was happening just miles from my apartment in Columbus, Ohio. Members from nearly every state, and as far away as Australia, were in attendance. I met a 70-year-old man who walked up to the registration table with a newspaper in his hand. He didn't know about the TMA until he read an article about the RNDS in the newspaper.

I estimate that I hugged, shook hands, or said hello to about 200 people or more during that first month. After I was diagnosed in 2012, I had support from my friends and family, but something was missing. For every car ride to an appointment and thoughtful text, there was a nagging sense that I was alone. I knew no one else with transverse myelitis. No one knew the searing pain, the fatigue, the loss of self. Suddenly, I am surrounded by people who are like me.

As Community Partnerships Manager, my goal for 2018 is to try and connect as many of our members as possible. No one should feel like they are alone. I want a support group or Walk-Run-N-Roll in every state. We've already had several members reach out this year and offer to volunteer or become support group leaders. Please contact me at *jbennett@myelitis.org* and help me achieve my goal.

ANNOUNCING THE 2018–2020 JAMES T. LUBIN CLINICIAN–SCIENTIST FELLOWSHIP AWARDS

The Transverse Myelitis Association's Board of Directors has approved funding for two TMA James T. Lubin Clinician-Scientist Fellowship Awards to Dr. Kyle Blackburn at The University of Texas Southwestern in Dallas and Dr. Jonathan Galli at The University of Utah in Salt Lake City. Dr. Kyle Blackburn will receive clinical and research training under the mentorship of Dr. Benjamin Greenberg and Dr. Jonathan Galli will be mentored by Dr. Stacey Clardy. The Fellowships will be focused on multi-disciplinary clinical training in neuro-immunology with a focus on rare neuro-immune disorders.

Dr. Blackburn received his medical degree from the University of Kentucky College of Medicine in Lexington, KY, and is completing his neurology residency at The University of Texas Southwestern in Dallas, TX, where he also worked with Dr. Greenberg. During his fellowship, he plans to launch a study that will collect patient reported outcomes measures on adult and pediatric patients with transverse myelitis. The study aims to assess current outcomes in transverse myelitis, and to inform the development of outcomes measures for future clinical trials.

Dr. Galli received his medical degree from the University of Vermont College of Medicine in Burlington, VT, and is completing his neurology residency at The University of Utah in Salt Lake City, UT, where he also worked with Dr. Clardy. As part of his fellowship training, he plans to conduct research to look for biomarkers in individuals with NMOSD. He intends to see whether individuals have aquaporin4 (AQP4) autoantibodies prior to their symptom onset of NMOSD, and also look for other inflammatory biomarkers. He hopes the study will help us understand how biomarkers occur over the course of the disorder, which will hopefully help identify predictors of disease development, and ultimately therapeutic targets.

These are the sixth and seventh grants to be awarded since the launch of the James T. Lubin Clinician-Scientist Fellowship program. Past recipients include Dr. Allen DeSena, currently at University of Cincinnati; Dr. Michael Sweeney, currently at University of Kentucky; Dr. Elena Grebenciucova at

"I look forward to a career full of discovery, and with our understanding of autoimmune neurology only just beginning, I cannot think of a more fulfilling area to contribute to, both as a physician, researcher and educator."

– Dr. Jonathan Galli

"The James T. Lubin Fellowship will provide me the resources to develop into a sound clinician and researcher. Under the guidance of Dr. Greenberg, I will not only see patients with immune-mediated neurological disease, but also have the time and resources to learn the logistics of conducting clinical research in rare diseases. These skills are essential to my success as an academic physician, and I am grateful to the TMA for this opportunity."

– Dr. Kyle Blackburn

Northwestern University, and current Fellows, Dr. Cynthia Wang at University of Texas Southwestern and Dr. Olwen Murphy at The Johns Hopkins University. Over the last five years, the TMA has committed over $780,000 to the training of clinicians and researchers dedicated to careers focused on rare neuro-immune disorders. Institutions currently participating in the Fellowship training are The University of Texas Southwestern, The University of Pennsylvania, The Johns Hopkins University, and The University of Utah.

"We announced the James T. Lubin Fellowship in 2008. The program was established from our need to expand the number of researchers and clinicians focused on the rare neuro-immune disorders. We understand the great need for the acceleration of research, as well as the critical need for our community to be offered the best medical care possible. Our Fellowship program accomplishes both needs. We are so grateful for the support we have received from our community. Without your generosity, the Fellowship program could not succeed." Sandy Siegel, President of the TMA.

For more information about the James T. Lubin Fellowship, visit *tma.ong/james-t-lubin-fellowship*.

WHAT IS ANTI-MYELIN OLIGODENDROCYTE GLYCOPROTEIN (MOG)?

As researchers continue to study disorders like neuromyelitis optica spectrum disorder (NMOSD) and multiple sclerosis (MS), we are learning more and more about factors that contribute to the disease processes seen in these conditions. For example, demyelination from MS is thought to be caused by the activation of white blood cells called T cells (and maybe B cells), while most cases of NMOSD involve antibodies to aquaporin-4 (anti-AQP4 or NMO-IgG). There has recently been more discussion about Myelin Oligodendrocyte Glycoprotein or MOG, and its relationship to NMOSD. Although MOG's exact function is not fully known, it is thought to be an important glycoprotein that influences the myelination of nerves in the central nervous system. Anti-MOG antibodies have been found in individuals diagnosed with NMOSD who do not have antibodies to AQP4, in acute disseminated encephalomyelitis, transverse myelitis, and optic neuritis. Those with anti-MOG NMOSD tend to have attacks most often in the optic nerve, or optic neuritis (ON), but can also present with inflammation in the spinal cord (transverse myelitis) and brainstem.

Recently at The European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) annual meeting, there was a discussion about anti-MOG and whether it should be its own diagnostic category or another variant of NMOSD (*tma.ong/ectrims-mog*). Dr. Douglas Sato of the Brain Institute of the Rio Grande do Sul in Porte Allegre, Brazil, argued that there are enough differences between anti-MOG disease and NMOSD, and proposed that it be called MONEM, an acronym for "anti-MOG associated optic neuritis, encephalitis and myelitis (MONEM)." In contrast, Dr. Roman Marignier of the Hospital Pierre Wertheimer of Lyon University Hospital in France argued that anti-MOG disease is a variant of NMOSD that occurs without antibodies to AQP4. His argument was that patients with anti-MOG and patients with anti-AQP4 disease have similar cerebrospinal fluid characteristics, clinical characteristics, MRI characteristics, and the same acute and long-term treatment options.

Another presentation at ECTRIMS (*tma.ong/ectrims-mog-2*) described a study that followed 33 children and 26 adults who were anti-MOG-positive over an average of five years. Researchers from the Kids Research Institute at the Children's Hospital at Westmead in Sydney, Australia, found that 54% of all patients developed optic neuritis as their first disease sign. They found that the individuals in the study responded well to steroids, but relapsed when steroids were stopped. They found that their study participants had reduced relapse rates when they were on maintenance steroids, intravenous immunoglobulin (IVIg), or immunosuppression with rituximab or mycophenolate.

Participate in Research on anti-MOG

Dr. Michael Levy and the NMO lab at Johns Hopkins University are developing tests for Anti-MOG (myelin oligodendrocyte glycoprotein) disease. They are especially looking for participants with recurrent clinical events of optic neuritis and/or transverse myelitis with either a negative anti-AQP4 antibody test or a positive anti-MOG antibody test from another lab. You can find more about the research here: *tma.ong/anti-mog*.

ARE REMYELINATION STRATEGIES REALISTIC?

Notes from the 2017 RNDS

At the 2017 Rare Neuro-Immune Disorders Symposium, Dr. Benjamin Greenberg from the University of Texas Southwestern Medical Center gave a talk (*youtu.be/nPSGKpaQEyg*) about remyelination strategies and announced the beginning of a Phase I trial in transverse myelitis. This is the first FDA sanctioned cell therapy to promote repair through myelin regeneration in Transverse Myelitis, which is set to begin in 2018. The University of Texas Southwestern, Q Therapeutics, Inc. and The Transverse Myelitis Association are collaboratively sponsoring this first human safety study to treat central nervous system disease.

How did this trial become reality?

Dr. Greenberg presented the stages of clinical research. The first step is preclinical development to develop the agent, whether it's a cell or a molecule that then has to be tested for efficacy. The next step is to prove that there is no obvious or expected toxicity from that therapy. This preclinical development can literally take years or even decades to complete. In the United States, regulatory approval is required through the FDA where they grant what's called an IND, or an Investigational New Drug application. A Phase I trial is primarily meant to measure safety. As long as we make sure an intervention is safe, then Phase II and Phase III studies are the next steps to get approval to market that therapy to the rest of the world.

How does this cell therapy remyelinate?

Q Therapeutics developed a glial-restricted precursor cell called a Q cell that develops into oligodendrocytes. Oligodendrocytes are cells that produce myelin, the insulation around nerves. In mice that are born with nerve cells without myelin, these cells have been shown to produce myelin.

So where are we now?

UT Southwestern and Q Therapeutics, with input from the TMA, collaborated and put in an IND application to the FDA, that was granted in July 2017. This means the FDA gave approval to move into human remyelinating trials for transverse myelitis in a Phase I trial. This type of study requires significant funding. 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. This study is enrolling patients diagnosed with transverse myelitis who are between one and ten years from their event and remain unable to walk.

How can you get involved?

If you are interested in learning more about this trial and other research, please go to *tma.ong/research-form*. You can also contribute to The Pauline H. Siegel Eclipse Fund to raise money to cover the cost of the trial.

UNDERSTANDING DISABILITY IDENTITY AND IMPLICATIONS FOR FUTURE STUDY

TMA Board Member and Paralympian Dr. Anjali Forber-Pratt and her colleagues recently published a systematic review of studies on disability identity development. In past years, psychologists and researchers have developed models of both identity development and disability identity development. Dr. Forber-Pratt is interested in how individuals develop their disability identity, and believes this research could be critical in developing support systems for individuals with disabilities and the greater disability community. By conducting a review of existing articles, the researchers aimed to provide individuals with disabilities, community leaders, special educators, counselors, psychologists, and the disability community with more information on the process of disability identity development.

The researchers searched academic journal article databases and results were limited to peer-reviewed articles written in English between 1980 and 2017. Of the 144 articles they found, 41 were included in the review.

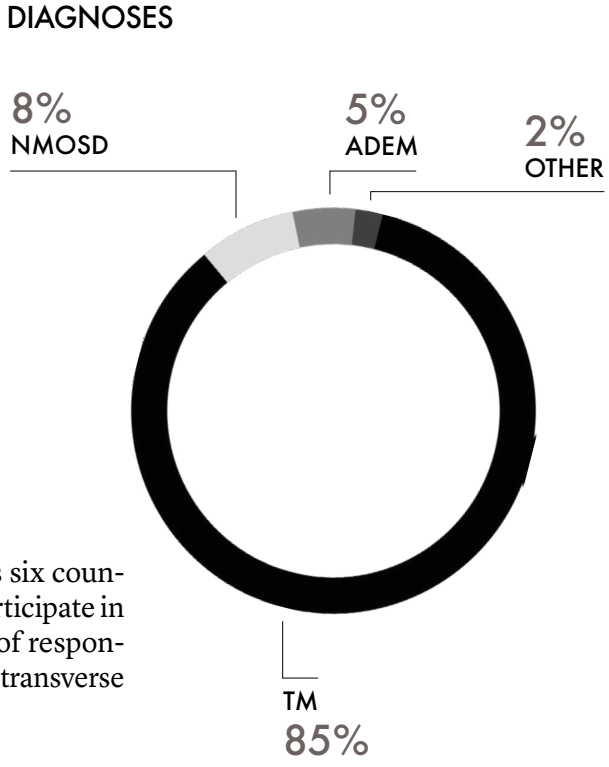
The researchers' review yielded two main findings. First, disability identity shapes the way individuals see themselves, their bodies, and interactions with their surroundings. People with disabilities not only have to navigate physical components of their disability but also what social meaning is attributed to that disability. These physical and social aspects combine to form a person's disability identity, which should be considered both in relation to other intersectional identities (such as LGBTQ, racial identity, cultural identity, etc.) and independent of other aspects of identity. The second finding from this review is that disability identity development has been studied mainly through qualitative measures rather than quantitative measures. Larger scale studies that use a more comprehensive approach are needed to better understand disability identity development. Support is needed for research that spans across different disability groups to better understand the effects of multiple disabilities on a person's development of disability identity.

This literature review highlights the need for awareness of disability identity development, especially for individuals and organizations that impact the lives of people with disabilities. This is especially true of rehabilitation professionals, educators, and caregivers, who are often able-bodied which can cause tension and cause the person with a disability to seek out support independently. Additionally, with more research, we can gain a better understanding of disability identity development and create interventions that better assist individuals who are in the process of developing a disability identity. Another finding of this literature review is that disability identity includes both an acceptance of one's disability as well as involvement with the disability community. Large-scale, community level research is needed to learn more about the role the disability community plays in identity development.

There are barriers that can prevent people with disabilities from participating in research. For example, people may be reluctant to participate in research or may not have access to materials. Some people may not wish to be identified with having a disability at all. Also, there were few studies which included individuals with higher support needs, such as those with adaptive communication devices or those who have more than one co-occurring disability. These barriers are representative of the struggle people with disabilities face with accessibility and social stigma.

Forber-Pratt AJ, Lyew DA, Mueller C, Samples LB. Disability identity development: A systematic review of the literature. Rehabil Psychol. 2017 May;62(2):198-207. doi: 10.1037/rep0000134. Epub 2017 Apr 13.

PRELIMINARY FINDINGS FROM THE TMA REGISTRY



After months of planning, designing, and reviewing, the TMA launched a new research study called the TMA Registry in early 2017. The TMA Registry consists of a survey which asks individuals diagnosed with a rare neuro-immune disorder about their diagnosis, the treatments they received, and their ongoing symptoms. The goal of the TMA Registry is to collect information about individuals' experiences with their rare neuro-immune disorder, gain a better understanding of the disorders, and create a registry of individuals who are willing to be contacted for future research studies.

While the information reported here is preliminary, we wanted to share some of the information we have gathered so far. We plan to do additional analyses when we have more respondents.

118 members from across six countries have consented to participate in this registry. Most (85%) of respondents were diagnosed with transverse myelitis.

75% of respondents reported that their symptoms were at their worst either on the day of onset or within the first week of onset. Almost half of participants reported that they received a diagnosis less than one week after the onset of symptoms. However, it took longer than six weeks for 27% of participants to receive a diagnosis.

The overwhelming majority of participants received IV steroids as their first treatment, and only about a quarter of participants received a second treatment that was different from their first treatment.

TIME BETWEEN SYMPTOM ONSET AND DIAGNOSIS

46%
LESS THAN ONE WEEK

19%
1-3 WEEKS

8%
4-6 WEEKS

27%
MORE THAN 6 WEEKS

Activity and rehabilitation are key to living optimally with a rare neuro-immune diagnosis, and are important for recovery after a rare neuro-immune disorder diagnosis. Encouragingly, about 84% of participants received rehabilitation therapy. Of those that received rehabilitation therapy, 79% received inpatient therapy and 85% received outpatient therapy. You can find more about rehabilitation here: *tma.ong/rehab-factsheet*.

The most common current symptoms experienced by participants in our registry were weakness or paralysis in the lower extremities, numbness or loss of sensation in the lower extremities, spasticity or uncontrolled muscle spasms in the lower extremities, neuropathic pain, bladder and bowel symptoms, and fatigue. About half of respondents currently use mobility aids, such as a cane, a manual wheelchair, a walker, a motorized wheelchair, and/or orthotics.

Prior research has shown that individuals with one autoimmune disorder are likely to have another autoimmune disorder, so we wanted to learn how many of our members had another autoimmune condition. We found that the majority of participants do not have a second autoimmune disorder. However, 13.8% have hypothyroidism, 6% have inflammatory bowel disease, 5% have Hashimoto's Thyroiditis, 3% have Sjögren's Syndrome, 3% have psoriatic arthritis, and 16% reported they had some other autoimmune disorder.

There are a variety of implications for future study that can be drawn from these preliminary results. Over half of the participants did not receive their rare neuro-immune diagnosis until more than a week after onset of symptoms, including 27% who did not receive their diagnosis until six weeks or more after their onset of symptoms. Receiving aggressive acute treatment swiftly after the onset of symptoms is imperative to stop damage from an inflammatory attack as quickly as possible. Awareness and education for physicians and other medical professionals may help to combat delays in diagnosis.

The TMA Registry is an ongoing initiative, and those who are interested in participating can still sign up! To join the TMA registry and complete the survey, please go to *tma.ong/tma-registry*. We look forward to sharing more information with you in the coming months!

The TMA is excited to announce that our partnership with the Center for Courageous Kids (CCK) in Scottsville, KY continues with our 2018 TMA Family Camp. Be sure to mark your calendars for Sunday, July 22 through Thursday, July 26, 2018, for the next annual TMA Family Camp!

HOW TO APPLY?

To begin the application process, please complete the form located at *tma.ong/2018-camp*. A TMA staff member will contact you via email within 48 hours to share additional information about the application process.

WHO IS ELIGIBLE?

- Families with children diagnosed with ADEM, NMOSD, TM, ON and AFM who are 5 to 17 years old are eligible to apply to camp. Camp is open to families around the world.
- Applications are welcome from older and younger children, who may be accepted on a case-by-case basis. If you are uncertain about your eligibility, please complete the initial application and we will be in contact with you if there are any questions!
- Up to two adults living in the same household as the camper and the camper's siblings may participate in camp.
- All applicants must be members of the TMA. Membership is free. If you are not a member, please complete the membership form prior to completing the initial application: *myelitis.org/join*.

ARRIVAL AND DEPARTURE INFORMATION

Families will receive detailed information about arrival and departure times along with their acceptance confirmation directly from CCK. In general, most families arrive at camp around 3:00 pm on the first day of camp. Camp closes at noon on the last day of camp. The closest airport is Nashville, Tennessee. It is your responsibility to arrange for transportation to and from camp. CCK and the TMA are unable to offer transportation to and from camp. For a listing of ground transportation options between the airport and camp, please contact the TMA at *tmakids@myelitis.org*. Please do not make airline reservations until you receive an acceptance email or letter from CCK.

WHAT IS THE COST?

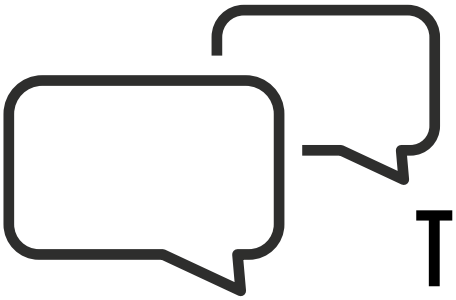
There is no cost for families to come to camp besides personal travel expenses. The TMA and CCK have a partnership under which we cover the cost of camp. The TMA will be able to offer limited financial assistance based on need and eligibility, via travel grants to families. All accepted families will receive an email with an application form and guidelines to apply for this funding in early summer 2018. They will be offered on a first come, first served basis to eligible families until grant funds are no longer available. Grant funds are disbursed as reimbursements and only once each of the grant requirements are met.

EDUCATION PROGRAM

Medical professionals and specialists from our community will be attending camp and provide a three-day education program for the parents and any of the children, teens, or young adults who attend camp and are interested in the education program. All medical volunteers attending the TMA Family Camp have been invited by the TMA to join as camp volunteers and to participate in an educational program during the camp. The medical volunteers may share their experience and make recommendations, but will not be able to provide specific medical advice.

QUESTIONS?

Please feel free to contact us at any time for additional information or to learn more about our Family Camp!
Contact Rebecca Whitney: *rwhitney@myelitis.org*
855-380-3330 ext 5 or 616-889-5573



THE MYELITIS HELPLINE

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

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

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

myelitis.org/mhl

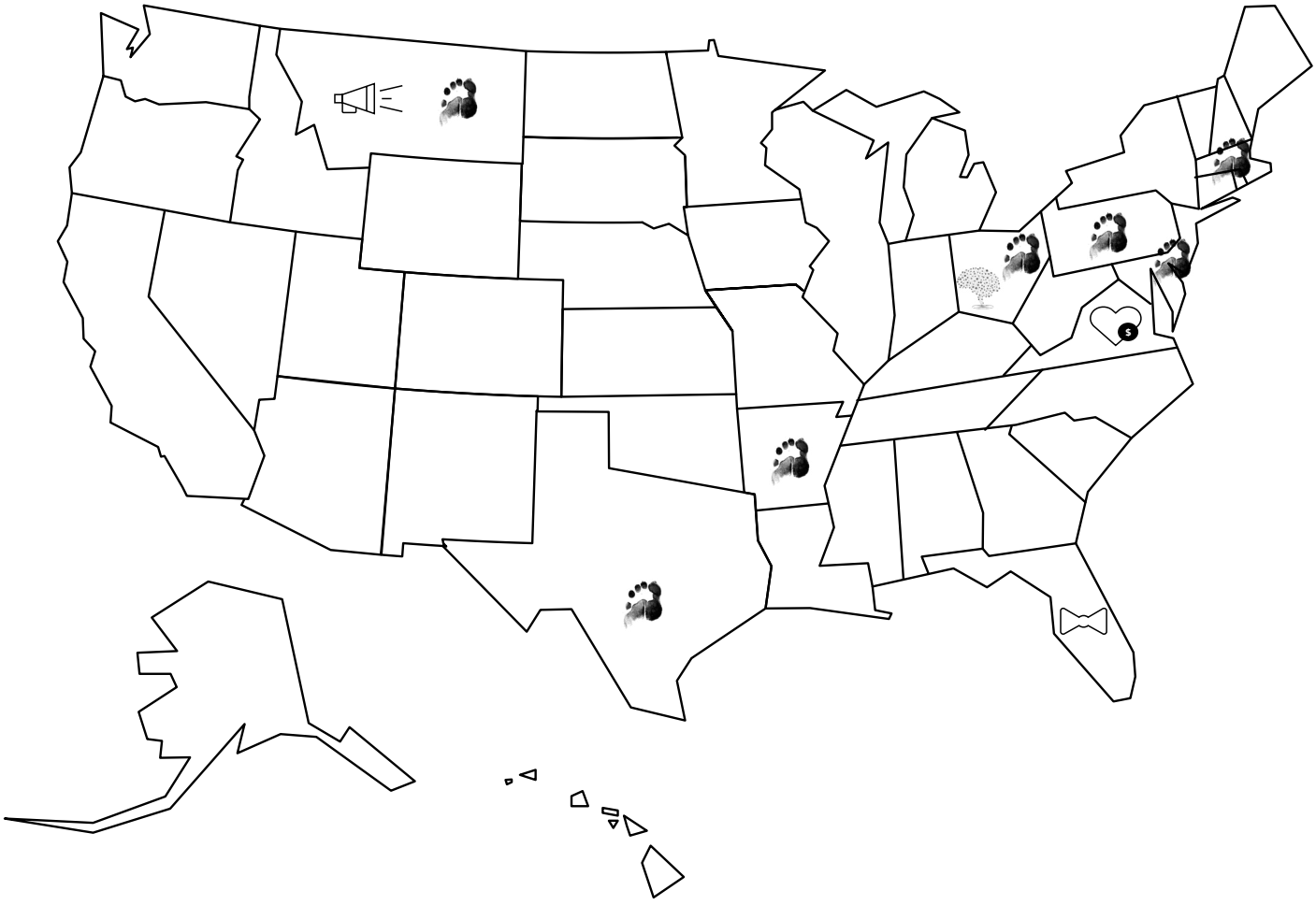
VISIT OUR RESOURCE LIBRARY

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

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

2017 EVENTS

In 2017, TMA fundraising and awareness events were held across the United States, providing fun opportunities for our community members to come together and raise awareness, form lasting relationships, and raise money for much needed research and education programs. We are so appreciative of our volunteers who took on the huge responsibility to make these walks, galas, and education events happen! Thank you for your hard work, committment and dedication.



Walk-Run-N-Roll

Gala & Auction

Fundraiser

Awareness Day

Rare Neuro-Immune Disorders Symposium

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

While these events are often a team and community effort, we want to give a special **thank you** to the following individuals who served as volunteer leaders for the events, and their friends and family who helped make these events a success.

Barbara Ferguson
Barbara Nichols
Colleen Spaeth
Dana Deidloff
Dianne Elliott
Dr. Cynthia Wang
Dr. Sara Qureshi
Elisa & Mitch Holt
Kara Compton
Mark McCloskey
Patty Holston
Tina & Jason Robbins

Thank you to our Sponsors:

Ability Plus Therapy
Alexion Pharmaceuticals, Inc.
Beechwold Veterinary Hospital
Boniface-Hiers Automotive Group, Inc.
Bush Ross, PA
C. Elliot Photography
CAI Builders, LLC
Cake Krush
CCI Communications, Cape Canaveral
Chasing Fireflies Photography
Chef Beau MacMillan
Chick-fil-A Northshore, MA
Chick-fil-A, North Beltline Irving, TX
Children's Health Dallas
Coloplast
Comfort Keepers
Created by Noah
Creative Entertainment, Mike Funch
Cure Medical
Daydream Vacations
DeLorenzo's The Burg Pizza
Eraclides Gelman, Hall, Indek & Goodman, Llp
Everyday ABA
Fraternal Order of Eagles
Freckle Face Painting
Georgianna United Methodist Church
Hanger Clinic
High Stack Gordon Kirby, PA
Honda North
Horowitz, Matheson and Devonmile, PA
Huddleston, Robbins and Riddle, PA
iHeartRadio Media
Imperial Cleaners
International Center for Spinal Cord Injury, Kennedy Krieger Institute (KKI)
Jacqueline's Bakery
Jay Olsson, MD
Law Office of Jason S. Robbins, PA
Linda Barlow
MedImmune, Inc. | A member of the AstraZeneca Group
Monarch Title Agency, Inc.
Northshore Mall
Novartis
OhioHealth
Palm Beach Autographs
PepsiCo
Peruzzi Buick GMC
Professional VisionCare, Inc.
React Spinal Cord Injury Recovery
Restorative Therapies, Inc (RTI)
Salpeter Gitkin, PA
Shari K. Miller
Stuart Borton at Yellow Dog Café
Summer Illusions Tanning Salon
The Cookie Monstah
The Hemp Depot, Inc.
The Mediation Group, Inc.
The Ohio State University Medical Center
Thorne and Associates, PA
University of Texas Southwestern Medical Center
VFW: The Veterans of Foreign Wars of the US
Villa Mannino Ristorante

TMA VOLUNTEER SPOTLIGHT

TMA volunteers are some of the most powerful members of our community. These individuals dedicate their time, energy, and resources towards advancing our mission of supporting people 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 Heidi Bournelis. Heidi, and her husband Nicholas, are organizing the 2018 Walk-Run-N-Roll in NE Ohio. The event will take place on April 29, 2018 in Canton, OH at Veteran's Park. Heidi held a fundraiser during Thanksgiving. This is the first Walk-Run-N-Roll for NE Ohio, and the TMA is excited for the opportunity to bring together our members in that part of the state. This would not be possible without volunteers like Heidi. We want to thank Heidi for her hard work and dedication to our mission and increasing awareness about rare neuro-immune disorders!

When Alexis was finally diagnosed, and her doctor introduced us to the TMA, we were amazed by the support we received from other families that had some form of Transverse Myelitis. They really are like a second family that we care for. That's just what people in the TMA do, they take care of each other and their families.

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

My family and I first learned about the TMA when my daughter, Alexis was diagnosed with AFM in November 2016. She had just turned 3. We were introduced to the TMA by Alexis' neurologist. He suggested it to learn more about her condition and thought it would be a great way to find support.

What made you decide to become a volunteer?

The reason I decided to become a volunteer was because we just wanted to find a way to give back to the TMA. We wanted to be able to raise awareness for AFM and the many other conditions that the TMA supports. I figured if Alexis can wake up and deal with everything that she has to deal with, and with a huge smile on her face, then why can't we give back and help in some way.

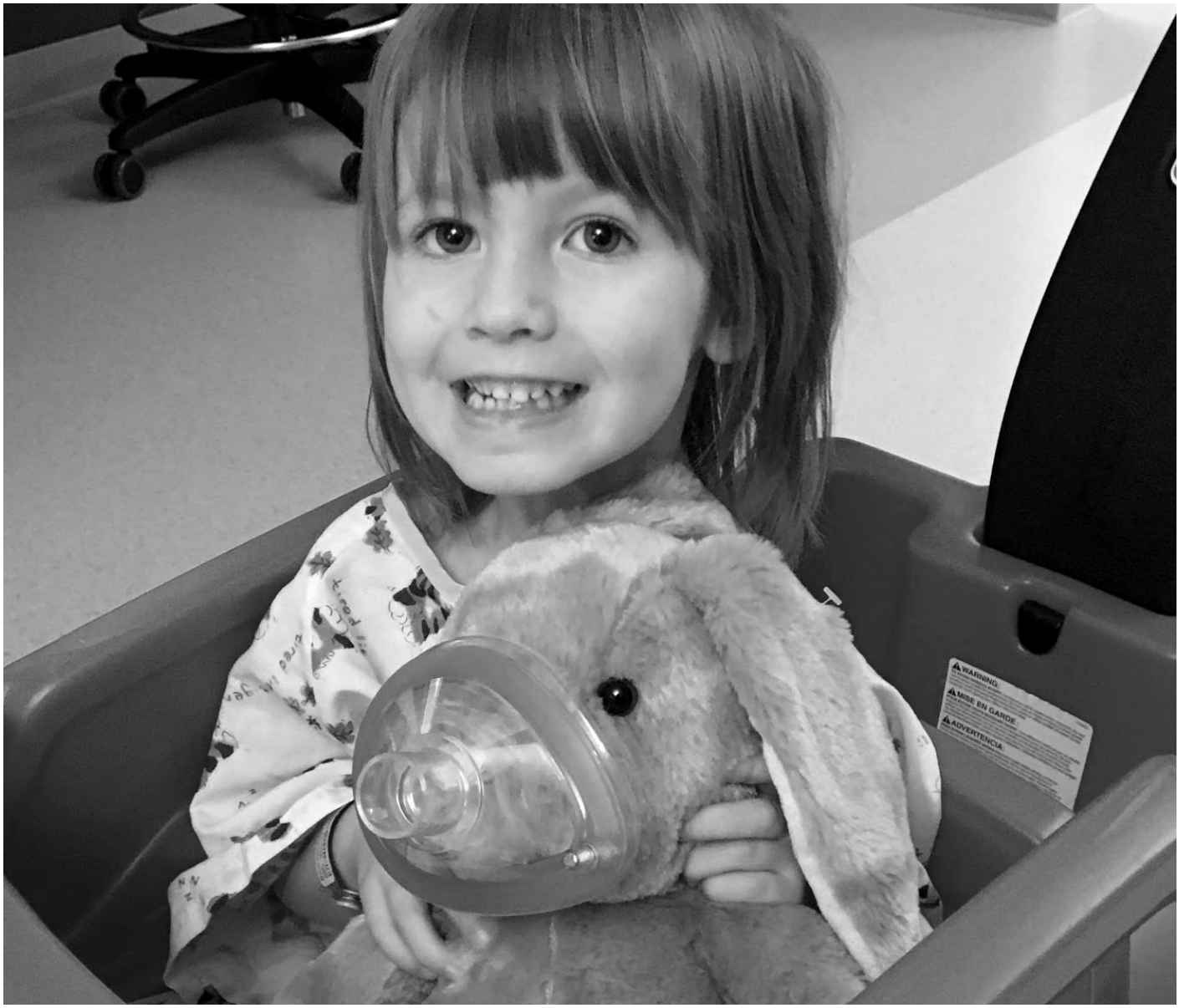
What are your goals as a volunteer?

My goal as a volunteer is to raise funds to go towards research for Transverse Myelitis, ADEM, AFM, NMOSD, and ON. We would like to be able to help other families struggling like we were and let them know that they are not alone; let them know there is a community here to help them.

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

The mission means so much to me. Over a year ago, we really had nowhere to go for help. We were going from doctor to doctor trying to figure out what was wrong with Alexis. When she was finally diagnosed, and her doctor introduced us to the TMA, we were amazed by the support we received from other families that had some form of Transverse Myelitis. They really are like a second family that we care for. That's just what people in the TMA do, they take care of each other and their families.

I am really excited that we are starting a walk here in Ohio to be able to raise more awareness in our local community. Our hope is to raise money that will go towards research and to advocate for families.



What advice would you give someone who is reading this and thinking about becoming a volunteer or Support Group Leader?

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

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

NEW HOPE AMBASSADOR STORIES!

Last year, for 100 days, we featured a story of a person touched by acute disseminated encephalomyelitis, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, including acute flaccid myelitis as part of our **myelife. my hope.** campaign (*myelifemyhope.org*). 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 three new Hope Ambassadors: Lilly, Ruth, and Greg.

Lilly

Diagnosis: TM
Location: New York

tma.ong/lilly

Ruth

Diagnosis: TM
Location: UK

tma.ong/ruth

Greg

Diagnosis: ADEM
Location: Michigan

tma.ong/greg

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

THE ECLIPSE FUND

*You are a **star**. With your help, we have raised over $355,000.*

Thank you.

We continue to work hard to achieve our goal of $2 million towards diagnosis, restoration and repair research.

Learn more:

myelitis.org/the-eclipse-fund

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
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
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

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

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

5 A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

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

6 The PREVENT Study

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

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

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

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

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

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

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

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

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

11 **The TMA Registry**

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

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

2017 SYMPOSIUM VIDEOS ARE HERE!

The 2017 Rare Neuro-immune Disorders Symposium (RNDS) was held on October 20th-21st in Columbus, OH at the Hilton Columbus at Easton. We hope that the opportunity to meet the medical professionals, to connect with others in our community, and to learn more about TM, AFM, ADEM, ON, and NMOSD was a beneficial experience for those who attended. For those who couldn't join us in person, symposium sessions were recorded and are available on the TMA's YouTube Page and our Resource Library: *tma.ong/2017-rnds-videos*.

We strive to continue hosting educational events to fulfill the TMA mission of promoting awareness and empowering patients, families, clinicians and scientists through education programs and publications.

"The word rare doesn't really apply in this room because for you it's not rare, it's real," said Dr. Brenda Banwell as she opened the symposium with an overview about rare neuro-immune disorders.

Workshop sessions were held on Transverse Myelitis, Neuromyelitis Optica Spectrum Disorder and Optic Neuritis, Acute Disseminated Encephalomyelitis, and Acute Flaccid Myelitis, to provide an opportunity for interaction with medical professionals and peers. Other topics included neuropathic pain; fatigue; bladder, bowel, and sexual dysfunction; neuropsychological issues; and rehabilitation.

We ended the 2017 RNDS with an afternoon on research updates, where scientists and researchers shared exciting and promising information about the future of diagnosis, management, and treatment of these disorders.

We look forward to seeing more of our community at the 2018 Regional Symposium we are planning for later this year in Boston. Please check our website for more details.

AUTHOR MARGARET PETERSON HADDIX TO SPEAK AT BENEFIT FOR THE PAULINE H. SIEGEL ECLIPSE FUND

Date
Wednesday March 28

Time
6:00 pm

Venue
McConnell Arts Center
777 Evening Street
Worthington OH 43085

Admission to the event is FREE. Your donation to The Pauline H. Siegel Eclipse Fund is welcome. A table will be set up at the reception to accept your donation. If you are not able to attend the author talk but would like to donate to The Pauline H. Siegel Eclipse Fund, please visit: *myelitis.org/the-eclipse-fund*.

Margaret Peterson Haddix has written more than 40 books for children and young adults including *Double Identity, Uprising, The Shadow Children Series* and now has a new book, *Summer of Broken Things* coming out in April. Her books have been honored with New York Times best-seller status, The International Reading Association children's books award, among many other awards. She was a favorite of Worthington Estates teacher, Pauline Siegel.

The Pauline H. Siegel Eclipse Fund was established shortly after Pauline died in a tragic accident in August 2017. The Fund supports and accelerates research on rare neuro-immune disorders. Pauline was an elementary school teacher for 25 years in the Worthington School district. She was diagnosed with transverse myelitis in 1994 and shortly thereafter helped to establish The Transverse Myelitis Association.

6:00 pm Meet the author and Eclipse Fund reception
7:00 pm Author talk and book signing to follow

The Transverse Myelitis Association
Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065-8806

CHANGE SERVICE REQUESTED

Announcements

2018 AZ Walk-Run-N-Roll: March 24, 2018
Author Night for The Eclipse Fund: March 28, 2018
2018 OH Walk-Run-N-Roll: April 29, 2018
2018 Quality of Life Family Camp: July 22-26, 2018

Contact us

The Transverse Myelitis Association

PO Box 826962
Philadelphia PA 19182-6962

info@myelitis.org
855-380-3330

myelitis.org