

the transverse myelitis association

newsletter

fall 2017



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

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

IN LOVING MEMORY OF PAULINE SIEGEL

It is with deep respect and admiration, and a profound sense of loss, that we remember our dear friend, Pauline Siegel, who passed away on Tuesday, August 15, 2017.

Pauline was our “Queen,” and her light will continue to guide us. It was Pauline’s 1994 diagnosis of TM that catalyzed the formation of the TMA. For over 20 years, she worked with her husband and TMA President, Sandy Siegel, to educate, support and inspire others in the TMA community. It would be difficult to find a TMA member who has not been touched by the Siegels’ collective warmth, compassion, and commitment to the organization.

Outside of the TMA, Pauline’s life revolved around her family, students, and friends. She taught elementary school in Ohio for twenty-five years. She was loved – as a wife, a mother, a sitte (grandmother), a daughter, a sister, an aunt, a teacher and a friend to many. She was also a loving mom to her cherished service dog, Kazu.

Pauline and Sandy shared an incredible bond that was evident whenever you saw them together or spoke to one of them about the other. Pauline was the light and love of Sandy’s life, and the driving force behind the incredible and impactful work Sandy has done on behalf of the TMA community.

At Pauline and Sandy’s wedding, their son, Aaron, sang “Here Comes the Sun.” In remembering that celebration, Aaron noted that “the sun was an important symbol for the hope and optimism of their new life together.” During their honeymoon, on a beach in the US Virgin Islands, Pauline and Sandy watched a solar eclipse. And just after Pauline was laid to rest, her mourners joined people across the country in lifting their eyes to the heavens to witness that very same sun go dark during the recent total eclipse. In hiding its face in darkness, the sun mourned the loss of Pauline, a truly beautiful soul, with us.

Despite the difficulties she faced, Pauline always managed to see and feel the blessings of her experience, and never lost hope for a better tomorrow. Pauline lived her life trying to improve the future of other people with TM and other rare neuro-immune disorders – NMOSD, ADEM, ON, and AFM. She was a powerful advocate, and touched us all with her compassion and vitality. It is with great honor that we announce the establishment of The Eclipse Fund in memory of Pauline H. Siegel. The fund is designed to drive transformative research that will eclipse all of our efforts to date in further restoration and repair.

Pauline’s is a legacy of hope and, in her name, we will drive research forward to find a cure for rare neuro-immune disorders and enable spinal cord repair.

myelitis.org/pauline



HOW TO PARTICIPATE IN A GENETIC STUDY OF TRANSVERSE MYELITIS

In our summer newsletter, we published an article about a rare genetic mutation found in familial transverse myelitis. The mutation, named VPS37A, was discovered in two sisters who were both diagnosed with TM at different points in their life. Dr. Michael Levy screened an additional 86 TM patients and found another patient with the same rare mutation. According to Dr. Levy, “It is statistically beyond coincidence to find three human beings with this same rare genetic mutation unless it has something to do with the rare disease they all share, TM.”

Dr. Levy and his colleagues at Johns Hopkins University have recently been awarded a research grant from the TMA to continue studying this genetic mutation in TM patients. The study will be conducted by collecting DNA samples from consenting participants using saliva kits. Dr. Levy hopes to recruit TM patients from across the United States and potentially worldwide. Travel will not be required to participate in this study as the saliva kits can be mailed, and clinical information can be provided electronically.

If you are interested in participating in the study, please visit our website: myelitis.org/clinical-studies-and-trials/neuromyelitis-optica-anti-mog-disease-transverse-myelitis-optic-neuritis-biorepository.

The potential implications of this study are vast, as this is the first finding of a genetic cause of transverse myelitis. Although the study may yield only a small percentage of TM patients with the VPS37A genetic mutation, it can still help researchers learn about other cellular and immunological mechanisms that play a part in transverse myelitis.



WELCOME OUR FALL INTERN!

ROZALINA SULEYMANOVA

Rozalina Suleymanova is currently a public health graduate student at George Washington University. She graduated with a Bachelor's in neuroscience and linguistics from the University of Pittsburgh in 2015. Rozalina aspires to become a healthcare provider in the future and plans to use what she learns from her public health program to become a patient advocate in health policy.

Rozalina has always been passionate about research in neuroscience and is excited to join the Transverse Myelitis Association to serve the community of individuals affected by rare neuro-immune disorders. Her past experiences include working in a laboratory setting to investigate potential environmental effects on dopaminergic degeneration, the latter of which cause Parkinson's disease. She has also worked on a project investigating the effects of mutations on genes encoding neuropeptides on synaptic transmission, which is the way cells in the nervous system communicate and relay messages. Although she primarily has experience with the *C.elegans* biological model systems, Rozalina is excited to contribute her efforts to the research being done at the TMA.

UNCOVERING THE RELATIONSHIP BETWEEN HCV AND TRANSVERSE MYELITIS

*By Dr. Elena Grebenciucova / Instructor of
Neurology at Northwestern Memorial
Hospital/Northwestern Medicine*

Dr. Grebenciucova was a recipient of the James T Lubin Clinician Scientist Award in 2016 under the mentorship of Dr. Brenda Banwell at the Perelman School of Medicine of The University of Pennsylvania.

During my Fellowship year, I had the opportunity to take care of patients with transverse myelitis and other neuro-inflammatory conditions. I was able to learn extensively from my experiences and from working with many of the adult and pediatric experts in the management of transverse myelitis and other neuro-inflammatory conditions. This experience allowed me to appreciate the many unique challenges in the diagnosis and care of patients with transverse myelitis and has strengthened my dedication to the community of patients affected by neuro-inflammatory conditions.

My research focused on the association between transverse myelitis and hepatitis C virus (HCV). Although most people are familiar with hepatitis C virus because it can cause liver cirrhosis and failure, many may be unaware that HCV is also considered to be an infectious cause of myelitis. However, literature explaining how these two disorders are connected is poor, resulting in many neurologists no longer testing for HCV in the setting of TM.

I hypothesized that the reason people with HCV may develop TM is because HCV predisposes them to several autoimmune mediated disorders such as lupus, Sjogren's or possibly neuromyelitis optica spectrum disorder (NMOSD), all of which can cause TM. I retrospectively looked at the charts of 262 patients with TM in order to assess whether these autoimmune

disorders occur more frequently in patients who are positive for HCV versus those who were HCV negative. HCV was tested in only 45% of cases presenting as TM. After excluding records with insufficient data (where TM was mentioned, but there was no sufficient description or testing to ascertain the inflammatory nature of TM; or if TM was mentioned in the history without any data), as well as duplicates and coding errors, 118 evaluable cases remained. Out of 118 cases, 53 were tested for HCV. Further detailed screening of the medical record for exclusion criteria (vascular/ischemic event, infectious etiology, history of spinal radiation, history of

spinal trauma/compressive etiology, neoplasm) resulted in elimination of 14 additional patients from the cohort. Of the 39 remaining cases, 34 were HCV antibody negative, and 5 patients were HCV antibody positive. Out of 65 cases coded as TM but not checked for HCV, 51 were subsequently confirmed as TM.

I found that all cases of TM in the setting of HCV seropositivity were associated with either lupus or NMOSD, but not Sjogren's disorder. However, my sample was ultimately small, as only 45% of patients with TM were tested for HCV and some charts could not be included in the study, as they

did not contain all the information necessary to ascertain the nature of myelitis and its workup.

Currently, the Centers for Disease Control and Prevention (CDC) estimates that in the U.S. 3.5 million people live with HCV, while 40-85% of these people are not aware of their infection status.

As HCV has recently become nearly always curable, testing for HCV in the setting of TM is strongly warranted. Further larger-scale studies to characterize HCV's role in TM and its recurrences are needed.

THE 2017 TMA FAMILY CAMP

By Rebecca Whitney, Pediatric Programs Manager, TMA



Our TMA family was once again welcomed by the awesome staff and volunteers of the Center for Courageous Kids in Scottsville, KY, July 15-19, 2017, for five days of fun, learning, and networking. The hot, humid Kentucky summer was in full swing as families, medical professionals, and TMA volunteers from across the U.S. and Canada arrived and were greeted by familiar friends, friends we've only known by voice or social media, and those that

many of us have come to consider our extended family. It was another year of coming together, of getting to know one another, reconnecting with old friends and colleagues, and of learning more about our children and the support available for them. Most importantly, we gathered to simply have fun and enjoy each other's company without having to worry about being different from peers or other families.



Camp is a true highlight of the year for us at the TMA, too. The families and children of our community are at the forefront of our hearts and minds as we discuss, prepare, and plan for the following year's camp week all while we're still in the middle of enjoying the company of everyone at CCK. It's amazing to see the culmination

of both the TMA's and the community's efforts come together in such an awesome way. Camp offers an opportunity that so many in rare disease communities don't get the privilege of experiencing once diagnosed. This is true for many in our own community. While at camp, the focus is on enjoying the time and the traditional camp

experiences that may otherwise be difficult for our children because of their diagnosis. At CCK, the staff and volunteers make certain that if a child wants to ride a horse, go fishing for the first time (maybe ever!), do archery, create in woodshop, go bowling, or try their hand at various arts and crafts, they get to do so.



Our medical and educational volunteers come from across the country too, and provide their time and undivided attention to our children and parents in ways that speak volumes of their hearts and character. They come to camp on their own time to share and connect with those who may not otherwise be able to access a specialist in rare neuro-immune disorders. They allow for the parents and children to ask questions and glean knowledge that they are then able to take back to their own providers, enabling them to be the very best advocates for their children's care. Likewise, the medical professionals learn from the families and their needs in ways that aren't conducive to a 15-minute clinic visit. Camp is a vital program not only for our children and families, but for our community as a whole. The reciprocity between families and clinicians means we have the ability to take what we've learned from one another back to our various daily lives with the hope that we may ultimately improve the quality of life of all of those diagnosed with a rare neuro-immune disorder.

Overall, camp this past year was an incredibly fun time. Seeing the joy and the happiness on the kids' and parents' faces was simply incredible. From watching some get on horseback for the very first time, to catching their





first fish (and kissing it before throwing it back!), to the artistic talents that came out of woodshop, and dancing after breakfast to get our blood really pumping for the day...there are so many moments that are remembered so fondly and always bring a smile to my heart. Of course, I would be totally remiss if I left out messy games! An initiation of sorts for those new to camp and a welcome tradition for those returning, it's amazing to see just how much joy a little paint, ice cream (not to be eaten!), a lot of oatmeal, chocolate pudding, and shaving cream can bring to kids and adults alike. Even for those opting out of the mess, it's a riot to witness how much crazy fun everyone is having. One of the biggest joys of getting messy is the chance to dance in the overwhelming shower of water from the fire truck that washes away the worries and concerns of these rare diagnoses even if only for that blessed moment. Seeing the practitioners, volunteers, parents, siblings, kids, volunteers – everyone come together and have such an insane amount of fun is nothing short of inspiring. I personally opted out of messy games this year but part of me wanted so badly to dance in the cold water to wash away the mess of stress and worry, too. Next year...

The TMA is pleased to announce that our treasured partnership with CCK continues and they are welcoming us back next year. If you've never experienced camp and have a child diagnosed with ADEM, NMOSD, ON and TM (including AFM), please look for the announcement on our website for TMA Family Camp 2018! Be sure that you are signed up to receive our email announcements so you are informed when applications become available. If you've been to camp before and it has been a couple of years since you joined us at CCK, we welcome you back with open arms, and can't wait to see you again! It truly is an inspiring week and an opportunity to be together with our extended family. As always, our dear Sandy was never without his camera and because my words simply cannot express the full depth and breadth of what camp is to so many, I'll let his beautiful photos and the smiles he captures do the rest of the talking.

Spinal Life
AUSTRALIA

It's your place.

Be part of a leading group for
people with Transverse Myelitis

- › Share lived experiences with peers
- › Stay in the know with current advice
- › Be in safe hands with
our qualified professionals

spinal.com.au





Spinal Life Australia presents the Transverse Myelitis Awareness Series

Jeanette Kretschmann

This year, Spinal Life Australia made a decision to highlight the community of people living with Transverse Myelitis and other neuro-immune conditions.

The first event in our Transverse Myelitis Awareness series of three was to hear the journey of one of our members living with Transverse Myelitis. Gyl Stacey, a director on the board of Spinal Life Australia, was diagnosed at the age of 15.

Gyl lived in Inverness, Scotland at the time and took us on her personal journey, not allowing her disability to get in her way. Gyl's inspirational message included:

1. Recognise there's a time to move on and make the most of how things are
2. Don't make disability define you
3. Find your "purpose" and create a plan
4. Feel some fear but do it anyway – take up opportunities when they arise
5. Create a good support network

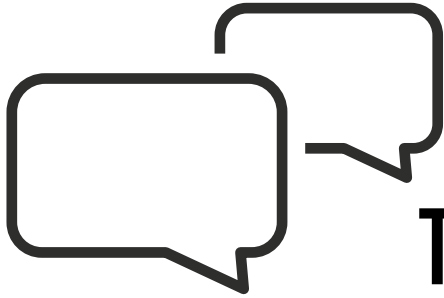
Members joined us for lunch and took the opportunity to network with others, welcoming a newly diagnosed person who was only eight weeks into her journey.



The second program in our series was dedicated to the memory of Pauline Siegel. For this day, we were joined via video link with Dr. Benjamin Greenberg in Texas, USA. Dr. Greenberg's talk was on "The importance of understanding Upper and Lower Motor Neurons." Dr. Greenberg's talk was very well received and the news about the upcoming research using stem cells was very exciting. A small group of members joined us at our offices in Woolloongabba along with nine people via video link from their home computers. A question and answer segment followed, and the people joining us remotely were able to type their questions for Dr. Greenberg to answer. We thanked him for graciously giving up his

Sunday evening to talk to us. Special thanks also go to Jim Lubin whose expertise with linking us all together is fantastic, along with many thanks to the TMA for making this all possible. We received wonderful feedback from people around Australia and New Zealand who shared the day with us. For anyone interested, Dr. Greenberg's recording of the day can be viewed using the following link, youtu.be/rAHyD3NvIDc.

The third day in our series will be in November (date TBA) and will deal with pain management in Transverse Myelitis.



THE MYELITIS HELPLINE

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

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

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

myelitis.org/mhl

VISIT OUR RESOURCE LIBRARY

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

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

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 Nancy Dove. Nancy is the Chicago Support Group Leader. Due to our community members being so spread out across the Chicago area, a few months ago Nancy decided to hold multiple support group meetings in different sections of the city to ensure that as many people as possible had the opportunity to attend a support group meeting close to home. We want to thank Nancy for her hard work and dedication to our mission and increasing awareness about rare neuro-immune disorders!





For more information on how to volunteer with the TMA please email info@myelitis.org

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

I first became aware of the TMA shortly after I was diagnosed with TM in 2012. I had been misdiagnosed for 17 years. My symptoms, including heavy arms and legs, foot drop and falls, extreme fatigue, neurogenic bladder, muscle pain, and numbness, began in 1995. This onset, at age 44, occurred after a bad bout with the flu and was gradual over a few months. I was never completely paralyzed but was laid up at home because of difficulty walking. I saw various doctors, including a neurologist, who did an MRI of my lumbar spinal cord, but found no problems. I was diagnosed with severe depression and put on anti-depressants based on the conclusion that I was having a conversion reaction to my mother's illness and death from ALS. The doctor visits, tests, lumbar MRIs, and struggles with walking, fatigue, catheterizing and pain continued as the years went by. ALS was ruled out. I eventually gave up, concluding I had chronic depression and just had to live life with a greater degree of difficulty than before.

Then, through a series of unlikely events and a very smart endocrinologist who thought I "walked funny," I found a new neurologist at Northwestern Hospital in Chicago and underwent a cervical MRI. There it was at last! A

lesion at C5-C6 that explained every one of my physical difficulties for the past 17 years. Not only that, but it had a name: Transverse Myelitis. I googled it immediately and spent the next several hours reading about my uninvited traveling companion that now had a name. I discovered the TMA and the miraculous revelation that I WAS NOT ALONE. This was life changing!

As I followed the TMA online, I saw references to events in some states called "Walk-Run-N-Rolls." I kept looking for one in Illinois; maybe I could actually talk to another human being who would understand what no one, including me, had understood about my life for 17 years. But there were none. I even sent a message to TMA, asking about a Walk near me. Chitra Krishnan, Executive Director, said there were none, but I was welcome to start one. I had no experience in such things and no idea where to begin, but I was on a mission so of course I said yes. My motivation was two-fold; first was the astounding lack of awareness of TM among medical professionals and the world at large. Second, was the loneliness and lack of support I experienced in those 17 years. No one should go through that. I believed that a successful event could address both problems.

What has your volunteer experience been like?

In 2013, I chaired the first Illinois Walk-Run-N-Roll with a fantastic committee of volunteers. I believed then, and still believe now, that besides my family and my career, it may be the most important thing I have done in my life. Nearly 300 people attended and we raised nearly \$40,000 for the TMA. It was more exciting and successful than I had ever imagined, thanks to the collective creativity, energy and generosity of everyone involved. Best of all, many patients with rare neuro-immune disorders met others like themselves for the first time and families learned more about the illnesses that changed their lives. The support we received from Chitra and innumerable TMA staff and volunteers made it all possible. Illinois Walks were held again in 2014 and 2015. I was proud to serve on the steering committees those years, but so happy and grateful that volunteers Liz Beutel and Debbie Bertolami took over leadership when I found that my full-time job, four-hour daily commute, and general struggles with the effects of TM were more than I could handle, at least for the time being.

Always in the back of my mind was the fact that retirement would be possible within a few years. In the years since the first Walk, I had not been surprised to discover that once-a-year events were wonderful, but many in our community needed more. Years earlier, Nicki Garrigan, a dedicated volunteer, had convened support groups in Illinois. These had been very popular and Nicki had been a beloved leader. Sadly, Nicki had passed away and the support group meetings had not continued. I expressed my interest in learning more about set-

To me, the TMA means hope, support, education and the opportunity to serve others. It also means friendships and being part of a community, with its up and downs, love and loss.

ting up a support group program, and the TMA offered training. I started working with Timi Schruppf, who walked me through the screening and training process. I retired as of December 31, 2016, and after sleeping for about a month, started baby steps toward beginning a support group program. Because the Chicago area is so large and populations are so widely dispersed, we started by setting up "formation" meetings in four different suburbs. Those initial meetings have all taken place and we are now refining logistics and programming.

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

Yes, and of course it's "just do it." Other than a commitment in supporting others with TM and related disorders and a willingness to respect patients' privacy, no specific qualifications are required. I'm not a social worker or medical professional. I don't have personal experience as a parent or fundraiser, and I'm certainly not wealthy. However, the skills I do bring to the table are easily

augmented, and then some, by other volunteers. There is so much talent and such a willingness to share in the TMA community. You don't need to think of and do everything yourself. You will find a wealth of resources both nationally through the TMA and locally in your community.

What does the mission of the TMA mean to you?

To me, the TMA means hope, support, education and the opportunity to serve others. It also means friendships and being part of a community, with its up and downs, love and loss. I love that the TMA is so hands-on. Many times, volunteering in non-profits means having infrequent and tangential contacts with leadership. That is not true with the TMA. Chitra took the time to have lunch with me when I first expressed an interest in the TMA shortly after my diagnosis. She and Dr. DeSena attended our first Walk. Rebecca Whitney came to our 2014 Walk. Sandy and Pauline Siegel came to the 2015 Walk. Hearts in Chicago were broken along with everyone in the TMA family when we lost Pauline. The TMA is a lifeline in every sense.

CONTINUING OUR 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.

The **myelife. my hope.** campaign raised awareness and shined the spotlight on people diagnosed with rare neuro-immune disorders, caregivers, and medical professionals.

As we continue to raise awareness and learn from our community, we are honored to share the story of another Hope Ambassador, Huy Tran.

For more information on how to become a Hope Ambassador and to read about our other Hope Ambassadors, visit: tma.org/2vYLFbR

Meet Huy Tran

In February of 2015, I was unexpectedly rushed to the emergency department at UC San Diego after showing signs of altered mental status. The next month, I was airlifted to a medical center closer to my hometown in Santa Clara for ventilator weaning and rehabilitation. The memories are still crisp and clear when I woke up from my medically-induced coma. When I was told I was diagnosed with acute disseminated encephalomyelitis (ADEM), a rare neurological disorder, my outlook on life ahead completely changed. My dream of one day becoming a doctor seemed to be impossible and shattered when I was a patient.

I was in a very dark place in my life not knowing if recovery was possible and even if so, what it would entail. I was absolutely frustrated that I had to undergo comprehensive therapies in addition to taking Keppra, an antiepi-

leptic medication, on a daily basis. However, witnessing the immense love and commitment from the healthcare providers and my family pushed me to try my hardest to comply with anything that was required to get me better. Thankfully, given my rapid recovery, I was discharged to my older sister's home in late May for continued comprehensive therapies through Rapid Without Walls®. I successfully completed my speech therapies in late October while concurrently enrolled in one course at community college. I was overcome with joy and felt so blessed when I was finally approved to return to UC San Diego last January to complete my undergraduate degree in public health. My life seemed to have picked up momentum in a bright direction.

I officially graduated last June and then started the post-baccalaureate program through the UC Davis School of Medicine. Every day, I feel incredibly grateful to be surrounded by unimaginably bright, supportive, and inspiring people who believe in my potential to become a doctor. They are my family away from home. There aren't enough words to express how grateful I am for everyone and everything that has happened to get me to where I am today. The most difficult part about living with a rare neuro-immune disorder for me is its invisibility. Even though I was fortunate enough to return to school, I still faced significant academic and emotional challenges that required me to reach out to the student disability center for appropriate accommodations and counseling office for additional help. I also realize that the stress of critical illness on family is just as significant as for patients. Since I am currently a full-time student living hours away from home, I realize the importance of keeping my family updated as often as possible. My current goals, aside from performing well in school, are to visit Starbucks (my guilty pleasure) less often, be more physically active outdoors, and most importantly to make my unique journey more visible to others within the community in order to empower those who are going through what I did.





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

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

Principal Investigator: Michael Levy, MD, PhD

Study Site: Johns Hopkins University

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

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

Study Sponsor: AstraZeneca

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

Principal Investigator: Nadia Barakat, PhD

Study Site: Boston Children's Hospital

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

Principal Investigator: Benjamin Greenberg, MD, MHS

Study Site: University of Texas Southwestern



7 **The PREVENT Study**

Study Sponsor: Alexion Pharmaceuticals

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

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

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

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

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

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

11 **Patient Reported Outcomes for Bladder Management in Spinal Cord Injury**

Study Sponsor: Neurogenic Bladder Research Group (NBRG)

12 **The TMA Registry**

NIH/NCATS GRDR® Program

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

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

NEW RESOURCES AVAILABLE! PODCAST AND SYMPOSIA VIDEO TRANSCRIPTS

If you have ever visited the TMA's website and used the Resource Library, you know that it contains hundreds of resources filled with information on rare neuro-immune disorders. All information in the library is categorized by disorders, symptoms, and type of resource such as podcast recordings, symposia videos, newsletter articles, published literature summaries, information sheets, and more. The *Resource Library* is one of the best sources of information available to people who are diagnosed with a rare neuro-immune disorder.

Under the direction of our Board Member Jim Lubin, the TMA is excited to announce a new type of resource - transcripts of our Ask the Expert Podcast recordings and educational symposia video recordings! The goal of this project is to make our audio and video resources available in written format. This will provide a better format to share the information with health care providers, insurance companies, and others.

Due to the work of Jim and several volunteers, we have already transcribed and published four podcast transcripts and two symposium video transcripts on our website. Our goal is to create transcripts for all of our symposium videos and podcasts. We hope that by providing these resources, we can empower our members and all who are diagnosed with a rare neuro-immune disorder with more information and help them advocate for themselves.

If you are interested in volunteering to transcribe symposium videos or podcasts, we can use your help! Please email jlubin@myelitis.org for more information on how to get involved.

Upcoming Podcasts

Rheumatological conditions and ADEM, NMOSD, TM and ON
Monday, December 11, 1:30 pm ET

More info: tma.org/2017-dec-podcast

MONTANA AWARENESS WEEKEND

By Dianne Elliott, Montana Support Group Leader

The TMA Montana support group hosted its first Educational Conference and Walk-Run-N-Roll event in August 2017. This two-day awareness weekend featured a mini-symposium on Saturday with guest speakers and a Walk-Run-N-Roll on Sunday morning at a beautiful community park in Billings, MT. The support group members, and their family and friends agreed both days were amazing, and the comradery was unforgettable!

Saturday included a four-hour informational and collaborative session for those with ADEM, NMOSD, ON and TM (including AFM), along with family and friends. Approximately 50 people were present and shared their stories and tears, listened to speakers including Sandy and Pauline Siegel, Billings Clinic's own Dr. Sara Qureshi, and Dr. Brenda Roche, and created lasting relationships. Sunday brought perfect weather for the 2017 MT Walk-Run-N-Roll and even more people joined for this special occasion. Both days created amazing memories. We certainly look forward to another event next year!

A special thank you to Ferguson Enterprises for being such a generous sponsor!



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