the transverse myelitis association

newsletter

winter 2017

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 https://facebook.com/myelitis.

THE EDITOR'S COLUMN

For 100 days, The Transverse Myelitis Association presented the stories of 100 Hope Ambassadors from our community. The Myelife. My Hope Campaign (*https://myelifemyhope.org*) has offered us insight into the diversity that exists among our members. The Hope Ambassadors who have ADEM, NMOSD, ON or TM/AFM, had one or multiple inflammatory attacks somewhere in their central nervous systems. These attacks manifest as long-term symptoms quite differently between people. Some of that diversity is accounted for by the level or levels of the spinal cord that are impacted; or the involvement of the optic nerve or the brain, or the severity and the permanence of the damage that is done. And some of that diversity emanates from the unique qualities that belong to each person who has this experience. Nerve pain, for instance, is a highly subjective phenomenon that can only be expressed and characterized by the person who, unfortunately, has this pain.

Our members come from every continent on the face of the earth, and while we have members from more than 100 countries, I believe it is likely that people from every country, society and culture have these disorders. We just don't know about them, because they lack the technology to find us or communicate with us, or their society does not have the medical systems in place to accurately diagnose these disorders. Can you imagine being totally paralyzed, unable to urinate or defecate, with nerve pain and spasticity and have no one be able to explain what is going on with you? Of course you can, because so many of our members go through this experience in getting a diagnosis; some for very long periods of time. Well, there are likely some people who never receive a diagnosis of any kind. And while this may happen with greater frequency in Ethiopia, I think it is also happening in Kansas.

These disorders happen to males and females; the acute attack can happen to a person at any age, from infancy and throughout adulthood. Our members represent the incredible diversity of human beings that exists on our planet.

Despite this diversity, there is a very human experience that is shared by the people who have these rare disorders and their families. I am in the process of completing a book about Transverse Myelitis. The following paragraphs characterize how people experience this inflammatory attack; and the same applies to ADEM, AFM, NMO and ON.

It is not easy to deal with change when you can see it coming. Even the most exciting and joyous events in our lives, such as marriage or becoming a parent cause us emotional and psychological stress, because change is stress. Getting TM is another kind of stress. It is the worst kind of stress. There is nothing positive about getting sick and being left with permanent spinal cord damage. It happens without warning so that no one is given any chance to prepare. And it happens with such immediacy that no one is given a chance to adapt. There is nothing great about breaking one's neck in a car accident, but there is an understandable cause and effect. One might be pretty resentful or angry or bitter about a

football injury, but they aren't going to be particularly confused about how they became paralyzed. This is not the case with TM.

No one is told by a doctor, "I've got some bad news for you. We just got back your test results and you're going to be developing some pretty challenging symptoms." No, with TM, all of the symptoms happen – sometime between now and tomorrow morning. After you are completely paralyzed, unable to urinate, unable to have a bowel movement, having horrible spasms and/or excruciating nerve pain, some doctor tells you, "Well, you know the bad news, and it's called Transverse Myelitis."

Transverse Myelitis is the perfect storm of emotional and psychological chaos – without warning, inexplicable, immediate, aggressive, severe, and for many, permanent. Getting TM is like the nuclear explosion of human experience; no one will ever have a more memorable event in their entire lives, regardless of what else happens to them. When you talk to a person who has TM and ask them to describe their experience with the disorder, it does not matter if they had the acute attack yesterday or forty years ago, they are going to describe their acute attack to you; in the most amazing detail. They will tell you the date and the time of day that the inflammatory attack began. They can describe the first tingling sensation and what toe on which foot it began in; how it traveled up their leg and at what speed. They can tell you just how far up the tingling and numbness went before it headed back down the other leg. They will tell you when and how they figured out that they could not urinate. They can tell you when and how they figured out that their legs would no longer move or allow them to stand. They can tell you precisely how difficult and horrible the pain was for them. And they can chronicle their entire experience in the emergency room, in the hospital, with the doctors, nurses and therapists and their time in a rehabilitation hospital, if they were fortunate enough to get rehabilitation. And if the TM experience happened to a child, the child and the parents will be able to describe this experience in the same detail.

Everyone needs to tell their story. I have seen it at every opportunity we've had to bring people together who have these rare disorders. At the very first meeting in Columbus in 1997, a small group of people sat in a circle and took turns telling their stories. When we came together in Seattle in 1999, the most poignant event was the question and answer session where people were given the opportunity to share their stories. Over the years, I've had support group leaders ask me what they should do

for their programs. I've told them that all they should do is make a circle, and people are going to tell their stories; and the meeting isn't going to end until everyone has had their turn.

In all the years I've been doing this work, I've never heard a single story that wasn't way beyond incredulous. I can remember the first time I spoke with a person who had NMO. It was many years ago, and I didn't know anything about NMO. The lovely woman I was speaking with was quadriplegic and totally blind. How does this happen to a person? I thought about this woman non-stop for a very long time...and I still think about her often. Some parents put a totally healthy baby to bed at night and arrive at the crib in the morning to find a totally paralyzed child; how does one get their mind around that kind of experience?

And beyond the little that is being uncovered about the disease process in NMO, we're still pretty much clueless about what is going on with ADEM, ON, TM and AFM. Whatever you might hear about associations with viruses or other environmental triggers, those relationships aren't explaining anything about how and why the immune system is performing this horrible, dysfunctional activity. The experience is horrendous for the person who goes through it, and for everyone who loves this person. The experience is unexplainable. It is the magnitude of the event, the intense and lifelong consequences, the total mystery surrounding the how and why that drives people to want and need to share their stories. There is something cathartic about the sharing, but the telling is about more than the emotional release. I believe it is also a way to grapple with the reality of the most surreal kind of experience a human being is ever going to have. And what better audience for this ritual telling than a group of people who understand precisely what the person is talking about...because it also happened in this same way to them!

We identified about twenty people to be Hope Ambassadors to initiate the campaign. The remaining 80 people who made up the 100 day, 100 stories campaign, read the stories and wanted to be a part of this experience; they approached us. People need to tell their stories. This is by far the most effective awareness campaign about these disorders that I have witnessed since the inception of the TMA. People from our community have been given an opportunity to learn about the disorders, to meet some of the remarkable people who are our members, and to also meet some of the medical professionals who are

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devoting their careers to improving the quality of life for people who have these rare neuro-immune disorders. I have observed the sharing of so many of these stories among family and friends who are not a part of our community, and the comments associated with this sharing reflect a great deal of empathy and compassion.

The Myelife. My Hope Campaign has created a tremendous platform for sharing these stories and for offering the public an opportunity to learn something about our community.

Given the profound impact these stories have had for the participants and for the people who have read and shared the stories, the TMA is urging you to share your own story, if you have not already done so. We will continue to collect and share the stories, and we will create a permanent home for them on our website. It is a beautiful and effective way for us to learn about each other and to educate the world about your incredible experiences. And for people who have lost a loved one who had one of the rare neuro-immune disorders; please consider sending us their stories, as well. It would be a wonderful way to honor their memory. You can send your stories to *info@myelitis.org*.

Please take good care of yourselves and each other,
Sandy

2017 TMA JAMES T. LUBIN CLINICIAN–SCIENTIST FELLOWSHIP AWARDED TO JOHNS HOPKINS TRANSVERSE MYELITIS CENTER

The Transverse Myelitis Association's Board of Directors has approved funding to Dr. Olwen Murphy to pursue a clinical-research Fellowship at The Johns Hopkins Transverse Myelitis Center (JHTMC) in Baltimore, MD, under the mentorship of Dr. Carlos Pardo-Villamizar, Director of the JHTMC.

The two-year Fellowship starting in 2017 will be focused on multi-disciplinary clinical training in neuro-immunology with a focus on rare neuro-immune disorders. Dr. Murphy's research will be on predicting outcomes after a diagnosis of a transverse myelitis using current imaging techniques and spinal fluid analysis. The goal of the research project is to identify patterns or biomarkers that can be used in day-to-day clinical practice to identify benefits from therapies and help make better decisions about care.

Dr. Olwen Murphy is currently a neurology resident at The Royal College of Physicians in Ireland with a passion for neuro-immunology. She would like to establish a career as a clinician scientist in neurology and neuro-immunology, with special focus on rare immune-mediated disorders.

This is the fifth grant 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, and current Fellows, Dr. Cynthia Wang at the University of Texas Southwestern and Dr. Elena Grebenciucova at the University of Pennsylvania. Over the last five years, the TMA has committed $700,000 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 and The Johns Hopkins University.

"It is our goal to expand the centers of training and research over the next few years and investment in training clinician-scientists remains a high priority for the Board of the TMA. This Fellowship would not be possible without the generosity and support of our community," shared Chitra Krishnan, Executive Director of the TMA.

For more information about James T. Lubin Fellowship funding, visit https://myelitis.org/shaping-the-future/our-programs/james-t-lubin-fellowship

I am excited to start working at the Johns Hopkins Transverse Myelitis Center in 2017. The James T. Lubin Fellowship grant will facilitate my clinical training in neuroimmunology. We also have an interesting research programme planned, focusing on potential biomarkers in patients with transverse myelitis. I feel privileged to be able to work in a department with vast clinical expertise and academic achievements in the field of neuroimmunology. This is possible due to the support of The Transverse Myelitis Association

- Dr. Olwen Murphy

THE TMA REGISTRY

The Transverse Myelitis Association has joined The NIH/NCATS GRDR® Program (Global Rare Diseases Patient Registry Data Repository) to create a new patient registry. 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. Our 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 here: *https://ncats.nih.gov/grdr*.

Many of our members have shared information about their diagnosis, treatment and outcomes over the years. The information you shared continues to help us guide our programs and research. **Thank you!**

The TMA registry has been designed to learn more about the natural history of rare neuro-immune disorders, treatments and outcomes using standardized tools.

WHO CAN PARTICIPATE

› Individuals diagnosed with

- Acute Disseminated Encephalomyelitis
- Neuromyelitis Optica Spectrum Disorder
- Optic Neuritis
- Transverse Myelitis, including Acute Flaccid Myelitis

› Consent to participate must be provided by an eligible adult participant or a legal guardian, if the participant is under the age of 18 or is an adult who is unable to provide consent for him/herself.

› Parents or a legally-authorized representative can also enroll on behalf of patients who are deceased. When a legal guardian/representative is completing The TMA Registry, an additional signature is required for participant assent, which is required if an individual is 7 years of age or older and is cognitively able to provide assent.

CONTACT US

For more information and questions about The TMA Registry, please contact The TMA's Research and Data Manager, GG deFiebre, at *gdefiebre@myelitis.org*.

AN UPDATE ON CAPTURE

2016 marked the second full year of active enrollment for CAPTURE. As of November 4, 2016, a total of 83 children (33 online, 50 in-person collectively for all participating sites) had enrolled to participate in this critically important and the first large-scale study of pediatric Transverse Myelitis and Acute Flaccid Myelitis. Our enrollment has continued to increase since November; however, we need your help.

We are hopeful and still working diligently towards obtaining our original goal of enrolling 180 children diagnosed with TM or AFM to track outcomes of their acute treatments. Since the start of CAPTURE, we have made changes to aid us in reaching this goal. The enrollment timeframe was moved from 90 to 180 days after symptom onset to allow families more time to learn about the study and consider participation. We also added two centers, University of Colorado (Dr. Teri Schreiner) and Cincinnati Children's Hospital Medical Center (Dr. Allen DeSena), to enroll in-person participants.

If your child has been diagnosed with TM or AFM within the last six months, please contact us about the study.

We are happy to answer your questions and provide you with the additional information you may need to consider participation. Online enrollment in CAPTURE consists of sharing treatment and imaging records with the study investigators and completing questionnaires at different time points post diagnosis. There are no travel requirements or changes required to your child's treatment or therapy programs. If you have any questions at all or are hesitant to participate, please contact Rebecca Whitney of The TMA or Tricia Plumb of UTSW. Either one of us are willing to help answer your questions!

Children diagnosed with Transverse Myelitis or Acute Flaccid Myelitis between the ages of 0 to 18 years (or 17 years at onset) within 180 days of the initial onset of symptoms and within North America, are eligible to enroll in CAPTURE. Please continue to spread the word about the study on your social media outlets, and within your hometown hospitals and rehabilitation centers. If you hear of a child diagnosed, encourage families to contact the TMA, not only for additional information regarding CAPTURE, but also for support and resources.

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Impact of Autologous Mesenchymal Stem Cell Infusion on Neuromyelitis Optica Spectrum Disorder: A Pilot, 2-Year Observational Study

Bone marrow-derived mesenchymal stem cells, or MSCs, are a type of stem cell that can differentiate, or turn into other types of cells. They are taken from a patient's own bone marrow. They have been used in several autoimmune diseases, including multiple sclerosis. MSCs can repair tissue and also inhibit the immune system, offering a potential treatment for neuromyelitis optica spectrum disorder (NMOSD). MSCs are given through an infusion.

Researchers recruited participants between September 2013 and January 2015. Participants were individuals with a diagnosis of NMO (based on criteria from 2006; diagnostic criteria were recently updated and can be found by going to *https://myelitis.org/international-consensus-diagnostic-criteria-for-neuromyelitis-optica-spectrum-disorders*), or with either recurrent optic neuritis or longitudinally extensive transverse myelitis and who were anti-AQP4 antibody positive. They were assessed at baseline, which was the day before treatment with MSCs, and 1, 3, 6, 9, and 12 months after treatment. The researchers looked at functional and structural outcomes. Functional outcomes were a scale (EDSS) that measures disability, a visual acuity test, and a cognitive test called the Paced Auditory Serial Addition Test (PASAT). Structural outcomes were MRIs of the optic nerve, brain, and spinal cord, and optical coherence tomography (OCT), which looks at the retina. They looked for relapses, which were new or recurrent neurological symptoms that lasted at least 24 hours. These symptoms were not counted if they were because of fever or infection. To be counted as a relapse, there had to be at least 30 days of separation from a previous episode. They also looked at the safety of the MSC treatment.

The study included 15 patients, with an average age of 47 years. Most (87%) participants were anti-AQP4 antibody positive. All of them had failed a different treatment prior to the study, meaning they had had at least one attack after receiving treatment. These prior treatments were cyclophosphamide or azathioprine, with or without steroids.

The MSC treatment did not cause side effects for most participants. Only one patient developed a low-grade fever and knee pain after the treatment, but these symptoms went away after treatment was completed. Weekly blood tests after the treatment were normal and no participants developed tumors within one year of treatment.

Twelve patients had no relapse at 12 months after MSC treatment, and three had at least one relapse. The relapses were mild. Their disability scores did not get worse and their symptoms went away after a month. The average annualized relapse rate was significantly lower after MSC treatment. Also, there were significantly fewer lesions in the optic nerve and spinal cord after treatment. The av-

erage disability score was also lower, and there was improvement in visual acuity and cognition. They had increased retinal nerve fiber layer thickness, optic nerve diameter, and upper cervical cord area. Three months after treatment, levels of anti-AQP4 antibodies decreased, but these levels went back to baseline again at 6-12 months. During the second year of the study, 13 participants were relapse free. Like the first year, the average annualized relapse rate was lower than before treatment and the average disability score was also lower than before treatment.

This small study did not have any obvious, serious, adverse events and supports an investment in larger controlled studies to understand the potential benefit of MSC treatment for NMOSD.

Original article: Fu Y, Yan Y, Qi Y et al. Impact of autologous mesenchymal stem cell infusion on neuromyelitis optica spectrum disorder: A pilot, 2-year observational study. *CNS Neurosci Ther*. 2016.

A Retrospective, Multicenter US Study on Acute Disseminated Encephalomyelitis (ADEM)

A recent study published on acute disseminated encephalomyelitis (ADEM) is the largest study on ADEM that has been conducted. This study was a retrospective multicenter study where the authors looked at data from the past and from several sites. The authors searched five hospitals for billing codes used for ADEM to get the data.

The study included 228 patients who were initially diagnosed with ADEM; 122 were children and 106 were adults. The authors looked to see whether the diagnosis of ADEM was based on diagnostic criteria from the 2007 International Pediatric Multiple Sclerosis Study Group (IPMSSG). For 70% of the pediatric patients and 47% of the adult patients, the diagnosis was based on the IPMSSG criteria. Many patients included in this retrospective study (spanning years from 1985 to 2014) would not have been diagnosed with ADEM according to current criteria.

More than half (61%) of the patients had an infection less than four weeks prior to the onset of ADEM. Ten (4%) patients had received a vaccination less than four weeks prior to their onset, and seven of them also had an infection in that time frame. Seasonal differences in onset were not seen. The most common presenting symptoms reported were headache, issues with walking, weakness, and fever.

Patients were followed for a median of two years. At the end of follow-up, most patients (68%) did not have another attack, and 32% were given a diagnosis other than monophasic ADEM, which included MS (11%), and NMOSD (4%). The authors identified multiphasic ADEM as a diagnosis in 22 patients (10%). Most (85%) of the patients who had another attack, had it within 2 years of onset.

In this retrospective study, the authors reported that 82% of the patients received steroids, and some received IVIg and/or plasmapheresis (PLEX). The article did not describe the effectiveness of these treatments but found that those who needed PLEX or IVIg had a significantly lower chance of having a favorable outcome. A favorable outcome was defined as a modified Rankin Scale score that was equal or less to 2.

The authors also looked at what factors predicted relapses. Females were more likely to have relapses. Patients without encephalopathy at onset were more likely than those with encephalopathy to have relapses (and would not have met strict ADEM criteria under current approaches). Pediatric patients who had relapses were more likely to be diagnosed with multiphasic ADEM than adults. This might be because physicians are inclined not to want to diagnose children with MS, because it is a disease that requires treatments throughout life. Children were more likely to have a favorable outcome than adults.

This study indicates that follow-up after the onset of ADEM should happen for at least two years to monitor for recurrence. This is because most relapses occurred within two years. 10% of patients in this study who were monophasic for two years had a relapse after this time (some had a relapse 5-10 years after onset). This study is limited by the fact that patients were not followed consistently, patients who had a multiphasic disease were followed for a longer period of time than those with a monophasic disease. Also, because there is no biomarker for ADEM, an accurate diagnosis can be a significant challenge. The authors argue that the IPMSSG diagnostic criteria may be more useful for diagnosis in children than in adults. The authors also state that, "most patients with a relapsing disease after an initial ADEM diagnosis are probably representations of MS."

Notably missing from this study was an analysis of outcomes other than relapse or modified Rankin Scale. Patients, especially pediatric patients, will require longer follow up to understand the potential cognitive impacts of ADEM. Also, this study did not include anti-Myelin Oligodendrocyte Glycoprotein (MOG) antibody testing, which may explain the percent of patients who relapsed. In general, ADEM (when strict criteria are applied) remains a one-time event. Prospective studies, or studies that follow patients starting at diagnosis and into the future, are needed.

Original Research: Koelman DL, Chahin S, Mar SS et al. Acute disseminated encephalomyelitis in 228 patients: A retrospective, multicenter US study. *Neurology*. 2016 May 31;86(22):2085-93.

DIAGNOSING TRANSVERSE MYELITIS

Many patients struggle through the initial evaluation before receiving a transverse myelitis (TM) diagnosis. A primary focus of the TM Center at Johns Hopkins University School of Medicine (JHTMC) is to facilitate a precise diagnosis and treatment for TM.

It is not infrequent that some patients are initially misdiagnosed and treated for conditions that they don't have. Many patients are given diagnoses, such as Multiple Sclerosis, Guillain-Barré syndrome (GBS) or even psychogenic problems before reaching a final diagnosis of TM.

Some of these issues are caused by a lack of understanding among some doctors in the community about TM and the diagnostic approaches required for patients who are experiencing symptoms suggestive of this disorder. This problem is further complicated when patients are dismissed and sent home from emergency departments or when patients need multiple visits or even multiple hospital admissions before obtaining a final diagnosis. Additional delays are created when patients are forced to find practitioners familiar with TM. All of these complications and delays ultimately postpone the correct treatments, almost all of which should be administered as quickly as possible.

One of the most important missions of the JHTMC is to identify better ways to improve the diagnosis of TM and to disseminate the strategies that would help doctors make a proper diagnosis from the very beginning. We have focused on studying the factors that may influence misdiagnosis and erroneous treatment. We are also interested in the identification of the factors that influence relapses and the outcomes of the disorder.

In one of our recent studies, we analyzed more than 500 clinical records from patients referred to the JHTMC for evaluation of TM. In our study, we found that nearly 40% of the patients were erroneously diagnosed as TM when they really had other problems, such as strokes, herniated disks, tumors and metabolic problems that affected the spinal cord. Not surprisingly, a high percentage of the patients that were properly diagnosed were also initially misdiagnosed as GBS or other neurological disorders. These findings immediately point out a lack of understanding of TM and a lack of understanding of the disorders that present with similar symptoms to TM but are not TM. As part of our study, we analyzed the presentation pattern of TM. By combining clinical information, the time-frame of clinical presentation, the findings of imaging of the spinal cord by magnetic resonance imaging and the results of the cerebrospinal fluid, we have been able to identify clinical profiles that facilitate an approach to achieve an accurate diagnosis of TM and differentiate TM from other disorders that may mimic TM. When looking at the factors that best predicted who really had TM versus other diagnoses, two things came up as the most important ones: the temporal profile of symptom presentation and the features of the first MRI of the spinal cord. The time from the onset to the peak of symptoms correlated with the diagnosis, as most strokes of the spinal cord occurred very fast (i.e., in a couple of hours), while the truly inflammatory problems took several hours to days to establish. The localization of the lesion in the MRI was also very helpful: the strokes of the spinal cord were more frequently located in the anterior part of the cord and were longer than the myelitis lesions.

We hope this information is useful to doctors in the community and for our patients to help with a proper diagnosis. If we are able to avoid confusion between a diagnosis of TM and other problems of the spinal cord, we can avoid unnecessary and potentially harmful treatments, while offering the proper treatments as quickly as possible.

Paula Barreras Cortes, MD | Postdoctoral Fellow
Johns Hopkins Transverse Myelitis Center, Baltimore, MD

UNDERSTANDING EXPERIENCES WITH VACCINATION BEFORE AND AFTER A RARE NEURO-IMMUNE DISORDER

The TMA is launching a new study entitled, "Understanding Experiences with Vaccination Before and After a Rare Neuro-Immune Disorder." We want to learn from our member community about their experiences.

The study participants will be randomly selected based on the inclusion criteria in order to reduce selection bias. Selection bias can make study results less accurate. Participants will be contacted via email and/or postal mail. We will also post the survey on our website and on social media, and are seeking participation in this way from everyone in our community who meet the inclusion criteria. We will then have two groups in the study for analysis; the randomly selected group, and people from our community who participated in the study from our web site or going through social media. Study participation will involve an online survey, and some respondents will be asked to participate in a short phone interview and/or send some medical records for review. All identifying information will be removed and no participants will be identified in any way in reports of the data. This research project (IRB# 2254) has been reviewed and approved by the Institutional Review Board of the Institute for Family Health on October 17th, 2016.

STUDY INCLUSION CRITERIA

- 18 years of age or older
- Diagnosed with a rare neuro-immune disorder (acute disseminated encephalomyelitis, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, including acute flaccid myelitis) who is able to consent
- A parent or legal guardian of a child below the age of 18 with a rare neuro-immune disorder
- Living in the United States
- At least one year since diagnosis

If you have any questions or want any additional information about this study, you may contact: GG deFiebre at *gdefiebre@myelitis.org* or 855-380-3330 ext 6.

NEUROVIRUSES EMERGING IN THE AMERICAS STUDY (NEAS)

Laura Muñoz-Arcos, MD | Postdoctoral Fellow
Johns Hopkins Transverse Myelitis Center

Since January 2016, researchers from the Johns Hopkins Transverse Myelitis Center have focused their attention towards the emergence of neurological complications associated with the Zika virus in Latin America and the Caribbean. The Zika virus was discovered in the 1950s in Africa where it was documented to cause a mild-febrile illness with no neurological complications described. Little to no information regarding the virus was available until 2007 when the Zika virus caused the first epidemic of infection in the Yap Islands. In 2013, the Zika virus led to a similar outbreak of illness in French Polynesia and the medical community was advised about the risk of developing neurological disorders secondary to this viral infection. In fact, in 2015 when the Zika virus reached the Americas, neurological complications such as Guillain-Barré syndrome (GBS) and microcephaly were observed. The temporal relationship of the Zika infection outbreak and the emergence of such neurological problems suggested a possible link between them.

GBS is described as a post-infectious disorder which affects the nerves that are responsible for movement, sensory functions and even vital functions, such as the beating of the heart and breathing. Frequently, GBS is confused with TM and vice versa. Clinically, patients with GBS present with a rapidly progressive ascending paralysis that commonly starts in the lower extremities and in a matter of days or weeks ascends and can potentially involve the respiratory muscles. Even though GBS has the strongest evidence of a link with Zika virus infections, other neurological disorders, such as myelitis and encephalitis have also been described in adults affected by the infection.

As part of our studies, researchers from the Johns Hopkins TM Center, and investigators and health care providers in South America established a collaborative network known as Neuroviruses Emerging in the Americas Study (*https://neasstudy.org*). NEAS is a multi-center study looking to combine the efforts of researchers, health care providers and patients in the Americas to establish a comprehensive registry of the clinical, radiological and laboratory profile of patients with new onset of neurological disorders associated with Zika virus infections, including GBS, myelitis, encephalitis and acute disseminated encephalomyelitis (ADEM). The purpose of our study is to determine whether there is a causal relationship between Zika virus infections and neurological complications in adults, as well as the underlying mechanisms which can help in the development of treatments, and prevention strategies, such as vaccines.

EVERYTHING HAPPENS FOR A REASON

Galen Hlavsa

Everything happens for a reason, and I truly believe this. I want to start my story with an overview of my experience as a child diagnosed with TM and written from the perspective of my parents, as I was not even a year old when it began.


BEMIDJI STATE
UNIVERSITY

Galen Clark Hlavsa was born November 4, 1995. He was a healthy, happy child and exhibited no symptoms of medical note. In mid-May, 1996, Galen received the six-month inoculations normal for his age.

Thirty days later, on June 12, 1996, Galen had a low-grade fever and appeared lethargic. His parents—Resurecion and Larry Hlavsa—were not unduly alarmed, but gave Galen Tylenol to reduce his fever. It seemed like a normal infant fever, and Galen showed no evidence of being in any pain. While the Tylenol did seem to work, within twenty-four hours, Larry noticed that though Galen was again moving normally above the waist, he was not moving his legs at all.

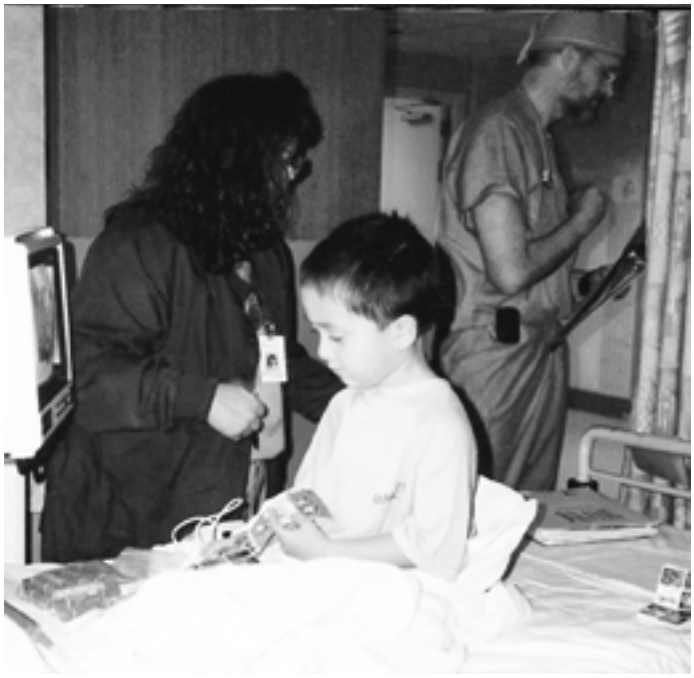
It was off to the Children's Hospital in St. Paul and what became a five-day ordeal. Galen was given many tests, but received no medications. For days, the doctors could not supply a diagnosis; it was a medical resident who first used the term transverse myelitis. Towards the end of Galen's hospital stay, we were told by the doctors of their concurrence in the transverse myelitis diagnosis. By the end of his hospital stay, Galen had again begun slowly moving his legs. There was really no treatment offered at the time.

We took Galen home on June 18, 1996 with the doctors advising us to watch him closely. We felt hope that Galen had survived his TM attack without any long-term damage, but our optimism was short-lived. Galen began walking by the end of his first year, but his gait was abnormal. As the months passed and he grew, the abnormality increased. The doctors we talked to spoke about nerve damage and explained that as a baby grows, its legs straighten, but that the nerve damage had something to do with the fact that Galen's legs were not straightening out as he aged. Galen walked on his toes with a pronounced inward pronation of his feet. We were told he would eventually need surgery to correct the resulting abnormal bone structure, but that they would not do that until Galen was older.

In March, 2000, when Galen was four and a half years old, the time had come; Galen underwent a quad osteotomy on his legs. It was a horrible experience for a child so young, but the results were excellent. Doctors said his leg bones were now aligned perfectly. Yet months after his recovery, Galen still walked abnormally due to the lingering spasticity of his leg muscles. Thereafter, Galen received physical therapy, and had some Botox injections as well, but neither of those seemed to provide any further improvement in his gait. Throughout these difficult months of surgery and recovery (there were many weeks of wearing bulky, heavy casts), Galen showed a wonderful attitude, great courage, and a welcome propensity for smiling.

In 2002, when Galen was seven, a doctor at the Shriner's Hospital in Sacramento, California said Galen could have surgery to lengthen his leg muscles, but not until he was more fully grown. This might provide an improvement in his gait. Meanwhile, in 2007, Galen moved with his family back to Minnesota and he began seeing a new doctor at the Shriner's Hospital in Minneapolis. This doctor, however, was unwilling to entertain the muscle-lengthening idea, saying it was a temporary measure that would not result in the long-term result we were seeking, so Galen continued with his schooling, and his journey to adulthood.

Though Galen Hlavsa did not come out of his transverse myelitis unscathed, it did not paralyze him either. He has shown great courage throughout the onset of his transverse myelitis, and through the many years of its aftereffects, but as might be expected, Galen still hopes to walk someday with a normal gait.




BEGINNERS POLITICAL UNITED STATES
BEGINNERS POLITICAL ALASKA
May 22 2014


Spelling Words

I continue to try and find things that push my limits, and I hope that others will too.

It's now 2016, I am 21 years old. I am a college student at Bemidji State University studying Business Administration and Political Science, working at Walgreens Pharmacy as a CPhT, and advocating for students as a Campus Organizing Intern through Students United. I have associated myself with a number of clubs on campus from leadership roles in the Society for Human Resource Management, to being a Student Senator for Bemidji State University. While the question, "What do you want to do when you get older" is becoming more and more of a reality, I still am trying to find the answer.

As a kid, I thought to myself, "Why me?" Why couldn't I be like the other kids and walk normally? I always felt like I had some sort of restrictions to what I was doing, and I let that mentality really get to me growing up. But the older I have gotten, the more I have come to realize that while I may have difficulties doing certain activities, I am still able to do them. As a kid, my parents always pushed me to do the things I loved. I played soccer, basketball, and baseball as a kid, and golf while I was in high school, and I loved every minute of it. I continue to try and find things that push my limits, and I hope that others will too.

My story is one of the best-case scenarios for a child diagnosed with TM; I very well could have ended up in a wheelchair for the rest of my life. If it weren't for my parents and their constant support, I am sure that things may have been different for me. It goes without saying that I am forever in the debt of my parents, doctors, friends and family for their support, but I also feel like I owe the TM community.

Growing up, I thought the odds of me meeting someone diagnosed with TM were the same as winning the lottery, and I never knew there was an Association until 2016. On October 17th, I applied to volunteer for The Transverse Myelitis Association. The day I received a response back was probably the happiest day of my life, knowing that I can help bring awareness and support to an illness that not only changed my life, but the lives of many others.

My name is Galen Hlavsa, and I am ecstatic to say that I am a Volunteer for The Transverse Myelitis Association.

SMART PATIENTS UPDATE

The TMA and Smart Patients have partnered to provide an online health community for patients and caregivers affected by Acute Flaccid Myelitis, Acute Disseminated Encephalomyelitis, Optic Neuritis, Neuromyelitis Optica Spectrum Disorder, and Transverse Myelitis.

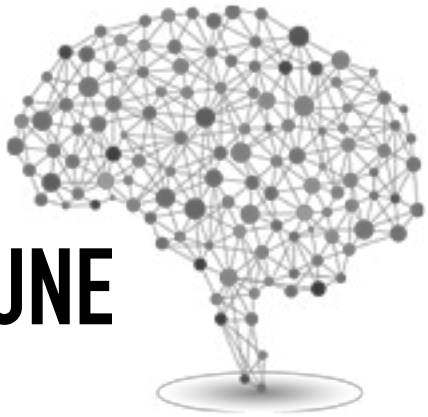
The community was designed to create more effective access to resources for people in our community, as well as to extend these resources to an even broader group of patients to accelerate and intensify the sharing of information about treatments, the latest science, and how it all fits into the context of personal experience.

2016 welcomed 334 new members to the Smart Patients Transverse Myelitis Community for a total 807 confirmed members. There were 237 new conversations started totaling 2,670 posts. Conversations varied greatly, as do the members of our community. All topics of conversation related to living life with one of these rare disorders is a possibility for discussion. Members from around the world have shared their stories, asked difficult questions, provided honest answers, and supported one another with words of advice

and encouragement for the good and the bad days.

We are overwhelmed and grateful for the support Smart Patients offers The TMA community. There are many options available for connecting patients virtually with one another and sharing our very personal stories of our lives with these diagnoses. Smart Patients moderated forums offers a safe and inviting place for all those living with or providing care to someone they love with one of the rare neuro-immune disorders.

If you haven't joined the community yet, we encourage you to not miss out on this invaluable resource. If you have joined but haven't introduced yourself yet, please stop in and say hello! Ask a question and find support from others. Share your story and your knowledge to support another community member. If you have questions about Smart Patients and our partnership, please email us at *info@myelitis.org*. We'll be happy to help get you started!



2017 RARE NEURO-IMMUNE DISORDERS SYMPOSIUM

OCTOBER 20-21, 2017
HILTON COLUMBUS AT EASTON
COLUMBUS, OH

This symposium will be an education and advocacy conference for families, caregivers, and individuals diagnosed with Transverse Myelitis (including the subtype Acute Flaccid Myelitis), Neuromyelitis Optica Spectrum Disorder, Optic Neuritis, and Acute Disseminated Encephalomyelitis.

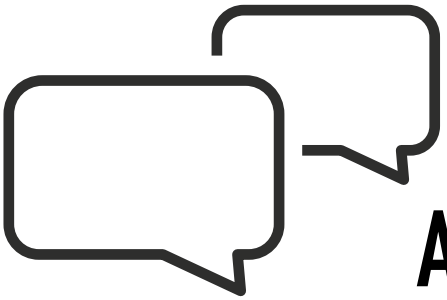
Hosted by The Transverse Myelitis Association (TMA), The Johns Hopkins Transverse Myelitis Center (JHTMC) and NMO Clinic, The University of Texas Southwestern Medical Center (UTSW) and Children's Medical Center CONQUER Program, this conference will look back at what we have learned about rare neuro-immune disorders, and examine what the future will look like for individuals and families affected by these disorders. It is dedicated to the exchange of information regarding diagnosis, research, and treatment strategies, and to providing an opportunity to bring together the community of individuals diagnosed with these rare neuro-immune diseases, families, caregivers, and the medical professionals who have interest and are specializing in these diseases.

For more information on the program, logistics and to register, please visit *https://myelitis.org/2017-rnds* or contact Timi Schrumpf at *tschrumpf@myelitis.org*.

The Transverse Myelitis Association

CONQUER
Collaboration on Neuroimmunology

JOHNS HOPKINS
NEUROMYELITIS OPTICA CLINIC



ANNOUNCING 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.

https://myelitis.org/mhl

ASK THE EXPERT PODCAST SERIES

Every month the TMA holds a podcast on a topic that affects those with rare neuro-immune disorders. Experts in the field share the latest knowledge and answer questions from our community. Podcasts have covered topics, such as vaccinations and rare neuro-immune disorders, rehabilitation, and clinical trials.

On January 19th, we kicked off our 2017 podcast series with experts Dr. Benjamin Greenberg and Dr. Sara Qureshi, who discussed a multidisciplinary approach to rare neuro-immune disorders. In February, we will take a closer look at vaccinations and rare neuro-immune disorders, with Dr. Augusto Miravalle. We will return in March for an important conversation on managing health after a rare neuro-immune diagnosis, with expert Paula Hardeman.

Listen and subscribe to our podcast via iTunes today. You can find all past recordings in our resource library: *https://bit.ly/tma-podcasts.*

TMA Ask the Expert Podcast Series sponsored in part by

ALEXION

Alexion is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development and commercialization of life-transforming therapeutic products. Their goal to deliver medical breakthroughs where none currently exist is driven by the knowledge that people's lives depend on their work.

** The Executive Committee of the TMA with the medical and scientific council determines the content and topics of the podcasts. Sponsors are not able to influence the education program.*

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 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 **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

11 **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

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.

7

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.

8

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.

9

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.

10

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.

11

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.

2017 OHIO WALK-RUN-N-ROLL

The second Ohio Walk-Run-N-Roll will be held Sunday, October 22, 2017 from 10am to noon at Coffman Pavilion Park in Dublin, Ohio. We hope to raise awareness about our community and raise funds for research and for improving clinical care for patients.

This year, we will be hosting the walk during the same weekend as the 2017 Rare Neuro-immune Disorders Symposium (RNDS). We hope this allows for many more people from our community to attend and come together to share stories, experiences, and form lasting relationships.

All are welcome to join. Please indicate your interest to attend the walk when you register for the symposium. We will send you an event registration confirmation with more details. If you are interested in getting involved in the planning process or would like to start a fundraising team, please email Timi Schrumpf at *tschrumpf@myelitis.org.*

2017 OH Walk-Run-N-Roll

Coffman Park Pavilion
5200 Emerald Parkway
Dublin, OH 43017

Sunday, October 22, 2017
10:00 am - 12:00 pm

More info:

2017 TMA GALA DINNER & AUCTION

Please join us for a special fundraising event to support The Transverse Myelitis Association (TMA) and to honor our daughter Sarah Robbins, who was diagnosed with transverse myelitis in 2011. The 2017 TMA Gala Dinner & Auction is dedicated to raising awareness and funds to support research to better understand these disorders and to find new therapies for restoration of function; to offer support to people with these disorders and their families, and to offer education about these disorders.

- Tina & Jason Robbins

2017 TMA Gala Dinner & Auction

Radisson Resort Port
8701 Astronaut Blvd
Cape Canaveral, FL 32920

Friday, June 2, 2017
6:00 pm - 10:00 pm

More info:

JOIN THE TMA WALK-RUN-N-ROLL CAMPAIGN TO RAISE AWARENESS ABOUT RARE NEURO-IMMUNE DISORDERS!

Potential Walk-Run-N-Roll events to be held in 2017

Walk-Run-N-Roll campaigns are a national effort which help the TMA reach its goals of increasing awareness, developing and strengthening our community, and raising funds for research, education and support.

In 2016, four states (Florida, Ohio, New Jersey, and Massachusetts) had walks. We have set a goal to double the number of walks this year. In 2017, we would like to have at least 10 walks across the country. We need your leadership, enthusiasm, and support to achieve our goals. We look forward to partnering with you in spreading the word about these rare neuro-immune disorders and raising funds to support crucial research.

To learn more about joining or starting a planning committee for a Walk-Run-N-Roll in your state, please visit *https://myelitis.org/walk* or contact Timi at *tschrumpf@myelitis.org*.

TMA SUPPORT GROUP LEADERS

Those in our community have so many different perspectives, experiences, and feelings toward their journey with a rare neuro-immune disorder, but there is one thing that most will agree on; they have few people in their lives who really understand. This is why sharing our experiences is so important. Support groups are one of the most powerful ways to provide this critical need and to serve our community.

As our community continues to grow, the need for strong support groups is becoming increasingly evident, and a support group can only be as strong as its leader. We want to ensure that our support group leaders have all the tools and knowledge necessary to lead an effective and engaged group and to provide the support that our community members need. To do this, we are launching a new Support Group Leader program that includes a training component and a virtual meeting for SGLs every quarter. This new program will create the best opportunity for a safe and successful group.

We have had dedicated and hard working support group leaders who have assumed this role, almost since the inception of the TMA. We are so grateful for their loyal service to our community. We are excited that we are getting new members to become champions for our community and to take on the important role of being a support group leader. Meet a few of them, and read why they chose to get involved!

Heather Reynolds: It has been an absolute privilege to be able to take on the role as the new support group leader for the Central TX Support Group. When I was presented this opportunity, I was nervous and scared but after meeting everyone and making the contacts throughout the process it has allowed my confidence to soar! Living with NMOSD, transverse myelitis or any other rare auto-immune disorder is never something easy to do by yourself. My goal is to reach out to patients, families, and caregivers that are all going through the same thing by providing helpful and useful information, knowledgeable speakers, and just an overall support system for everyone involved. I like to think that I am one of the lucky ones that didn't suffer great damage from my attack, but I also like to think that this has blessed me with the opportunity to take on this role and bring us all together. I look forward to continuing to learn, grow and meet others in this community!

Hope Paider: I decided to become a support group leader for transverse myelitis because when my son was diagnosed, we had never heard of the diagnosis before. We were left to find things on our own through the internet. Through our searches we found the TMA; if it weren't for the TMA we would feel very alone. It was a terrible feeling at first but being able to connect with others who have gone through the same things was incredible. We have learned so much with the support of others and what I hope is to be able to bring that same feeling of hope to others. Even if the person or family with TM have a large home support, it is still beneficial to hear from others who are going through the same issues and to get other perspectives.

Dianne Elliott: Montana had its first support group meeting for rare neuro-immune disorders in November 2016. Dr. Qureshi, a Neurologist who specializes in these specific conditions, supported me in the journey of creating a support group for such a vast region. It has been a goal of mine to find others like me (who have TM) to share my experiences. We had no idea if 1 or 40 people might show up for our first group meeting. We had 14, including some family members so this was a great start! Since the weather is so inclement in Montana we did not meet in December but are re-convening on January 14, 2017. I could not be more excited to have the support of the National TMA team and exploring new horizons in Montana at our next gatherings. We will be taking time to share our stories and how to have some of the difficult conversations with our providers and the ones that help care for us on sensitive issues. Looking forward to Physical Therapy, Nursing, and Rehabilitation Provider support with future meetings.

If you are interested in getting connected with other members, or creating a support group in your area, please contact Timi at tschrumpf@myelitis.org.

ANNOUNCING THE 2017 TMA ANNUAL QUALITY OF LIFE FAMILY CAMP

We are excited to announce the TMA will partner once again with the Center for Courageous Kids (CCK) in Scottsville, KY for our TMA Family Camp. Camp will be held Saturday, July 15 through Wednesday, July 19, 2017.

HOW TO APPLY?

To start the application process, please complete the form located at *https://thetma.wufoo.com/forms/q1ve64gj0uv650p*. A TMA staff member will contact you via email within 48 hours to share additional information about the application process.

ELIGIBILITY

- Families with children diagnosed with ADEM, NMOSD, TM, ON and Acute Flaccid Myelitis (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.
- Up to two adults living in the same household as the camper and siblings may participate in camp.
- All applicants must be members of the TMA. Membership is free. *https://myelitis.org/join*

ARRIVAL AND DEPARTURE INFORMATION

Families will receive detailed information about arrival and departure times along with their acceptance information 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. For help with ground transportation between the airport and camp, please contact the TMA at *tmakids@myelitis.org*. Please do not make plane reservations until you receive an acceptance letter from CCK.

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 some financial help, based on need, via travel grants to families. All accepted families will receive an email with an application form and guidelines to apply for this funding in late spring or early summer 2017. They are offered on a first come, first served basis until grant funds are no longer available. Grant funds are disbursed as reimbursements once grant requirements have been met.

EDUCATION PROGRAM

Medical professionals and specialists from our medical 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 are able to share their experience and make recommendations, but will not be able to provide specific medical advice.

CONTACT US

Erin Coriell: ecoriell@myelitis.org | 1-855-380-3330

Rebecca Whitney: rwhitney@myelitis.org |1-855-380-3330 ext 5

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

Announcements

2017 TMA Gala Auction & Dinner: June 2, 2017

2017 TMA Quality of Life Family Camp: July 15-19, 2017

2017 Rare Neuro-Immune Disorders Symposium: October 20-21, 2017

2017 Ohio Walk-Run-N-Roll: October 22, 2017

Contact us

The Transverse Myelitis Association

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