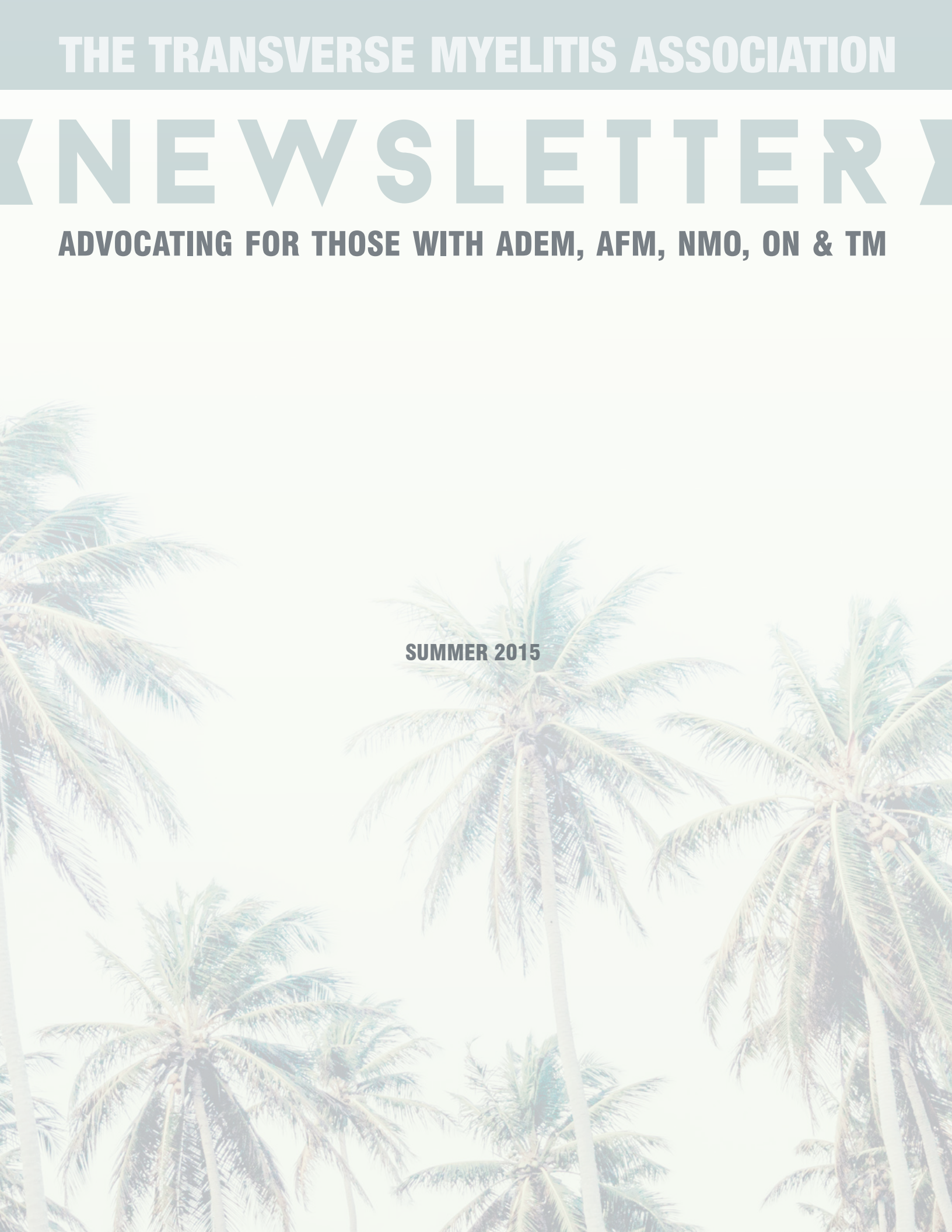
THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

ADVOCATING FOR THOSE WITH ADEM, AFM, NMO, ON & TM



SUMMER 2015

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

THE EDITOR'S COLUMN | Sandy Siegel, PhD

I have had more than 20 years of experience being a caregiver for a person with a rare neuro-immune disorder. Pauline was diagnosed with transverse myelitis in 1994.

Before I venture any further in this column … I'm not particularly fond of the term 'caregiver'. The concept in my mind connotes a passivity that just doesn't characterize what is going on with Pauline or my relationship with her. While Pauline has a boatload of physical issues, there's very little about her relationship with me that is passive. I don't really 'care' for Pauline. I sort of take orders, and I comply. There are times when I attempt to resist these demands in some form or fashion, but at the end of the day, I'm pretty much doing what I'm told. Thus, I don't feel like a 'caregiver;' the manservant more accurately fits the dynamic!

For the purpose of psychic karma, I'm going to refer to myself as Pauline's partner. One of the more important roles that I have in this partnership with my supervisor is to offer the best support I possibly can to ensure that she is receiving the best medical care, and to encourage, to the extent possible, that she is doing what she can to be as healthy as she can be. The way that I offer this support to Pauline is to be certain that I am as well educated about all facets of these disorders as I can be, and to ensure that I am aware of new information that is being learned by researchers and physicians and as much as possible keep current with the published medical literature. This endeavor requires a lot of time and energy. It is also the case that there is little else I can do that has a greater payback for Pauline with regard to the nature and quality of her medical care and her quality of life.

The operative concept regarding this education process is that these disorders are rare. Additionally, there's so much that is not understood about these disorders. There is just so much research that needs to be done. When a loved one or you have a rare and little understood disorder, ignorance is going to carry with it some really horrible consequences. You are going to need to be a partner with your medical providers in receiving the best care. This is the case if you are seeing a physician who knows almost nothing about your disorder and this is also the case if you are seeing a specialist in one of these disorders. And being a good partner means that you have taken the time to educate yourself and are an informed partner.

Let me offer a few concrete examples of how Pauline and I are advantaged by taking the time to educate ourselves. First, we have a fairly good grasp about what modern medicine understands about these disorders and we've also developed some clear expectations about what modern medicine has to offer to Pauline, as well as what magic is not going to be forthcoming. We don't waste twenty minutes of a thirty-minute appointment trying to extract an explanation from the doctor about why this happened to Pauline. We understand how the diagnosis is performed, what rule outs were conducted, and then accept that idiopathic means just that; we aren't likely going to know what happened to her. We don't waste any time during our appointments seeking a stem cell repair because we've kept up with the research and we know that there just aren't any scientifically proven approaches at the current time. If a doctor presents a symptom management strategy that we've never heard of before, we definitely seek additional information and explanation from the physician, because we've reviewed pretty much all of what the experts are saying are the most effective approaches. We also offer suggestions to our physicians about approaches that we've heard from the experts. These are just a few examples; Pauline has been able to be a full partner in her medical care, because we are both well informed and as educated as we can be.

When I speak to people and they tell me that they don't have a computer and internet access, I tell them that if they aren't going to be able to access information on the internet, then they can't have a rare, little understood

disorder. I go about explaining to them ways that they can either afford a computer with internet access or how to contact agencies who provide computers to people who have financial need. Everyone can use a computer. My 90 year old mother uses a computer and goes onto the internet and uses email. Jim Lubin is entirely paralyzed from the neck down and he uses computers in ways that are so much more sophisticated than I could even imagine. There are just no excuses for not being on a computer with internet access. This is a critically important tool in support of your medical care. And you need to learn how to find trustworthy sites from which to receive your information, such as www.myelitis.org.

The single most valuable and greatest resource we have available for educating ourselves about these disorders are the symposia that we hold every other year with Centers at Johns Hopkins or The University of Texas Southwestern. Pauline and I have attended almost every symposium since the very first one in Seattle in 1999. The TMA, Johns Hopkins and UTSW bring in the experts in these rare neuro-immune disorders, and they provide an excellent overview of each of these rare disorders and then offer a discussion of the most effective treatments for each of the symptoms a person can have from these disorders. The presentations also cover additional very important subjects from caregiver issues to the availability of social and government programs. We have been able to attend these education programs because the TMA significantly subsidizes the cost and they've made it very affordable for Pauline and me to attend. It is difficult for us to travel, but we make it our business to attend, because we know the difference this knowledge is going to have on Pauline's medical care. We've learned that the benefits directly impact her day-to-day quality of life. We've come to appreciate the enormous cost of ignorance.

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It is just amazing how much is being learned all the time from the experiences the specialists are deriving, primarily from caring for more and more patients with these disorders. Pauline and I try to attend as many of these symposia as possible, because we know that we will learn the next increment of new and critical information.

Pauline and I will be attending the 2015 Rare Neuro-immune Disorders Symposium (RNDS) in Dallas this October (https://myelitis.org/2015-rnds). We've registered for the symposium online, we've made our hotel reservations and we've arranged our plane flights. Pauline will have to take a few days off from teaching to attend, but we know that it is important for us to be there and learn as much as we can.

We've also discovered very early on that when one has a rare disorder that it is so important for one's emotional and psychological well-being to make connections and to find support from the community. The symposia are the most intimate and intensive exercise of these connections and support. Over the years, we've made the strongest friendships and we rely on these relationships for companionship, support, encouragement and understanding all year long.

We hope to see you in Dallas this October!

Please take care of yourselves and each other.

Sandy Siegel
President, The TMA

NEW ADDITION TO THE TMA STAFF

On December 19th, 2009 I woke up with neck pain that was radiating down my arms. I spent the day trying to stretch the pain away but it continued to get worse. This was during my fourth and final year as an undergraduate student at New College of Florida. As the day progressed my neck pain got more severe. It became so severe that I decided it was time to find a walk-in clinic. I walked over to my computer to try finding a nearby clinic. I placed my right hand on my computer's trackpad and realized I couldn't move any of my fingers. I yelled to my grandmother, "I can't move my right hand!" At this point I realized I definitely needed medical care but was still not aware of the severity of my condition. I gathered my belongings and walked out of my grandparents' condo and to the elevator. While waiting for the elevator I almost collapsed, and my legs continued to weaken as I walked from the elevator to the car. I dragged my legs into the car and we sped away to the Emergency Room. That walk to the car was the last time I walked.

At the hospital, the doctor ordered an MRI of my cervical and thoracic spine and of my brain. The radiologists noticed a lesion between C5 and C7. At this point I had lost all sensation and movement from the chest down and had no triceps or finger strength on either side. I was started on high dose IV steroids that night, and in the following days, I received plasmapheresis, IV antibiotics, and antivirals. The latter two were discontinued when my blood tests came back normal. The only abnormal result was that my blood serum tested positive for mycoplasma pneumonia, although no doctor has definitively stated that that was the cause of my transverse myelitis.

I spent two weeks in acute care, and was then transferred to a rehabilitation hospital as close to my college's campus as possible. I slowly gained some strength and sensation while at the rehab hospital. I continued doing therapy at home and as an outpatient, and continued to make very slow progress. My triceps, fingers on my left hand, and trunk control are much stronger than they were when I first became paralyzed. I never regained leg function (just some toe and ankle movement on the right side), and am still a C6-7 quadriplegic.

Despite these challenges I received a bachelor's degree from New College of Florida in 2010, and a master's degree in public health from the CUNY School of Public Health at Hunter College in 2013. I will also be starting a Doctor of Public Health degree at the CUNY Graduate Center in the fall. I started volunteering with the TMA last year and started as a Research Associate with the TMA in May of this year. I'm very excited to have the opportunity to work for the TMA and advance research about these rare disorders!

As a Research Associate for the TMA, it is GG's role to ensure that the patient community is aware of current research including publications about TM, ADEM, NMO, ON and AFM, that the community has access to evidence-based educational materials about these rare neuro-immune disorders, and to design and implement patient-led studies.

DR. MICHAEL SWEENEY RECEIVES THE 2015-2016 JAMES T. LUBIN FELLOWSHIP AWARD

We are pleased to announce the 2015 James T. Lubin Clinician-Scientist Fellowship Award to Dr. Michael Sweeney under the mentorship of Dr. Stacey Clardy at The University of Utah. Dr. Sweeney completed his undergraduate degree in Biological Sciences with a focus on neuroscience at Purdue University. Following completion of medical school at the Medical College of Wisconsin, he entered into a combined pediatrics and child neurology residency/fellowship at Cincinnati Children's Hospital Medical Center. There, he focused his efforts into learning to manage both common and rare neurologic diseases in children. He developed clinical and research interests in immune-mediated neurologic diseases, including multiple sclerosis, neuromyelitis optica, transverse myelitis, optic neuritis and antibody mediated encephalitis. He also worked closely with medical students and residents, demonstrating a strong dedication to education.

"I am truly grateful to become involved in this fellowship. Through this unique opportunity, I will have a once in a lifetime chance to train with leaders in the field and to become part of this small community. I hope to gain knowledge and skills from mentors across the country in order to better serve patients with immune-mediated neurologic disorders. This intensive training will include not only diagnosis and management of the acute neurologic issues, but also long-term management and rehabilitation. I am excited to also become involved in areas of research, which will further the field and ultimately lead to better care and outcomes in these children."

– DR. MICHAEL SWEENEY, FELLOWSHIP RECIPIENT

“We are thrilled to have the opportunity to work with The Transverse Myelitis Association. This will be a fantastic and unique training opportunity for Dr. Sweeney, allowing him not only the invaluable opportunity to participate in the Quality of Life Family Camp at the Center for Courageous Kids in Kentucky, but it will also broaden his knowledge base regarding the treatment and care of transverse myelitis patients at two other leading academic centers in addition to the University of Utah. Owing to this fellowship, he will have unique expertise in the care of both adults and children with TM.”

— DR. STACEY CLARDY, MENTOR

Dr. Sweeney will be starting the Fellowship at the University of Utah in July 2015 to receive further training within this field in order to better understand the disease processes and how to provide the best possible care to these patients. Following completion of this fellowship, as a clinician-researcher, Dr. Sweeney hopes to start a clinic in which children with neuro-immune diseases will receive multidisciplinary care. As part of the Fellowship, Dr. Sweeney proposes to conduct research to evaluate the neurologic and neuropsychiatric outcomes in pediatric patients who have previously been diagnosed with an immune-mediated disease affecting the central nervous system. By evaluating the outcomes in these patients, he hopes to identify potential modifiable factors or treatment paradigms, which are associated with better outcomes. This will lay the groundwork for future prospective studies to evaluate the effectiveness of treatments. Dr. Sweeney will be joining a training program with a strong basic and clinical science background and a highly motivated and dedicated team at The University of Utah under Dr. Stacey Clardy’s mentorship and leadership, and he aims to improve patient care and to further the field of neuro-immunology though intensive research efforts.

FOR MORE INFORMATION ON THE UNIVERSITY OF UTAH PROGRAM

http://healthcare.utah.edu/fad/mddetail.php?physicianID=u0909730

INTERNATIONAL CONSENSUS **DIAGNOSTIC CRITERIA** FOR NEUROMYELITIS OPTICA SPECTRUM DISORDERS

The International Panel for NMO Diagnosis (IPND) recently released an updated set of guidelines for diagnosing Neuromyelitis Optica (NMO) and Neuromyelitis Optica spectrum disorders (NMOSD). NMO is an inflammatory disorder of the central nervous system. The guidelines for diagnosing NMO that were released in 2006 were recently revised based on research advances and an increased understanding of the disorder.

Wingerchuk DM, Banwell B, Bennett JL et al. International consensus diagnostic criteria for neuromyelitis optica spectrum disorders. Neurology. 2015.

The IPND has eliminated the use of NMO, and is now referring to the disease as NMOSD. This is because individuals with NMO and NMOSD generally do not have differing clinical behavior and should receive the same treatment. The IPND also agreed not to have the diagnosis of NMOSD be solely based on the presence of AQP4-IgG.

Diagnostic criteria for NMOSD with AQP4-IgG, NMOSD without AQP4-IgG or with unknown AQP4-IgG status were established along with a set of core clinical characteristics to aid in diagnosing those with potential NMOSD. The diagnostic requirements are more stringent in those without AQP4-IgG, and require 2 core clinical characteristics, one of which has to be optic neuritis, acute myelitis with longitudinally extensive transverse myelitis (a lesion extending 3 or more vertebral segments), or lesions in the area of the brain that causes vomiting, as well as other MRI characteristics. Those who are AQP4-IgG positive require just one core clinical characteristic. The panel recommends cell-based serum assays to detect AQP4-IgG because they are the most accurate, but unfortunately they are not yet widely available.

A set of "red flags" were identified that do not exclude NMOSD if present, but may indicate another diagnosis:

- A very short (less than 4 hours) time to the worst part of an attack,
- or very long (more than 4 weeks) time to the worst part of an attack,
- and presence of oligoclonal bands in the cerebrospinal fluid.

Neuroimaging characteristics of NMO include:

- LETM
- a lesion in the central part of the cord,
- and certain NMOSD-typical brain lesion patterns.

According to the panel, the characteristics of pediatric NMOSD are similar to adult NMOSD, and the proposed criteria can generally be used in this population, although they note that a LETM lesion is not as specific for NMO in children as it is in adults because LETM can occur in 15% of children with MS, and can also occur in ADEM.

5-10% of NMOSD cases are monophasic, but it is unclear what criteria indicate that someone will maintain a monophasic disease course. The panel recommends that someone be considered to have monophasic NMOSD only after they have been relapse free for five or more years, but those who are AQP4-IgG positive should be considered to be at high risk for recurrence regardless of the length of time between attacks.

DIAGNOSTIC CRITERIA FOR NMOSD WITH AQP4-IGG

1. At least 1 core clinical characteristic
2. Positive test for AQP4-IgG using best available detection method (cell-based assay strongly recommended)
3. Exclusion of alternative diagnoses

DIAGNOSTIC CRITERIA FOR NMOSD WITHOUT AQP4-IGG OR UNKNOWN AQP4-IGG STATUS

1. At least 2 core clinical characteristic occurring as a result of one or more clinical attacks and meeting all of the following requirements:

    b. At least 1 core clinical characteristic must be optic neuritis, acute myelitis with LETM, or area postrema syndrome
    c. Dissemination in space (2 or more core clinical characteristics)
    d. Fulfillment of additional MRI requirements, as applicable

2. Negative test for AQP4-IgG using best available detection method, or testing unavailable
3. Exclusion of alternative diagnoses

CORE CLINICAL CHARACTERISTICS

1. Optic neuritis
2. Acute myelitis
3. Area postrema syndrome: episode of otherwise unexplained hiccups or nausea and vomiting
4. Acute brainstem syndrome
5. Symptomatic narcolepsy or acute diencephalic clinical syndrome with NMOSD-typical diencephalic MRI lesions
6. Symptomatic cerebral syndrome with NMOSD-typical brain lesions

ADDITIONAL MRI REQUIREMENTS FOR NMOSD WITHOUT AQP4-IGG OR UNKNOWN AQP4-IGG STATUS

1. Acute optic neuritis: requires brain MRI showing (a) normal findings or only nonspecific white matter lesions, OR (b) optic nerve MRI with T2-hyperintense lesion or T1-weighted gadolinium-enhancing lesion extending over 1/2 optic nerve length or involving optic chiasm
2. Acute myelitis: requires associated intramedullary MRI lesion extending over 3 or more contiguous segments (LETM) OR 3 or more contiguous segments of focal spinal cord atrophy in patients with history compatible with acute myelitis
3. Area postrema syndrome: requires associated dorsal medulla/area postrema lesions
4. Acute brainstem syndrome: requires associated periependymal brainstem lesions

GABRIELLE (GG) DEFIEBRE, *Research Associate at The TMA*

INDIANA IS SUPPORTING THE TMA

I was diagnosed with Transverse Myelitis on August 13, 2013. I was admitted to 3 different hospitals for 2 weeks before my diagnosis. While I was at the hospital, my dad researched and researched about TM and tried to find me a support group. He was my fighter when I was too weak to fight. I was a single mom of a 3 year old and I was totally devastated that this would change my life forever. We could not find any local support groups that met, but I did find one on Facebook. My FB support group, TM Folks, helped me during my darkest and sickest days but I still longed to meet other people face to face who had TM and other rare neuro-immunological diseases.

This is why I have chosen to help lead Indiana's support group. I have always wanted to help people and have an interest in the medical field. Before my diagnosis with TM, I was a medical assistant in a pain doctor's office. I feel that my experience working with many pain doctors and patients has made me knowledgeable in pain medications, therapies and treatments. Living with TM for the last two years, I feel my medical background on top of my personal experiences can help others who have rare neurological diseases.

My hope is for Indiana to have a large support group meeting every 4-6 months in Indianapolis. I would love to hear from other TMA members in different parts of Indiana to be local support group leaders and host monthly meetings. I will also host smaller monthly meetings in Fort Wayne.

On top of providing support for people with rare neurological diseases, I have always felt that awareness is very critical. Please join me to help spread awareness, raise money for the TMA, and bring TMA members together to host Indiana's first Walk-Run-N-Roll in Indianapolis this Fall 2015. We will need a minimum of 5 people to form a Planning Committee. I would love to take on the responsibility as the Chairperson and we also need a Sponsorship Leader, Marketing and Communications Leader, Family Teams Leader, and Events Leader. For more information and a guide on hosting a walk, please visit http://myelitis.org/get-involved/walk-run-n-roll-campaign/start-walk. If you feel like you would be a great fit for one of the roles in the Planning Committee please contact me.

If you would love to be involved in a support group in Indiana or would like to be a part of the Walk-Run-N-Roll please contact me. More information will be posted as soon as the details start to come together. Also, if you are in Indiana and just need someone to talk to, I'm always available. These diseases have united all of us together for a reason, so let's rise up and win together as one!

NICOLE C MCFARLAND
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I VOLUNTEERED TO LEAD THE TMA NEBRASKA SUPPORT GROUP

Kelly Davis

Hello, everyone. I am the new leader of the Nebraska Transverse Myelitis Association's Support Group. I want to thank Nikki Goeschel for all of her hard work in getting this group off the ground and providing so much support during this transition. I look forward to meeting many of you soon to discuss the future and mission of our group. I have been asked to write a story about my life with transverse myelitis. Sorry it's not a shorter story but it has been a challenging couple of years.

My father was always healthy. He boasted that his only hospitalization occurred because his tonsils were removed when he was eight years old. He walked 3 miles every day and was seldom ill with anything even as simple as a cold or flu. At age 76, he was diagnosed with Idiopathic Pulmonary Fibrosis ("IPF"), a fatal disease in which deep lung tissue becomes scarred over time and ultimately robs a patient of the ability to breathe. My father died within 60 days of his diagnosis. I had never heard of IPF, even though it kills as many people every year as breast cancer. Like my father, I had been healthy all my life, with only one hospitalization for an appendectomy at age four. I told my family, tongue in cheek, that I would probably end up just like my dad. I imagined I would remain healthy all my life and then finally get some weird disease that no one had ever heard of. Enter NMO.

On December 24, 2012, in my early fifties, I had a whooping cough booster shot based on a doctor's recommendation because my husband had been exposed at work. About three weeks later, I started exhibiting symptoms that I blamed on the flu -- low-grade fever, mild headaches, and extreme fatigue. I was able to manage the headaches and fever with Tylenol, but the fatigue was relentless. Most nights and weekends, I couldn't even get off the couch. Three weeks after the initial symptoms started, I developed skin pain that felt like I had a sunburn over my enter body –even though I didn't have a sunburn. That's how I described it to my family doctor when I visited her on February 1, 2013. She did some blood work and attributed it to a virus. She told me it would pass in 7-10 days.

However, my symptoms quickly worsened: I began running a high fever and losing my balance. I also began falling. I would climb half way up a flight of stairs and suddenly realize I was no longer able to remain upright and falling was inevitable. Fortunately, I fell forward and not backwards down the stairs, which could have been disastrous for me. My husband also said he noticed that I was not going to the bathroom very often. So I contacted my family doctor again, and she referred me to an infectious disease specialist.

On February 12, 2013, I showed up at the specialist's office partially paralyzed and incontinent. She examined me for a few minutes and then said, "These two symptoms bother me. Do you mind if I call a neurologist?" The neurologist told her to admit me to the hospital immediately and was waiting for me in my room when I arrived. By the time I arrived at the hospital, I was paralyzed from the chest down. After an exam, the neurologist ordered a series of MRI scans. I had been given a lot of Ativan, but I recall that my neurologist phoned the same evening advising me that I had something called transverse myelitis ("TM"), which sounded to me like something from outer space. He said he planned to start treatment with high doses of corticosteroids the next day. Looking back, I am grateful that I had a neurologist who knew he was looking at TM.

I spent the next three days in the hospital receiving infusions of Solu-Medrol and undergoing a series of tests and more MRI scans. I learned that I had extensive inflammation throughout my spinal cord. I had what is known as Longitudinally Extensive Transverse Myelitis ("LETM"), which is a spinal cord lesion that extends over three or more vertebrae in length. My MRI revealed that I had a lesion that was effectively seven vertebrae in length. I also had some diffuse inflammation in other areas of my spine. The MRI scan of my optic nerves was normal, and my brain

MRI revealed lesions that are not typically seen in a person with multiple sclerosis. My neurologist ordered a lumbar puncture to test for Multiple Sclerosis and an NMO-IgG antibody whose presence could mean I have a rare disease called Neuromyelitis Optica ("NMO"). That is the first time I had heard of NMO. I researched TM and NMO at http://myelitis.org and refused to believe I had any of the diseases listed on The TMA website. Certainly, I couldn't have that weird disease described as NMO. I'm simply not that unique. Three days later, I left the hospital with the assistance of a cane and finished my last two days of Solu-Medrol infusion as an outpatient.

Since the beginning of my illness, I have displayed mixed clinical symptoms including seronegativity for three NMO-IgG antibody tests (despite LETM and other symptoms of NMO), which has made an official diagnosis of NMO difficult for physicians in Omaha and at Johns Hopkins University. Neurologists at the Mayo Clinic finally confirmed a diagnosis of NMO in September 2014. Since my initial presentation of TM, I've had five more relapses of the disease. I have had Longitudinally Extensive Optic Neuritis ("LEON") in my right eye, a less severe attack of Optic Neuritis in my left eye, and three separate incidences of disease activity in my brain. At the same time, I have been struggling with the damage left to my central nervous system ("CNS") by TM, such as chronic neuropathic pain.

I have suffered great indignities, along with professional and personal losses at the hands of this disease. As an attorney, I used to travel across the country handling arbitrations and mediations for a broker dealer. I loved my work. Now I am disabled and can no longer work as an attorney, in part, because I have chronic fatigue and I am constantly looking over my shoulder for the next relapse. Additionally, I still struggle with the damage done to my body by the initial attack of TM. I spend most of my time visiting physicians or otherwise tending to my care. I have had to fight with my employer, my health insurance company, my disability company and my own health care providers to get adequate treatment for this disease.

"I would also like to help people with NMO, TM and other rare neuro-immune associated diseases"

Two and 1/2 years after TM, I have assembled what I think is an excellent group of providers and caregivers with me as the captain of my care. I am stable for the first time in over a year thanks to the efforts of my local neurologist and my NMO specialist at Mayo. One of the greatest assets in my continued recovery and search for my new "normal" has been my personal trainer who has been instrumental in helping me with muscle strength, endurance, energy, self-confidence, and most importantly, balance and coordination. My hope is to continue to remain stable and improve my health. I would also like to help people with NMO, TM and other rare neuro-immune associated diseases, to navigate through the many challenges of this weird disease. That is why I have volunteered to help lead the Nebraska support group for the Transverse Myelitis Association.

TMA SUPPORT GROUP IN **HOUSTON, TX**

I am an RN and a fellow NMO survivor. After a complicated pregnancy four years ago, I began to suffer with leg numbness, tingling, and weakness. In 2012, I spent a week in the hospital with a diagnosis of transverse myelitis. After visits with 4 neurologists, 2 rheumatologists, and various other specialists, I was still left with no answers. Finally, in 2013, a neurologist diagnosed me with multiple sclerosis (MS) based on my symptoms. I tried 3 MS medications with continued disease progression, including optic neuritis, continued weakness, and a myriad of other "MS" symptoms. After a second opinion, and a positive AQP4 IgG, I was diagnosed with NMO earlier this year.

I currently live in the Houston metropolitan area and work for a Houston based company. I am married with a 5-year-old daughter and a 4-year-old son. My husband works in the refinery industry.

After researching support groups, I learned that there is a need in the Houston, TX area. It is my hope that a new group in Houston will help to bring survivors and their caregivers together to create a large network of support. I hope that our group can provide support, encouragement, education, and friendship.

TERESA CHAPMAN

WE DON'T WANT TO LOSE YOU

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes by going online to http://tinyurl.com/bswg6yp or via email at info@myelitis.org.

For those of you who wish to receive our communications by postal mail, the Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates.

We save a considerable amount of money by doing our mailings this way. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you after your grace period, and this class of mail is not returned to the sender.

The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

SUBSCRIBE TO THE TMA BLOG!

Have you read The TMA BLOG (https://myelitis.org/category/resources/tma-blog) lately? We publish weekly stories and articles written by individuals living with rare neuro-immune disorders, caregivers and families, as well as leading researchers and clinicians. The blog covers a wide variety of relevant topics, including stories about your experiences living with a rare neuro-immune disease, clinical care and management updates, new research studies, TMA awareness and education program announcements.

You don't have to wait for the latest publication of the TMA Newsletter or try to remember to visit the TMA website in order to receive the most up-to-date information on research and findings in the field of rare neuro-immune disorders. It's easy to stay informed about the latest events, programs and activities of The Transverse Myelitis Association. You can have all of this information delivered directly to your inbox so you won't miss a thing! To receive a weekly email with our latest blog posts in your inbox, please go to http://eepurl.com/xuoGr.

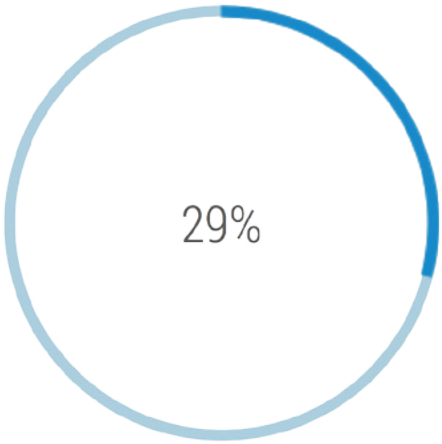
ACUTE IDIOPATHIC TRANSVERSE MYELITIS IN CHILDREN

Early predictors of relapse and disability

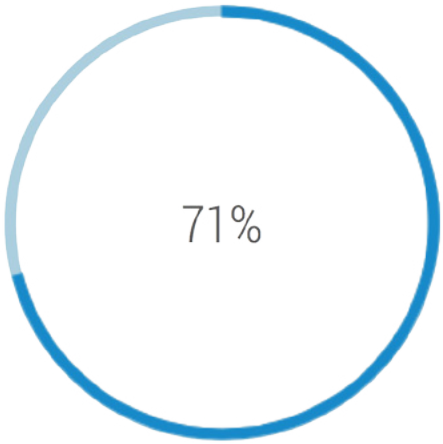
Deiva et al. published a study in 2014 describing predictors of relapse and disability in a pediatric sample of transverse myelitis. They included children who were 16 years or younger who had a first episode of acute idiopathic TM. Children were from 12 neuropediatric centers in France and from 3 centers in the United Kingdom who had presented between January 2004 and December 2011[a]. They also defined cases as having definite or probable TM[b]. At the last follow-up with the patients, children were assessed as either having a monophasic or relapsing disease course. Children were also rated as having a poor outcome if their ASIA score was less than D, or their Expanded Disability Status Score was greater than or equal to 4.

108 children were identified for this study, but 13 were excluded because they either had normal CSF or MRI or their data was missing, leaving 95 children in the sample. 67 of these children had definite TM, while 28 had probable TM. Of these 95 children, 16 ended up having relapsing disease (13 with MS, 3 with AQP4-positive NMO), and their relapses occurred relatively quickly after the first attack (median 3.5 months). There was a greater percentage of children who reached ultimate disability in under 24 hours in the monophasic group than in the relapsing group. Also, the percentage of children who had brain lesions at onset was greater in the relapsing group than in the monophasic group. Furthermore, 30% of the children had a poor outcome, and this was associated with time to ultimate disability of less than 24 hours, and sphincter dysfunction.

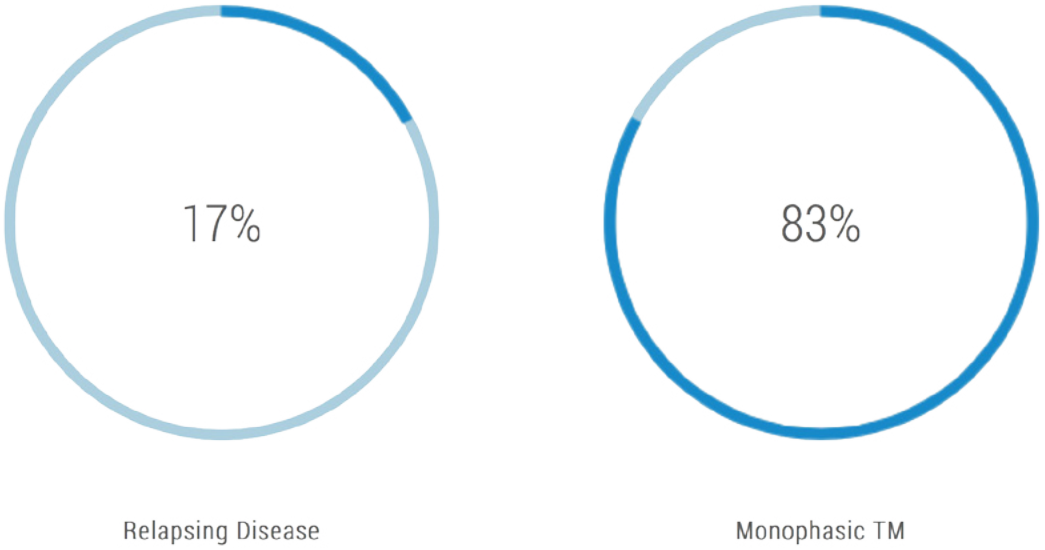
They found two risk factors for relapsing disease: abnormal brain MRI at onset (those with an abnormal brain MRI were almost 14 times more likely to have relapsing disease than those with a normal brain MRI) and female sex (females were 3 times more likely to have relapsing disease than males). They also found 5



Poor Outcome



Good Outcome



risk factors for poor outcome, which included a severe ASIA score at onset, spinal lesion with gadolinium enhancement, female sex, CSF pleocytosis <10 cells/mm, and no cervical or cervico-thoracic lesion.

The authors do note that the follow-up time for the monophasic group was significantly shorter than the follow-up time for the relapsing group, so it is possible that more children in the monophasic group would have eventually been diagnosed with relapsing disease. Though the authors believe that the follow-up time for the monophasic group was long enough to monitor most of the relapsing cases.

[a] They included cases if they fit these criteria: (1) sensory, motor, or autonomic dysfunction attributable to the spinal cord (2) bilateral signs or symptoms but not necessarily symmetric (3) progression to most disability less than 21 days following the onset of symptoms and (4) absence of symptoms from an acquired brain demyelinating syndrome.

[b] Definite TM included cases that had either (1) CSF pleocytosis greater than or equal to 10 leukocytes/mm3 (2) elevated immunoglobulin G index or presence of intrathecal oligoclonal bands or (3) MRI spinal gadolinium enhancement. Cases were considered probable TM if they did not meet the above criteria or if they did not have a lumbar puncture or spinal gadolinium MRI.

GABRIELLE (GG) DEFIEBRE, *Research Associate at The TMA*

Original research: Deiva K, Absoud M, Hemingway C et al. Acute idiopathic transverse myelitis in children: Early predictors of relapse and disability. Neurology. 2014;84:1-9.

PROTECTIVE **ENVIRONMENTAL FACTORS** FOR NEUROMYELITIS OPTICA

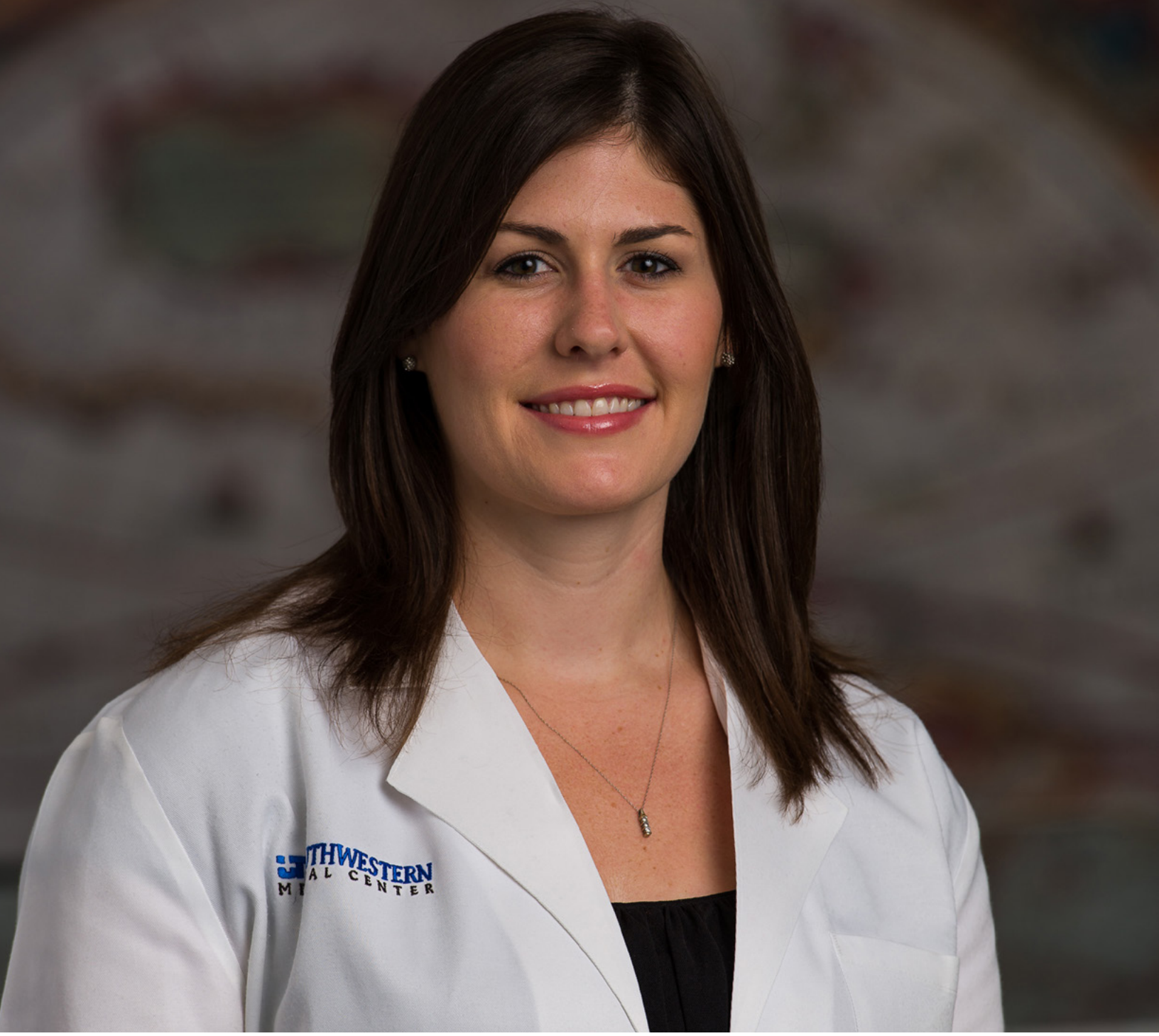
A study was recently published that discussed potential early-life environmental risk factors for NMO. MS has been shown to be associated with several environmental factors, but less is known about environmental factors and NMO. Graves et al. looked at environmental questionnaire data for children with NMO (36), MS (491) and clinically isolated syndrome (CIS) who had high risk of MS. All individuals in the study had disease onset before age of 18. Graves et al. also enrolled 224 healthy controls who had no history of autoimmune disease. Questionnaires included information about pregnancy exposure and complications, how the child was delivered (cesarean versus vaginal), and early childhood exposures (breastfeeding, length of breastfeeding, exposure to cigarette smoke, daycare attendance etc.).

NMO children were younger at onset than those with MS/CIS and were more likely to be African American. Most (58%) children diagnosed with NMO were AQP4-IgG positive, and those that were positive were more likely to be female and non-white than those who were AQP4-IgG negative. Exposure to daycare and breastfeeding were associated with lower odds of having NMO versus being a healthy control. Cesarean section delivery was associated with higher odds of having NMO versus being a healthy control. Also, children of mothers who had a college-level education or higher had lower odds of having NMO versus children of mothers who did not complete high school. Father's education, insurance type, exposure to cigarette smoking, and exposure to Epstein Barr Virus were not significantly associated with NMO.

Graves et al. theorized that breastfeeding is protective against NMO because of mother to child transmission of antigens and immune cells that lead to improved immunity for the child. They also theorized that daycare attendance is protective because children get exposed to many different pathogens in daycare, leading to increased immunity. Based on the results of this study, the authors believe that NMO and MS have different risk factors and are indeed different diseases. They also noted that the sample size of NMO patients in this study was small, so more studies with larger samples of NMO patients should be conducted.

GABRIELLE (GG) DEFIEBRE, *Research Associate at the TMA*

Original research: Graves J, Grandhe S, Weinfurtner K et al. Protective environmental factors for neuromyelitis optica. Neurology. 2014 Nov;83:1929-1929.



My favorite question to ask our teenagers in the TM and NMO clinic is "What do you want to be when you grow up?" This provokes a wide array of answers, from teacher to CSI agent to rocket scientist. Helping our teenagers identify how to reach their goals despite their disability is one of my passions.

YOU CAN AND **SHOULD** DREAM BIG!

Occasionally a young patient does not have an answer, and after digging deeper I learn that their hope of being independent from their caregivers has been lost. There is a feeling of anxiety that they will not be able to move away from their parents to go to college or start working. Sometimes the perspective of the teenager affected by TM, AFM, NMO, ADEM, or ON, or even the perspective of the family, is the greatest limiting factor preventing them from reaching their full potential. Their expectations of what life would be have not been met, and they are disillusioned about their future. This mental hurdle is by far the most challenging. When young people buy into the lie that they cannot go to school or work because they have issues with their sight or ambulation, then they cheat themselves and those around them out of reaching their full potential.

After diagnosis, the trajectory of the teenager's life is altered. How much it is altered depends on factors like the severity of the illness, its impact on daily activities, the degree of recovery, and psychosocial support. The child's dependence on their caregivers and others increases and their independence decreases. Hopefully this is for a short period of time, and as treatment interventions and rehabilitation are put into place the child resumes their previous trajectory. When that doesn't happen we assess for various barriers affecting independence and look for solutions. It is possible to overcome the mental barriers, but it requires getting help from others and a willingness to take a chance. There will be many trials, but it is important to remember that many times success is defined by our ability to overcome challenges and push through; it is the journey, not the destination that makes us.

We want to inspire our young patients to DREAM BIG! I tell them there are politicians who are in wheelchairs running entire states and there are chefs that are blind. I explain that their medical condition is not the driving force in their life, just a challenge. We hope to help them chase after their dreams and break down the obstacles into manageable steps to ultimately be the best they can be.

This is the first blog in the series on Transition of Care. Audrey Ayres, RN, BSN, MSCN is a clinical nurse at University of Texas Southwestern Department of Neuro-immunology. She was recently awarded the 2014 Excellence in Nursing Award by the Dallas magazine. Audrey provides care for adult and pediatric patients with Multiple Sclerosis, NMO, TM, AFM, ADEM and Limbic Encephalitis. She is also the primary nurse for the Pediatric Demyelinating Disease Clinic for Children's Medical Center in Dallas, TX.

FOR MORE BLOG POSTS PLEASE VISIT HTTPS://MYELITIS.ORG/CATEGORY/RESOURCES/TMA-BLOG

2015

RARE NEURO-IMMUNE DISORDERS SYMPOSIUM

Emerging Science and Treatments

An education and advocacy conference for families, caregivers and individuals diagnosed with Transverse Myelitis (including the subtype Acute Flaccid Myelitis), Neuromyelitis Optica, Optic Neuritis, and Acute Disseminated Encephalomyelitis

Friday & Saturday | October 23-24, 2015 | Dallas, Texas
UT Southwestern | T. Boone Pickens Biomedical Building

The Transverse Myelitis Association

UT SOUTHWESTERN Medical Center

children's health℠ Children's Medical Center

JOHNS HOPKINS TRANSVERSE MYELITIS CENTER

OBJECTIVES

- Acquire an understanding of the biology and causes of rare neuro-immune disorders (TM, NMO, AFM, ADEM, and ON) and how they relate to each other
- Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic rare neuro-immune disorders
- Gather information and knowledge on the latest acute and long-term immunotherapies, clinical studies, and future treatment strategies

AUDIENCE

This conference is open to all individuals diagnosed with AFM, TM, NMO, ON, or ADEM, their families and caregivers. Medical professionals interested in these diseases are also welcome to attend.

REGISTRATION FEES

TMA MEMBERS

	REGISTRATION DEADLINES		
	Early Bird - By July 31	Aug 1 - Sept 15	Sept 16 - Oct 15
Conference Participant	$ 40	$ 50	$ 60
Additional Participant	$ 30	$ 40	$ 50
Children (12 - 18 years)	$ 10	$ 15	$ 20

NON-MEMBERS

	REGISTRATION DEADLINES		
	Early Bird - By July 31	Aug 1 - Sept 15	Sept 16 - Oct 15
Conference Participant	$ 65	$ 75	$ 85
Additional Participant	$ 50	$ 60	$ 70
Children (12 - 18 years)	$ 15	$ 20	$ 25

* Children under 12 years of age can attend the symposium at no cost

** TMA Membership is free. To join The TMA go to https://myelitis.org/join

To register for the symposium, please go to http://myelitis.org/2015-rnds

All presentations will be video-recorded and made available at http://myelitis.org

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

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The PREVENT Study

PREVENT STUDY in relapsing NMO

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

AstraZeneca

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

Boston Children's Hospital
Until every child is well

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

BRIGHAM AND WOMEN'S HOSPITAL

Safety and Efficacy of Sustained release Dalfampridine in Transverse Myelitis

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A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

UT SOUTHWESTERN Medical Center

The Effect of Pregnancy on Neuromyelitis Optica

MASSACHUSETTS GENERAL HOSPITAL

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

International Center for Spinal Cord Injury at Kennedy Krieger Institute
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Neuroimaging and Neurobehavioral Outcomes of Pediatric Neuromyelitis Optica: A Pilot Study

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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

UNIVERSITY OF MICHIGAN

clinical studies & trials

https://myelitis.org/research/clinical-studies-trials

2015 ASK THE EXPERT PODCAST SERIES

Thank you to those who joined our podcasts as part of TMA's Ask the Expert podcast series. The podcast sessions provide an avenue for individuals diagnosed with these disorders and their family members to ask questions of experts who specialize in these disorders. The podcast recordings have not only been made available on our website at https://myelitis.org/education/podcasts, but you can also find all recordings on iTunes by going to:

HTTPS://ITUNES.APPLE.COM/US/PODCAST/TMA-ASK-EXPERTS-PODCAST-SERIES/ID893008309?MT=2

You will be able to listen and download all prior podcasts for free! Don't forget to stay tuned for more TMA podcasts featuring leading medical experts in the field of rare neuro-immune disorders.

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** 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.*

Welcome to the inaugural Transverse Myelitis get together in Sydney

Transverse Myelitis (TM) and similar rare neuro-immune disorders can have a devastating impact on the lives of both the individuals diagnosed and their families. The rarity of TM often adds to the stress of dealing with a life changing condition as it is difficult to access medical advice with professionals who are familiar with treating the condition and who keep up to date with research and treatment options. Given this situation Spinal Injuries Australia (SIA) encourages individuals to access resources and peer support to ensure they have the best possible opportunity to recover from the initial onset and deal with residual symptoms and long term disability.

Spinal Injuries Australia (SIA) is the Australasian affiliate for the Transverse Myelitis Association USA (TMA). In addition to establishing an annual Transverse Myelitis Day in May and a range of services offered by the organization to its members, we have facilitated a number of informal gatherings amongst members within local areas. These gatherings have enabled members to meet with their peers to share their experiences and benefit from peer support.

Gatherings have been held in Queensland with feedback being overwhelmingly positive. The current trend of connecting through social media provides a popular forum for many individuals dealing with the challenges of TM. Responses after one gathering were very encouraging with major interest from members throughout Australia who would like to attend a similar function in their own region. These mutual benefits included the opportunity to share ideas, strategies and information about vital resources, particularly in the local region. Interestingly, it was universally acknowledged that whilst social media provides an accessible forum for support groups it simply could not compare with the opportunity to meet face to face. The added benefit of the day was the opportunity for families and caregivers to learn more about the condition and share their specific challenges.

To this end, SIA intends to expand its activities to other States beginning with a gathering of TM network members in the Sydney region. The aim of this event is to facilitate a meeting of members to meet others who are dealing with TM to share knowledge and understanding of the condition and local resources. It would also enable SIA to provide information on the range of services that can be accessed by members.

For further details please email or phone

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Spinal Injuries Australia

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BENT OUT OF SHAPE

CONTRACTURE AND WHAT TO DO ABOUT IT*

*Originally published, New Mobility magazine, 3/15 issue.

ALLEN RUCKER

When I left the rehab unit at Cedars Sinai Hospital in Los Angeles eighteen years ago, newly paralyzed and completely freaked out, no one told me that if I didn't exercise my legs regularly, they would freeze up at the joints and not straighten out. When I followed up with additional rehab work, they made no mention of this, either. So, sure enough, within months, if not weeks, both of my knees, especially the right one, locked in at a 30 to 45+ degree angle and stayed there. We gave the crookedest leg a name: Crookie.

Many times over the course of these last eighteen years, I have been told by internists, neurologists, and even a rehab person or two that contracture -- the shortened and tightening of leg muscles and therefore tendons at the knee, hip, or ankle -- was an unsolvable problem. (Contracture of the hand is also not uncommon). You can stretch affected joint, massage the muscles to loosen them, and even wear cumbersome braces, but the results will be from miniscule change to no change.

Then I met someone who knew what they were talking about.

Dr. Christina Sadowsky, Medical Director, International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore and also a professor at the Johns Hopkins School of Medicine, deals with contractures every day and laughed when I first told her what others had said about my contracture. She fixes up people all the time.

Contracture is less common among those paralyzed in the last few years, simply because more health workers know about it, but according to Dr. Sadowsky, for people injured for 15-20 years or more, "I'd say that 99% have to deal with contracture." The scary thing about contracture – at least scary to me – is that it can set in within two weeks of a spinal cord injury. To prevent it from doing so, you have to combat it from day one.

The point of no return – meaning a contracture that probably won't respond to any non-invasive therapy – is the geometric angle of your knee or ankle. Anywhere from 90%, i.e., a complete bend, to 30%, you're in trouble. At thirty degrees or below, you got choices. There are a fistful of measures you can take and get a positive response.

Contracture generally doesn't hurt or prohibit you from living life in a chair – so why bother about it? You got a crooked leg or two – so what? Because, Sadowsky says, for at least three compelling reasons:

ONE, CONTRACTURE ALTERS THE MECHANICS OF SITTING AND LYING AND CAN LEAD TO PRESSURE SORES. At night, for instance, your legs splay outward and invite knee and ankle hot spots. Beyond pressure sores, your awkwardly positioned legs, say, are much more susceptible to injury. Dr. Sadowsky's example: you're lying on the couch with a severely bent knee and your four year old niece decides to hop on for a ride. Crack! Broken bone.

TWO, IT ALTERS THE MECHANICS OF TRANSFERRING, ESPECIALLY WITH ANKLE CONTRACTURE WHICH RESULTS IN A DROPPED FOOT. Easy to get caught under a car door, and if your bones are weak, easy to snap. Weak bones in general can prevent you

from pursuing any kind of corrective therapy. The first order of business is to get a bone test.

The third reason to conquer contracture is that **IT PROHIBITS YOU FROM TAKING ADVANTAGE OF ANY OF THE COMING TECHNOLOGIES THAT MIGHT HELP YOU STAND AND/OR WALK** – standing braces, exoskeletons, gliders, standing chairs (either weight-bearing or not weight-bearing), and other rehab options yet invented. In my current condition, the only repositioning I could do is squatting a la Yogi Berra behind home plate.

It's the prospect of Reason #3 that led me to finally take a first step and locate my own rehab specialist, Dr. Suzy Kim, currently at the Rancho Los Amigos Rehab Center in beautiful downtown Downey, CA. Dr. Kim, herself a C-7 incomplete from a diving accident while in medical school, had the same can-do attitude as Dr. Sadowsky. She examined me and first off, announced that my level of injury was lower than I had ever been told, close to T-12/L-1, which meant there was little chance that my leg and hip muscles would ever respond to therapy like epidural stimulation.

Now, the good news: in one leg, my left leg, my angle of contracture is such that I could very possibly correct it with a dynamic knee brace – meaning a brace where you can alter the angle and tension of prolonged stretching as your knee becomes more responsive. (There is also a more passive non-invasive therapy, called serial casting, in which you place your knee in a hard cast and replace the cast at a new angle as you improve.) In either case, my left knee, at an angle of about 45 degrees, wasn't a candidate. Crookie would need surgery.

Standard contracture surgery involves what Dr. Sadowsky calls "Z-plasty," a term also used in plastic surgery. Basically, a surgeon cuts the contractured tendon in a way that it can stretch out, and properly maintained, stay stretched and your knee/ankle/hip stays straight. Dr. Kim called it "fileting the tendon." Often the procedure cuts half of the tendon at one end and the other half at the other end, creating less resistance and more elasticity. Find a thick rubber band at home, cut it partially at both ends, and stretch it out. You'll get the same result and feel like an orthopedic surgeon for a day.

Not knowing exactly how to proceed, I turned to some real-world experts. Mackenzie Clare is a 19-year-old college freshman from Leesburg, VA. A T-4 complete from a car wreck in 2005, she knew all about the value of stretching and standing from day one. But, like most of us would do, when she got back home she returned to living the life of a teenager and slacked off. A few years down the line her hips locked up and she began the litany of therapies available.

First was sustained, rigorous stretching. Under the guidance of Janet Dean, a nurse practitioner working alongside Dr. Sadowsky, Mackenzie even attended rehab camp in the summer to stretch and stretch and stretch. It made no appreciable difference. She also tried Botox injections, a common way to relax contracted muscles. Nada. Then they fitted her with "super cushy little leg braces" to slowly loosen her hips, but they led to blisters while sleeping, even while sleeping on her stomach. Cushy or not, she decided, they weren't for her.

With her mother nudging her to try anything, she started standing upright with rigid full-leg braces on parallel bars. Again, with her contracture, she found this difficult, frustrating, and time consuming. Plus, the possibility of mastering these braces to the point that she could wear them in public mortified her. "I'd rather people stare at my chair than braces or a walker." Again, for a teenager (and in fact for an old timer like me), this made all the sense in the world.

Surgery worried her, too. First there was the prospect of spending untold hours stretching after surgery. Without a rigorous regimen before school, after school, and on every weekend, there was the possibility that her hip tendons could become rigid again and the whole thing would be a waste of time.

In the end she chose not to have surgery. Her plan is to wait until a "cure" for SCI came along, then get the surgery to prepare for it. "I wish my hips were straight," she says, "but I don't have time to focus on them right now. Maybe I can after college..."

Contracture therapy, either before or after surgery, demands the commitment of someone training for a marathon. But with that commitment, change can come.

Jamie Clendening is a 36-year-old new mom living in

"the great little town" of Shippensburg, PA. Born with Spina Bifida, she had to undergo back surgery three years ago to "untether" her spinal cord from nerves which were inhibiting its growth and flexibility. The surgery is called Tethered Cord Release and it left her paralyzed from L-3 down. She now spends her life in a wheelchair, waiting for nerve tissue to regenerate so that she can walk again.

Even though she was educated about contracture from the very start, she suffered a set-back when an infection put her in bed for eleven months. Along the way she developed pronounced contracture in her right hip, knee, and ankle. It not only inhibits her leg movement, it's painful.

Under the guidance of Dr. Sadowsky, she rededicated herself two months ago to strenuous contracture therapy. This involved a number of steps: 1) Stretching repeatedly during the day, not just a few minutes in the morning and/or at night; 2) Working out daily on a RT300 hand cycle equipped with FES (Functional Electrical Stimulation) electrodes to stimulate muscle groups up and down her legs; 3) a trip to Kennedy Krieger every three months for Botox injections; and 4) for spasticity, taking the drug, baclofen.

During this intensive two months, Jamie has seen, in her words, "a vast improvement" -- greater flexibility in her affected joints and a decrease in pain in her hip. She is very optimistic that if she sticks with her therapy with yeoman dedication, her contracture will be largely gone, or at least significantly improved, in the next six months.

Talking to Jamie, you can sense that she has the right stuff to get the job done -- limitless tenacity. Her doctors cannot tell her when she will walk again – the recovery from Tethered Cord Release could be months or even years away. But she wants her legs ready and straight when that moment comes.

Which brings me back to my own case. I may not have Jamie's tenacity or Mackenzie's pragmatism, but I am still going to jump into the pool. A month ago, under Dr. Kim's supervision, I started daily therapy on my left knee with a dynamic leg brace. Now at 6-8 hours a day, mostly at sleep, and increasing the angle of tension gradually, I hope to make measurable progress in another month or two. If not, I'm looking at surgery for both knees.

Whether one leg or two, I plan to go under the knife sooner than later. Given my age, I don't have a lot of time to fool around and I'm anxious to see if any device in the near future can change my life. Post-surgery, I will (hopefully) stretch my two straight legs everyday with the dedication of Jamie above, go to bed at night admiring my beautifully unbent legs, and start shopping around for the latest gadget du jour.

I'm doing this whole contracture rigmarole for future returns on my investment. I'm betting that something is out there or will soon come my way and give me some change in physical status. Maybe not huge – a non-weight-bearing standing device, for instance – or maybe something profound, a full out exoskeleton that allows me movement I haven't dared to dream about for eighteen years.

Maybe I'll get a standing wheelchair so I just stand around, with cocktail in hand, chatting it up at the next Hollywood party I weasel my way into. Or...God willing... maybe I'll casually walk over to the bar in my Robocop-spiffy exoskeleton to order up a refresher. Wouldn't that be grand?

ALLEN RUCKER

IN THEIR OWN WORDS ARTICLES

In each issue of the newsletters, we will bring you a column that presents the experiences of our members. The stories are presented In Their Own Words by way of letters we receive from members like you. We are most appreciative of your willingness to share very personal stories. It is our hope that through the sharing of these experiences, we will all learn something about each other and about ourselves. It is our hope that the stories will help us all realize that we are not alone. It is important to bear in mind that the stories are not written by The Transverse Myelitis Association but come from our members. It is also important to note that the newsletters are archived on our web site. Should someone do an Internet search of your name, your article is likely to be identified in his or her search results. You may submit your stories by sending them either by email or through the postal service to Sandy Siegel. Please be sure to clearly state that The Transverse Myelitis Association has your permission to publish your article.

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ANNOUNCEMENTS

2015 Illinois Walk-Run-N-Roll: September 20, 2015

2015 Maryland Walk-Run-N-Roll: October 4, 2015

2015 Rare Neuro-Immune Disorders Symposium: October 23–24, 2015

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