

**THE TRANSVERSE MYELITIS ASSOCIATION**

# NEWSLETTER

*...advocating for those with acute disseminated encephalomyelitis,  
neuromyelitis optica, optic neuritis and transverse myelitis*

Summer 2014

# 20 YEARS

# MAKING A

# DIFFERENCE



© The Transverse Myelitis Association Journals and Newsletters are published by The Transverse Myelitis Association, Powell, Ohio. Copyright 2014 by The Transverse Myelitis Association. All rights reserved. No part of this publication may be reproduced in any form or by any electronic or mechanical means without permission in writing from the publisher. We ask that other publications contact us for permission to reprint any article from The Transverse Myelitis Association Journals and Newsletters.

# INDEX

THE EDITOR'S COLUMN	/ 04
2ND ANNUAL REGIONAL TRANSVERSE MYELITIS SYMPOSIUM AT THE JOHNS HOPKINS TM CENTER	/ 05
DIFFERENTIAL DIAGNOSIS OF TRANSVERSE MYELITIS	/ 06
PARTIAL ACUTE TRANSVERSE MYELITIS IS A PREDICTOR OF MULTIPLE SCLEROSIS IN CHILDREN	/ 08
FACTORS ASSOCIATED WITH THE EFFECTIVENESS OF PLASMA EXCHANGE FOR THE TREATMENT OF NMO-IGG-POSITIVE NEUROMYELITIS OPTICA SPECTRUM DISORDERS	/ 09
CAPTURE: INSTILLING HOPE COLLECTIVELY	/ 10
HAVE YOU OR A LOVED ONE BEEN DIAGNOSED WITH TRANSVERSE MYELITIS?	/ 12
CLINICAL STUDIES AND TRIALS	/ 13
SUBSCRIBE TO THE TMA BLOG!	/ 15
THE TMA'S 'ASK THE EXPERT' PODCAST SERIES NOW AVAILABLE ON ITUNES!	/ 16
KNOWLEDGE IS POWER!	/ 18
A SEA OF YELLOW: 2014 TMA MD WALK-RUN-N-ROLL	/ 25
FIRST ANNUAL TMA GOLF OUTING: CHIPPIN' IN AGAINST TRANSVERSE MYELITIS	/ 26
HELPING TO MAKE A DIFFERENCE	/ 28
RILYNN'S JOURNEY: A STORY OF ENDLESS LOVE, DEDICATION, AND HOPE	/ 30
THE TMA'S 20 FOR 20 ANNIVERSARY CAMPAIGN	/ 36
JOHNS HOPKINS NMO PATIENT DAY	/ 38
EULOGY: AGNES KILLOUGH	/ 39

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

*"My doctor suggested that I should get a baclofen pump. Can you get me in touch with people who have had this procedure? I would like to discuss the kind of experience they are having, and how it has worked for them."*

*"I am in the process of applying for disability, and I would like to speak to people who can offer me some guidance about the process."*

*"I am considering a spinal cord stimulator for nerve pain. Could you please connect me with other people from our community who can share their experiences?"*

*"We are having our bathroom remodeled to make it entirely accessible. We'd like to discuss our project with other people who have gone through this so that we can be sure that we do all of the right things in the right way."*

There are so many complicated decisions people in our community have to make on a daily basis about medications, procedures, social services, and a myriad of other issues. I could make a very long list of the issues that I have been asked about over the years.

The TMA is initiating a new forum that we believe will facilitate and enhance communications between our members. We know that we have a great deal that we can learn from each other, and we also recognize the power that is involved in sharing experiences. Smart Patients is an online community where patients and caregivers can communicate and learn from each other about treatments, clinical trials, the latest science, and how it all fits into the context of their experience.

It was obvious to us very early on that one of the most important purposes for our organization is to provide a way for people in our community to be able to contact each other and to share information and experiences. We've had a very long history of doing just that. Jim Lubin started the first Transverse Myelitis Internet Club (TMIC) and a bulletin board system in the late 1990s. Since then, communication has expanded in recent years through social media sites like Facebook and Twitter. We realize that these tools have their limitations and more and more people are looking for a safe community to have meaningful conversations.

Over the years, our experience has been that the information our members share with each other is just as important as the medical guidance they receive from their doctors. In fact, one of the most important roles our community plays is to offer each other a way to establish what expectations one should have about the medical care they are receiving. For instance, people often do not receive aggressive enough physical therapy. The best way to find that out is by asking others to describe specifically what kind of therapy regimen they are following, how often and for how many hours a day. This is just one small example, but it demonstrates the real power in having this kind of communication between people.

These communications also form and reinforce our sense of community. Because we are a rare disease community, our numbers are relatively very small. And we aren't just small; we are spread out across the globe. Electronic communications allow daily contact with a large group of people. The emotional support that people share with each other is critical for managing all of these very difficult problems.

Smart Patients - <https://www.smartpatients.com> - is an online community dedicated to health and wellness, a unique forum for conversation that is private, secure, allows conversations within and between disease groups so we can learn and leverage lessons not just from within our



community but across a spectrum of related auto-immune diseases, stay up-to-date on advances in clinical care and research, interact as support groups, increase visibility for our rare diseases and foster learning from others.

You can sign up for Smart Patients from the following page:

<https://www.smartpatients.com/transverse-myelitis-association>

We have started a few conversations that you will be able to join in on, and you can start new conversations as well. We urge you to get involved in our Smart Patients community.

If you have had experiences that you would like to share with our community, please start a new conversation. The value of our communications will increase as more and more people from our community join and participate.

We can all learn so much from each other. We encourage you to get involved and to offer your experiences to others who will greatly benefit from your knowledge.

Please take care of yourselves and each other.

*Sandy Siegel, President of The Transverse Myelitis Association*

## 2ND ANNUAL JHTMC REGIONAL TM Symposium

On Saturday June 21, 2014, over 100 individuals diagnosed with TM, NMO and other rare myelopathic disorders came together with their caregivers and family members at Johns Hopkins Hospital in Baltimore, MD for a hugely successful Clinical Care Symposium. Many attendees met others with the same diagnosis for the first time! Participants came from as far as California, Utah, and even Australia to interact with experts from Johns Hopkins Hospital (JHH), Kennedy Krieger Institute (KKI), and International Neurorehabilitation Institute (INI). The symposium topics addressed issues that most affect patients on a day-to-day basis, including diagnosis of transverse myelitis, neuropsychiatric impact of the diseases, gait dysfunction and innovative rehabilitation strategies, spasticity management, bowel and bladder management, developments in stem cell treatments, and management of Neuromyelitis Optica. The program was a combination of lectures and breakout roundtable sessions, with some question and answer time made available in a day packed with information!

Thank you to the attendees and experts who joined us, volunteers from JHH and KKI, Alexion Pharmaceuticals for an unrestricted educational grant and the Bart A. McLean Neuroimmunology Research Fund for helping sponsor the event.

All sessions were video-recorded and will be made available shortly on the JHTMC ([http://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/transverse\\_myelitis/index.html](http://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/transverse_myelitis/index.html)) and TMA (<http://myelitis.org/education/symposia>) websites.







The Johns Hopkins Transverse Myelitis Center in Baltimore, MD was well represented at the **2014 American Academy of Neurology** conference, where the Center presented research on TM and other rare neuro-immunologic disorders. Among the research was a poster presentation entitled, “Differential Diagnosis of Transverse Myelitis,” which was a retrospective analysis of 591 patients who presented to our Center over a 36-month period with the presumptive diagnosis of TM. We performed an in-depth analysis into the validity of patients’ diagnoses based on the available data to determine just how many patients had inflammatory TM, and determine how many actually had some non-inflammatory cause for their myelopathy. Two-thirds of patients who presented were confirmed to have inflammatory TM, and the majority of these were monophasic and idiopathic. Nonetheless, it should be noted that over a quarter of patients who presented to the JHTMC had a variety of non-inflammatory causes for their myelopathies, with the largest contenders for non-inflammatory myelopathies attributable to compression, vascular, and metabolic etiologies. This large patient cohort alerts clinicians to recognize that the full differential diagnosis of TM is wide, and should draw attention to the fact that a comprehensive clinical work-up is necessary.

The Academy and Jeffrey Dunn of Stanford University honored the JHTMC by highlighting this research at a special MS/Neuroinflammatory session, where Dr. Dunn shared that the research represented the high level of expertise coming out of the Johns Hopkins Transverse Myelitis Center.

To read more, please visit our blog <https://myelitis.org/resources/tma-blog/research-studies/greetings-johns-hopkins-transverse-myelitis-center> by Maureen Mealy published on June 12, 2014.

Maureen A. Mealy, RN, BSN, MSCN  
Clinical Program Manager & Research Director  
Johns Hopkins Transverse Myelitis Center & Neuromyelitis Optica Clinic

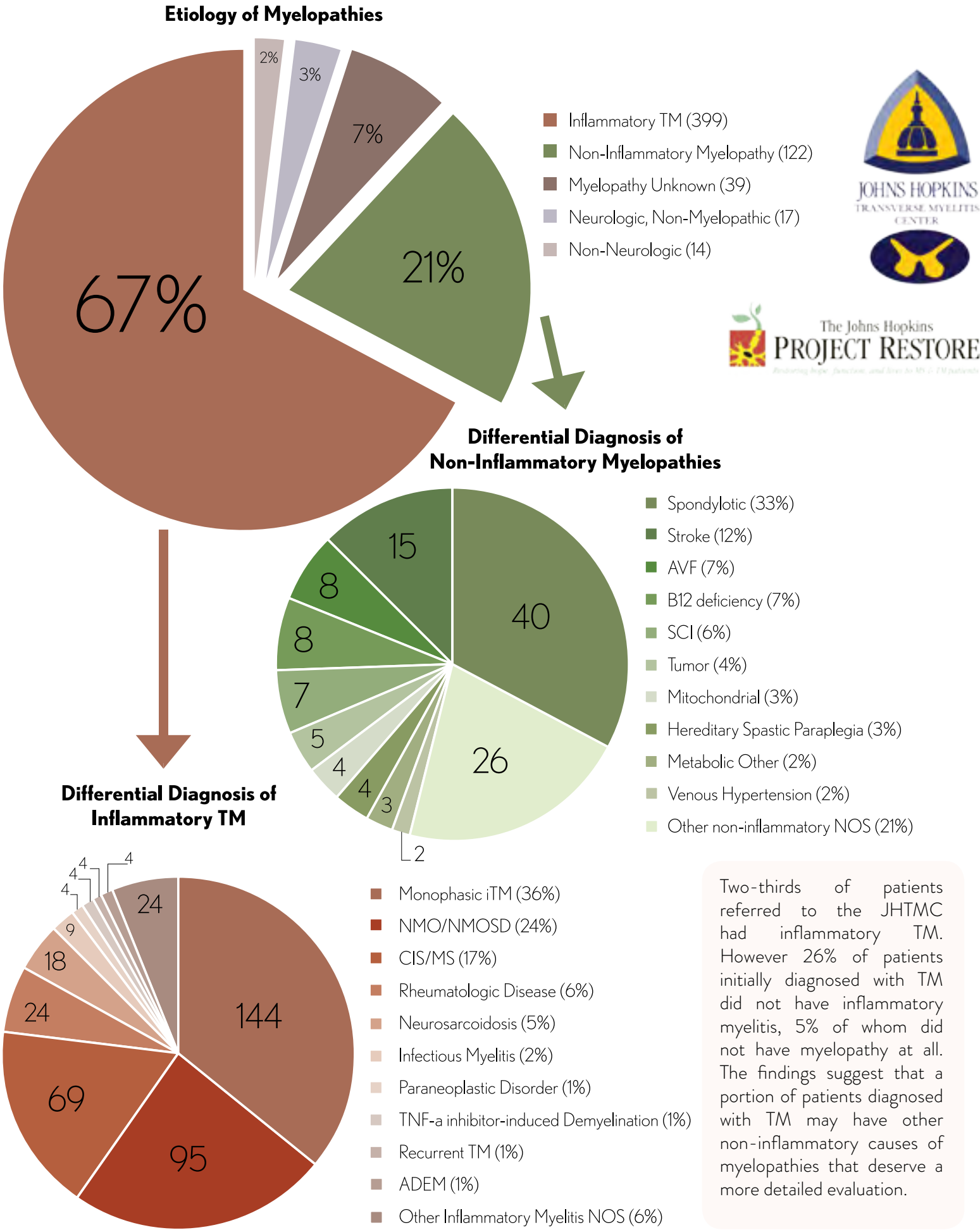
DIFFERENTIAL DIAGNOSIS OF TRANSVERSE MYELITIS

Maureen A. Mealy, RN, BSN, Daniel Becker MD, Scott D. Newsome, DO, John N. Ratchford, MD, Michael Levy, MD, PhD, Carlos A. Pardo, MD

The Johns Hopkins Transverse Myelitis Center performed a retrospective analysis to determine the true spectrum of diagnoses of those patients referred to and seen for the presumed diagnosis of TM at the time of referral.

As you know, TM is a non-specific inflammatory attack of the spinal cord. The common causes include monophasic idiopathic transverse myelitis (ITM), multiple sclerosis (MS), neuromyelitis optica (NMO) and rheumatologic diseases. The JHTMC is dedicated to the diagnosis and management of TM, and to other conditions that can mimic TM.

We reviewed 591 patients who presented between August 2010 and July 2013. The final diagnoses were based on clinical profiles, neuroimaging, and the specific diagnostic criteria for each disease or condition for which patients were eventually diagnosed after extensive work-ups were completed. The goal was to report the full differential diagnosis of TM, including non-inflammatory causes.



Two-thirds of patients referred to the JHTMC had inflammatory TM. However 26% of patients initially diagnosed with TM did not have inflammatory myelitis, 5% of whom did not have myelopathy at all. The findings suggest that a portion of patients diagnosed with TM may have other non-inflammatory causes of myelopathies that deserve a more detailed evaluation.

# PARTIAL ACUTE TRANSVERSE MYELITIS IS A PREDICTOR OF MULTIPLE SCLEROSIS IN CHILDREN

Meyer et al. published a study in March 2014 about the clinical course and factors contributing to the prognosis of children under the age of 16 after they were diagnosed with acute transverse myelitis (ATM). The authors reviewed the medical records of 30 children who were diagnosed with ATM at Montpellier University Hospital in France, and follow-up records for these children were available for between 6 months and 16 years after the initial presentation. The children were split into two diagnostic categories, those with acute complete transverse myelitis (ACTM) and those with acute partial transverse myelitis (APTM). Ten of the children were categorized as having APTM, which was defined as having "...incomplete or patchy involvement of at least one spinal segment, with mild to moderate weakness, asymmetric or dissociated sensory symptoms...", and those with bladder involvement were sometimes included. The rest of the patients were categorized as having ACTM, or "...symmetric, moderate or severe loss of function."

Meyer et al. split the patients into these two groups because studies involving adults have found that those with APTM are more likely to eventually be diagnosed with multiple sclerosis than those with ACTM. Upon

presenting to the hospital, the patients were also categorized as having:

1. Isolated transverse myelitis, meaning that they had a normal brain MRI (53% of patients),
2. Clinically isolated syndrome, meaning they had isolated ATM with abnormal brain MRI but no encephalopathy (17% of patients),
3. Polyfocal CIS, meaning they had more than one lesion but that they did not have encephalopathy (13% of patients),
4. Acute disseminated encephalomyelitis (ADEM) (17% of patients), or
5. Multiple sclerosis (no patients).

In contrast to a previous study, none of the patients had been immunized or received an allergy shot within 30 days of their first symptoms of ATM, but in this study 60% of the patients had ATM symptoms after an infection, and 17% of the patients had a minor fall or twist before their symptoms of ATM started. At the end of the follow-up period, 5 (17%) of the patients had a diagnosis of multiple sclerosis. Having APTM was associated with a five times higher risk of eventually being diagnosed with multiple sclerosis than those with ACTM. Other studies on

adults have found that patients with spinal lesions less than two sections in length are more likely to eventually have a diagnosis of multiple sclerosis than those with longer lesions, but Meyer et al. found no association between the length of the lesion in the spine and a diagnosis of multiple sclerosis. Meyer et al. attributed this to the fact that they had so few children with multiple sclerosis enrolled in their study. Furthermore, higher disability score at onset was associated with not having a subsequent diagnosis of multiple sclerosis. Meyer et al. also found that children with brain lesions were more likely to subsequently receive a diagnosis of MS than children without brain lesions. Because of this risk, and the increased risk of a subsequent diagnosis of MS in children with APTM, they suggest that children with APTM get MRI of their brain every year for at least five years.

*This summary was written by Gabrielle (GG) deFiebre, Research Associate at a Public Health non-profit in New York city who was diagnosed with Transverse Myelitis in 2009. GG volunteers with the Transverse Myelitis Association.*

**Original research: Meyer et al. Partial acute transverse myelitis is a predictor of multiple sclerosis in children. *Mult Scler.* 2014; 1-9.**

# FACTORS ASSOCIATED WITH THE EFFECTIVENESS OF PLASMA EXCHANGE FOR THE TREATMENT OF NMO-IGG-POSITIVE NEUROMYELITIS OPTICA SPECTRUM DISORDERS

Lim et al. published a study in 2013 on the effectiveness of plasma exchange (PE) in treating neuromyelitis optica spectrum disorders (NMOSDs). During plasma exchange, blood is removed from the body and the blood cells are separated from the plasma. The person receiving plasma exchange then gets their blood cells back, but the cells are mixed with donor plasma. The study included 31 women who were positive for NMO-IgG who received PE for a steroid-resistant attack of NMO. The NMO-IgG test indicates whether or not someone has antibodies for aquaporin 4 antigen, and being NMO-IgG positive is a characteristic of NMO.

In this study, 25 of the patients had an NMO diagnosis, and 6 had a diagnosis of longitudinally extensive transverse myelitis. All of the patients were characterized as moderately to severely disabled, and were given a disability score. The patients' responses to plasma exchange were measured at 1-month and 6-month intervals after treatment with plasma exchange. Functional improvement was seen in 18 patients (58%) at 1 month and 20 patients (65%) at 6 months. Short-term improvement was associated with attacks that did not involve the optic nerve and attacks in which the patients' reflexes were preserved. Similarly, long-term improvement was associated with non-optic nerve related attacks, but was also associated with a lower disability score at the onset of the NMOSD attack, and fewer prior attacks of NMOSD. Furthermore, improvement was seen more often in patients who did not have spinal cord atrophy than those that did. NMO-IgG levels at the beginning of plasma exchange and during the follow-up intervals were not different between those who responded favorably to the treatment and those who did not. Also, some patients received plasma exchange sooner after their onset of symptoms than other patients, but this was not associated with functional outcome. Lim et al. concluded that even though rapid onset of plasma exchange is recommended, it should be given to patients who have not recovered even after the acute phase of an attack of NMOSD.

*This summary was written by Gabrielle (GG) deFiebre, Research Associate at a Public Health non-profit in New York city who was diagnosed with Transverse Myelitis in 2009. GG volunteers with the Transverse Myelitis Association.*

**Original research: Lim Y, Pyun SY, Kang B, Kim J, Kim K. Factors associated with the effectiveness of plasma exchange for the treatment of NMO-IgG-positive neuromyelitis optica spectrum disorders. *Mult Scler.* 2013; 19(9): 1216-1218.**







# CAPTURE

## Instilling Hope Collectively

Recently, my son began another regimen of outpatient therapy through our regional rehabilitation facility. We're not new to this hospital, but the PT assigned this time around was new to us. I have struggled over the past several years communicating with various therapists, to explain and to have them understand what it is that my son is dealing with – spinal cord damage as a result of transverse myelitis. I find that some don't want to be given information about a particular diagnosis, current research or prognosis and, truthfully, that puts me off. A good therapist is going to want to know what is unique to your child and how they can help develop and meet the goals you have in mind. It's important to his outcome that they understand he isn't dealing with cerebral palsy and even though his "injury" was seven years ago, that there is still a need for continued therapy and it **is** beneficial. **His time period for recovery has NOT expired!**

What struck me most about this therapist was that on one of our first visits, she said she had been researching transverse myelitis. It was the first time any therapist we have seen at this hospital had indicated they were that invested in my son; I was shocked and impressed! She then remarked about how very little information there was available about transverse myelitis – diagnosis, treatment, prognosis ... and this was all coming from a professor of physical therapy! It was disturbing to hear her say this even though I know it is all too true. We had a great conversation



about transverse myelitis, the lack of information available, and the incredible opportunity that is right before us to begin to change the information that is available to all of those facing a transverse myelitis diagnosis.

I am sure you have heard of or seen the articles announcing the PCORI award for the first multi-center, innovative, pediatric transverse myelitis study, **CAPTURE**. If you haven't, please take a moment, bookmark this entry to come back to and read a bit more about CAPTURE on page 12! It's okay, I'll wait.

Now that you know about the study, I want to take a few moments to make sure **you** understand how you can help make this study successful and meaningful! We can't accomplish what Dr. Greenberg, et al. and the TMA have set forth to do without your help.

To be eligible as a volunteer for the study, a child does need to be newly diagnosed. The details for research volunteers can be found on page 12. Yes, please take a moment to read it carefully – **it's important!** Just be sure to come back to finish up this article.

Perfect – now that you're back, you're wondering either how to sign up or how this pertains to you if you or your child don't fit the criteria for research.



First, if you are interested and meet the criteria, please, please, **contact me via email or telephone** and I will be happy to discuss the study further with you. **You may also contact Tricia Plumb of UTSW, Research Coordinator for the study directly** ([patricia.plumb@utsouthwestern.edu](mailto:patricia.plumb@utsouthwestern.edu), (214)456-2464) and she will be more than happy to answer your questions as well.

Second, if you aren't newly diagnosed, **you can still participate and help us make a difference**. Share the letter we've written, the press release, and the flyer with your local physicians, hospitals, and therapists. It's an opportunity to raise awareness and share your family's story, and how an innovative study may have helped your child and your family to overcome and work through transverse myelitis. Chances are that you may also hear about newly diagnosed families simply via word of mouth before they ever hear of the TMA. **It's important that we reach families that have been recently diagnosed, not only for the study, but to offer our support. There is power and there is comfort in numbers. We don't have to face this alone.**

If your child has recently been diagnosed, please remember, I have been in your shoes. I know how raw, sensitive, frazzled, exhausted, confused and angry you are right now. You aren't sure what to do next and participating in "research" is the last thing that is on your mind. Please call me. I get it. I can still feel myself in that hospital, tears streaming down my cheeks, unable to hold my infant son and simply feeling lost. If someone had walked in and asked me to participate in research, depending on the moment, they may have just received my blank stare and silent tears or the closest heavy object hurled at them. But as time moved on over the course of a few days in the acute care and then rehab facility and I discovered that the physicians and therapists treating my son were themselves at a loss in regard to the future of my son, I wanted – no, I needed to make a change. If I understood that the foremost physicians in North America on pediatric transverse myelitis were going to review my son's records and follow him for the next twelve months, **AND** hear from me as to what our life was like since his diagnosis, I would sign up in a heartbeat.



A few key components I feel, as a parent and primary caregiver, are important and I want to make sure you are aware of:

There is a **virtual cohort** to this study. If you are interested but don't know that travel to one of the participating centers is feasible, please know that there still is an opportunity for you to be involved virtually. Sometimes a family may want to but simply can't get to one of the centers. Please know that we still want to discuss the possibility of participation in the virtual cohort.

This study is unique in **that it is collaborative with the child or parents themselves**. It is not strictly about clinicians gathering data from lab work or imaging but **it is about quality of life from your perspective**; how you or your child is feeling, coping, changing, and recovering through the year after the diagnosis.

When all is said and done with the study, we will have so much more information as to how the various treatment options affect the outcomes in more than just a clinical manner. We will have a foundation to build from for future research. And something really incredible; the results won't be sequestered to a medical journal and only accessible by clinicians. With the help of the TMA, you can be sure that the **knowledge and hope we glean from the study will be shared amongst our community. The information will be empowering, will instill hope, and will help you to be the best advocate for yourself or child.**

I often wonder why my son wasn't offered IVIG or PLEX, if the physicians knew about it, if it would have made a difference in his recovery .... I wonder how the conversations with the physicians would have changed and perhaps may not have been so bleak when they discharged us ... I wonder if the last seven years of therapy and specialist visits may have been more directed in the goals and treatment if I had access to information that gave me a better glimpse of what we were facing. Hopefully, **one day, families won't have to wonder so much and will feel enabled to be equal participants in their care.**

- Rebecca Whitney | [rwhitney@myelitis.org](mailto:rwhitney@myelitis.org) | 1-855-380-3330 ext 5



# Have you or a loved one been diagnosed with Transverse Myelitis?

Announcing a multi-center, innovative, patient-focused, observational research study on Pediatric Transverse Myelitis in North America called **CAPTURE: Collaborative Assessment of Pediatric Transverse Myelitis: Understand, Reveal, Educate.**

If you, your child, or someone in your family has been recently diagnosed with the rare neuro-immune disease called transverse myelitis, we want to hear from you.

Your participation will help families and healthcare professionals:

- **Understand** the current status of care in children diagnosed with TM;
- **Reveal** the best practices and treatment options available; and
- **Educate** physicians, clinics, the health care system, and families and individuals about the most important and achievable outcomes following a TM diagnosis.

## To be Eligible Research Volunteers must be:

- Diagnosed with Transverse Myelitis
- Between the ages of 0-18 (or 17 years at onset)
- Within 90 days of onset of symptoms

Participation in this study may involve travel to one of the five centers, whichever is closest to you geographically, 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 needed for completion of questionnaires by the child and/or parents.

## Participating Centers (IRB approved):

- University of Texas Southwestern/Childrens Medical Center, Dallas, TX
- Johns Hopkins Transverse Myelitis Center, Baltimore, MD
- Kennedy Krieger Institute, Baltimore, MD
- The Childrens Hospital of Philadelphia, PA
- The Hospital for Sick Children (SickKids), affiliated with the University of Toronto, Canada

**For more information, please call 855-380-3330 extension 5 or email [rwhitney@myelitis.org](mailto:rwhitney@myelitis.org)**

More details on the study and participating centers can be found on <https://myelitis.org/research/clinical-studies-trials>



# The Effect of Pregnancy on Neuromyelitis Optica

## INVESTIGATOR

Eric Klawiter, MD

## STUDY SITE

Massachusetts General Hospital,  
Harvard Medical School, Boston, MA

## ELIGIBLE PARTICIPANTS

The study is enrolling females age 18 or older with NMO. Participants do not need to have been pregnant in the past to participate. Participants can be NMO antibody positive or negative as long as they carry the diagnosis of NMO. Participation would involve completing a survey that will be administered over the phone and should take 10-20 minutes of your time. There is no monetary compensation. There is no cost to you. You will not receive any personal health benefits as a result of your participation in this research study. We hope that the results will help us better understand NMO, and might benefit patients with NMO in the future. Your participation is voluntary.

## STUDY DETAILS

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.

## CONTACT INFORMATION

If you are interested in participating, please contact: Dr. Eric Klawiter at 617-726-7643. Please be prepared to leave a detailed message, including the name of the study and your contact information (so that you can receive a confidential message in response).

## 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 either by going online to <http://tinyurl.com/bswg6yp> or via email at [info@myelitis.org](mailto: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.

## IN THEIR OWN WORDS ARTICLE

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.

# Safety and Efficacy of Sustained release DALFAMPRIDINE IN TRANSVERSE MYELITIS

## STUDY DETAILS

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.

## INVESTIGATOR

Michael Levy, MD, PhD

## STUDY SITE

Johns Hopkins University  
Baltimore, MD

## CONTACT INFORMATION

Maureen Mealy, RN  
[hopkinstmcenter@jhmi.edu](mailto:hopkinstmcenter@jhmi.edu)

# Efficacy & Safety Study of SA237 as Monotherapy to Treat NMO And NMOSD

SPONSORED BY CHUGAI PHARMACEUTICALS

## STUDY DETAILS

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.

## CONTACT INFORMATION

If you are interested in participating, please contact:

Clinical trials information [clinical-trials@chugai-pharm.co.jp](mailto:clinical-trials@chugai-pharm.co.jp)

SA237 Clinical trial [sa237@chugai-pharm.co.jp](mailto:sa237@chugai-pharm.co.jp)

<http://clinicaltrials.gov/ct2/show/study/NCT02073279?term=SA237&rank=1>

For more information on the European/Asian trial, please visit:

<https://www.clinicaltrialsregister.eu/ctr-search/search?query=SA237>

## ELIGIBLE PARTICIPANTS

Inclusion Criteria:

1. NMO or NMOSD
2. Age 18 to 74 years, inclusive at the time of informed consent.

Exclusion Criteria:

1. Pregnancy or lactation.
2. Evidence of other demyelinating disease or PML.
3. Known active infection (excluding fungal infections of nail beds or caries dentium) within 4 weeks prior to baseline.

## ELEGIBLE PARTICIPANTS

Patients (18-70 years) diagnosed with monophasic transverse myelitis confirmed by MRI will be eligible to participate in this study.

Diagnosis of recurrent myelitis or multiple sclerosis is an exclusion criteria for the study; however, patients may have a diagnosis of neuromyelitis optica, lupus, sarcoidosis or other rheumatologic or systemic disorder in the setting of monophasic myelitis.

Other exclusion criteria include:

- History Of Seizure(S).
- Pregnancy Or Positive Pregnancy Test (Mandatory Test For All Women Aged 18-55 To Be Done At First Screening Visit).
- Known Allergy To Dalfampridine Or Any Other Formulation Of 4-Aminopyridine.
- Patients Unable To Walk.
- Patients With History Of Severe Alcohol Or Drug Abuse, Severe Psychiatric Illness Like Severe Depression, Poor Motivational Capacity, Or Severe Language Disturbances, Particularly Of Receptive Nature Or With Serious Cognitive Deficits (Defined As Equivalent To A Mini-Mental State Exam Score Of 23 Or Less).
- Patients With Severe Uncontrolled Medical Problems (E.G. Hypertension, Cardiovascular Disease, Severe Rheumatoid Arthritis, Active Joint Deformity Of Arthritic Origin, Active Cancer Or Renal Disease, Any Kind Of End-Stage Pulmonary Or Cardiovascular Disease, Claudication, Uncontrolled Epilepsy Or Others).

## 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 diseases, 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 the latest 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>.



# A Double Blind Trial to Evaluate the Safety and Efficacy of Eculizumab in Relapsing NMO Patients

SPONSORED BY ALEXION PHARMACEUTICALS

STUDY DETAILS	ELIGIBLE PARTICIPANTS
<p>The primary objective of the study is to assess the efficacy and safety of eculizumab treatment as compared to placebo in relapsing NMO patients using a time to first relapse study design. This is a randomized double blind study, where participants will receive eculizumab or placebo and neither the participant nor the study doctor or their staff will know who received the drug or placebo. In this study participants will have a 67% chance of receiving eculizumab and a 33% chance of receiving placebo. The medication is given intravenously, initially weekly for 5 weeks and then every 2 weeks.</p> <p>Eculizumab is not approved for treatment of NMO. Eculizumab is a monoclonal antibody that blocks one component of the complement pathway, part of the immune system. Activation of the complement pathway is believed in part to be responsible for relapses in NMO. A pilot study of eculizumab in 14 female NMO patients suggested that eculizumab can reduce the risk of relapse. This study is intended to confirm that finding.</p>	<p>Participants maybe eligible if they are at least 18 years old, have a positive test for the NMO IgG antibody and have experienced 2-3 relapses in the last 2 years with at least one relapse in the last 12 months.</p> <p>This is an “add on study,” and patients can continue to be on their current NMO medications and receive the study medication. The duration of the study is 2 years. If participants have a relapse, the study will end, however there is a second study participants may be eligible to enroll where all patients will receive eculizumab.</p> <p>As with all medications there are potential side effects, which will be discussed prior to enrollment and detailed in the informed consent.</p>
CONTACT INFORMATION	
<p>If you are interested in participating, please contact the sponsor by email at <a href="mailto:clinicaltrials@alxn.com">clinicaltrials@alxn.com</a> or call 203-272-ALXN</p> <p>You may also contact:</p> <p>Warren W. Wasiewski MD   VP Clinical Development Neurology Alexion Pharmaceuticals Inc.   203-699-7701</p> <p>Idil Cavus, MD   Medical Director, Neurology Alexion Pharmaceuticals Inc.   203-699-7859</p> <p><a href="http://clinicaltrials.gov/ct2/show/study/NCT01892345?term=ALexion&amp;rank=5">http://clinicaltrials.gov/ct2/show/study/NCT01892345?term=ALexion&amp;rank=5</a></p>	

### THE TMA'S 'ASK THE EXPERT' PODCAST SERIES NOW AVAILABLE ON ITUNES!

Thank you to those who joined the podcasts on “Understanding & Managing Neuropathic Pain” in May 2014 and “The Role of Exercise and Rehabilitation in Non-Traumatic Spinal Cord Injury” in June 2014 as part of TMA’s Ask the Expert podcast series. With over 215 members registered, the podcast sessions provided an avenue for individuals diagnosed with these disorders and their family members to ask questions of experts who specialize in these disorders.

The physician-experts on the panel were Dr. Daniel Becker from the International Neurorehabilitation Institute in Lutherville, Dr. Allen DeSena & Dr. Melanie Farrar from University of Texas Southwestern in Dallas, Dr. Kathleen Zackowski from Johns Hopkins Medicine in Baltimore, and Dr. Scott Newsome from Johns Hopkins Transverse Myelitis Center in Baltimore.

The podcast recording has not only been made available on our website <https://myelitis.org/education/podcasts>; you are now also able 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 by going to <http://myelitis.org/education/podcasts>.

# An open-label Study of Bevacizumab for the Treatment of Acute Optic Neuritis and/or Transverse Myelitis in Neuromyelitis Optica and Neuromyelitis Optica Spectrum Disorder

INVESTIGATOR	STUDY SITE	ELIGIBLE PARTICIPANTS
Michael Levy, MD, PhD	Johns Hopkins University Baltimore, MD	Patients may be eligible who are between the ages of 18 and 70 who present with acute optic neuritis and/or transverse myelitis and have a known or suspected diagnosis of NMO or NMO spectrum disorder. Female participants must not be pregnant and must commit to not becoming pregnant in the next 6 months from time of consent.
STUDY DETAILS		
<p>NMO is a severe, demyelinating autoimmune disease of the central nervous system that preferentially affects the optic nerves and spinal cord. Although historically considered a subtype of multiple sclerosis (MS) with overlapping symptoms, NMO is distinct radiologically and prognostically, and has a pathophysiology unresponsive to typical MS treatments.</p> <p>This is a phase 2 investigator-initiated interventional trial of bevacizumab to evaluate the tolerability/safety and preliminary efficacy of bevacizumab as add-on therapy for treatment of acute optic neuritis and/or transverse myelitis in neuromyelitis optica (NMO) and neuromyelitis optica spectrum disorder (NMOSD). A single infusion of bevacizumab is added to standard-of-care high dose steroids and an additional dose of bevacizumab is added to plasma exchange (if necessary). The primary outcomes are clinical changes in the Expanded Disability Severity Scale, Timed 25-foot Walk and Low Contrast Visual Acuity, MRI parameters and safety.</p>		
CONTACT INFORMATION		
		Maureen Mealy, RN <a href="mailto:hopkinstmcenter@jhmi.edu">hopkinstmcenter@jhmi.edu</a>

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

INVESTIGATOR	STUDY SITE	ELEGIBLE PARTICIPANTS
Christine N. Sang, MD, MPH	Brigham and Women’s Hospital Boston, MA	Male and females (not of child-bearing potential) between 18 – 65 years old with a documented spinal cord injury will be eligible to participate in this study. Participants must have central neuropathic pain that is of at least moderate intensity, daily for at least 3 months before study entry. This study will be of no cost to the participant. Your participation is voluntary.
STUDY DETAILS		
<p>V158866 is an active inhibitor of FAAH1, an enzyme that metabolizes the endocannabinoid called Anandamide (AEA). It is hypothesized that inhibition of FAAH1 can decrease pain without generating side effects in non-activated pathways. Therefore, the primary objective of this study is to investigate the safety and tolerability of V158866 in subjects with central neuropathic pain following spinal cord injury (both traumatic and non-traumatic) and evaluate its analgesic and anti-hyperalgesic effect. The study will consist of four overnight visits to the hospital. All travel to and from the hospital will be reimbursed.</p>		
CONTACT INFORMATION		
<p>If you are interested in participating, please contact the Translational Pain Research Group by email at <a href="mailto:paintrials@partners.org">paintrials@partners.org</a> or call 617-525-7246.</p> <p><a href="http://clinicaltrials.gov/ct2/show/NCT01748695?term=V158866&amp;rank=2">http://clinicaltrials.gov/ct2/show/NCT01748695?term=V158866&amp;rank=2</a></p>		

# KNOWLEDGE IS POWER!

Spinal Cord Injuries and Transverse Myelitis present challenges, but we don't have to face them in ignorance.

*People with spinal cord injuries (SCI) and transverse myelitis (TM), especially those newly diagnosed, and their loved ones, need a Survival-to-Living Guide. Without a guide, they suffer more than necessary. My story is a case in point.*

## ALL THE KING'S HORSES AND ALL THE KING'S MEN...

In July, 2011, at age 58, I was walking my dog when a mosquito bit me on the earlobe. On August 4, 2011, I was admitted to the hospital. This small bite caused West Nile Virus, full body paralysis, encephalitis, a spinal cord injury and transverse myelitis. A relapse in December of that year marked the beginning of a gradual decline in my physical abilities, leaving me wheelchair dependent, unable to walk even one inch.

And I was sick—jerking spasms in my spine and legs both day and night that could last for up to an hour at a time, speech changes that made it hard to get my words out, muscle tightness around my rib cage that made breathing difficult, a low level of electricity that hummed through my body at all times, periodic bouts of extreme and sudden fatigue, eye spasms and vision fluctuations, periodic and repetitive arm flailing and, as if that wasn't enough, my singing voice was gone.

Prior to August 4, 2011, I had been a wife, mother, sister, aunt, friend, giver, painting teacher and writer. I had been independent, fun, funny, adventurous, nurturing, self-sufficient, my husband's ballroom dance partner and baker of the best brownies in the world. My roles and attributes shattered like glass on the floor. I mentally swept the pieces into an envelope marked "Never Again."

Where once I had had dominion over everything in my home and yard, I now had dominion only over the TV remote control. I spent my days weeping, contemplating suicide and praying for death.

Nothing in life had prepared me to be THIS—useless, fearful, helpless, hopeless, pitiful, scared, dependent, lonely, bored, wheelchair dependent, housebound, terrified, sarcastic, bitter, LOST.

We looked for medical help from five hospitals, twelve neurologists and a second opinion from Johns Hopkins University. No one had any answers. There were times when I went to physical and occupational therapy. These 45-minute, twice-a-week sessions were designed to help people restore one injured body part. The problem was that I didn't have just one injured body part. My whole body was injured and my life was completely broken.

I talked to a counselor. My world of terror, however, couldn't be fixed by anything that came in a bottle or dissipated by words of, "I understand

how hard that must be," spoken by a sweet young thing who had no understanding of how hard THIS must be.

One neurologist told me with alacrity, "You wouldn't inspire anyone." Oh, really? Was that supposed to be my job?

My caregiver risked her job to say, "Jeanne, get over yourself."

My sister said, "Think of those less fortunate than yourself." If that could help, then I need only watch the news on TV to feel better.

Most of my friends deserted me, or perhaps I pushed them away, saying, "I'll call you back." I never did. I was too sick to talk, didn't have answers to their questions and didn't want to hear about their happy, normal lives.

I existed in this state for almost two years. I knew I needed help on many fronts. If doctors, counselors and physical therapists, and the Internet had no answers, then **I would have to develop a Survival-to-Living Plan on my own.**

## TAKING STOCK

I started by taking inventory:

- West Nile Virus kills some people. In some people, it destroys their brains. **I am alive, brain intact.**
- **My arms and hands still work**, although everything I touch feels like sandpaper.
- **I am living at home**, not in a hospital, rehab facility or nursing home.
- **My husband retired from work to care for me**, which he does with patience, kindness and love.
- **I have two caregivers**; one who does our laundry and cleans our house, and one who helps me and brings me good foods. They love me on good days and bad.
- **I have some working nerves and muscles.** They can be exercised and strengthened. There is hope.
- **I have a computer and access to the outside world.**

All of this is more than some people have. **Gratitude was slowly sinking in.**



MY SURVIVAL-TO-LIVING PLAN

I broke down my seemingly insurmountable challenges into bite-sized pieces, then developed a plan based on my goals in each of the following categories:

Sickness

My #1 goal was to feel better. After many trips to various hospitals, I found that I had been having seizures (clonic, not grand mal) on almost a daily basis. Anti-seizure medication put an end to speech changes that made it hard to get my words out, extreme fatigue, eye spasms and vision fluctuations, as well as the periodic repetitive arm flailing.

My breathing difficulty improved over one year with physical therapy, massage and deep breathing exercises.

**Major improvements!**

Comments on medications I am presently taking:

- Carbamazepine to prevent seizures, 200 mg, 3 pills per day; effective but still have occasional breakthrough seizures
- Baclofen for spasms, 10 mg, 7-9 pills per day; doesn't seem to be effective
- Nitrofurantoin to prevent bladder infections, 50 mg , 1 capsule per day; very effective
- Aleve for times of feeling generally unwell, 220 mg, 1 tablet; very helpful

Fears

My assortment of fears needed to be tackled one by one.

I was afraid of being alone and needing help. A list of caregivers', neighbors' and my husband's cell phone numbers tucked into the side pouch of my wheelchair, along with a charged phone, made me feel more secure.

I feared catastrophes, like earthquakes or fires. I packed and kept a travel bag close to the front door, containing: medications, toiletries, clothes, socks and a sweater, a list of all of my contacts and phone numbers, passwords, account numbers and phone numbers, policy numbers and phone numbers; my medical history, list of medications and medical directive, checks, granola bars and water—in short, everything needed in

case I had to exit the house quickly for a trip to the hospital or alternative housing.

***I now feel better prepared for emergencies and less fearful!***

Transfers

We discovered that if I wore a Posey gait belt around my waist at all times, my husband could more easily lift, transfer and steady me as necessary.

***This saves his back and makes us both feel more secure!***

Power Wheelchair

I could not navigate a manual wheelchair, but getting a motorized chair proved to be a daunting task, one that took more than one year. Finding out what features were available and which ones I needed proved to be even harder. Why does it have to be this hard? Finally I got the chair I needed.

***I was now mobile and able to work hands free!***

Toilet Accessibility

Our 1950s home does not have wheelchair-accessible bathrooms, so my husband placed a porta-potty in a room that was accessible. He installed an 18-inch grab bar on the wall next to it (parallel to and 40" up from the floor). I can now wheel up to the bar, grab it firmly, pull myself up to a standing position, pivot, push down my pants and sit down on the porta-potty. It works for me, but my husband still has to empty the potty. And, since I could not get my legs on the wheel chair footrests by myself when I was finished, I was not yet potty independent.

***Toilet problem solved.***

Wheelchair Independence

My husband built a wooden box slightly lower than the height of my wheelchair footrests. When placed on the floor against a baseboard, I could wheel up to the box with my legs outstretched, rest my feet on the box, manually lower the footrests with my hands, use my hands/arms to slide my legs/feet from the box to the footrests, wheel forward (footrests sliding over the box) until the toes of my shoes touched the wall. I then slowly wheeled the chair forward, using the force of the wheelchair to push my feet firmly onto the footrests.

***I was now potty independent!***



Showers and Dressing

We devised a way for me to shower and dress using a combination of manual wheelchair, grab bars, a shower seat, and walker. Since I can't walk or lift my legs, my husband moves my feet and legs. I use a Panasonic ES2207P Ladies 3-Blade "Close Curves" Wet/Dry Shaver to shave my legs and underarms, after which my husband helps me dress.  
*I now start each day clean and neat!*

Clothing

I needed stretchable cotton clothing without zippers or buttons that would withstand weekly washing and drying. I found Karen Scott pull-on pants/capris/skimmers at Macys.com and cotton tee shirts, tank tops and cardigans at Landsend.com.  
*I was now comfortable and even colorful!*

Grooming

I set up a grooming station at a small table, complete with hair dryer and two-sided hand mirror (one side is a regular mirror; the other side is a 5x magnification mirror). To curl my hair around my face, I use a Helen of Troy ¾" Tangle-Free Hot Air Brush which doesn't burn me like a curling iron. Every few months, my husband trims my hair, maintaining my straight bob.  
*I look more like myself!*

Torso Stability

My wobbling torso and stiff neck required support to enable me to sit up for more than 10 minutes. I discovered the ObusForme by Homedics OFHB-BLK Highback Backrest Support, which fit perfectly on my wheelchair.  
*I am now able to work at a table and on my computer!*

Excercise

After physical therapy failed to produce the desired results (theirs, not mine), I begged to be allowed to join the therapy pool group sessions, one hour twice a week. The therapy pool is 3.5'-4.5' deep, has a constant water temperature of 92 degrees and a railing around the perimeter. There is a chair lift to lower and raise me in and out of the pool. Once in the water, I can walk, do deep knee bends, practice standing and more.  
*No therapist or lifeguard is provided; I am on my own.*

Elevator Lift

After getting a \$10,000 quote from a company to build an elevator lift to lower/raise my wheelchair with me in it from our deck to the ground, a distance of six feet, my husband decided to build it himself. Previously an engineer, he designed the lift and true to his word, built it. (Some cities provide accessibility aids, but ours isn't one of them.)  
*I was no longer housebound!*

Van Lift

My husband installed a lift on the back of our van to transport my wheelchair.  
*I could now go places!*

Art

Having been a watercolor painter for 25 years, I was eager to paint again, but my first attempts after TM were disappointing. I could no longer paint as I once did; I did not have the manual dexterity I once did, or the ability to stand over my work. Rather than give up, I decided to try new painting styles and techniques. The results were hit or miss, but I had fun, especially when four of my former students (adults) joined me for painting sessions every Thursday afternoon. One became interested in making greeting cards, so I began doing this, too. Since I could no longer go out and frame my work, I purchased a large bulletin board from Ballards.com and my caregivers hung it in the kitchen. I could now rotate my art exhibits as often as I wanted.  
*Art was now a big part of my life again!*

Social Interaction

I haven't come too far in this last area. I've just recently started to call a few people. It takes effort. First, I write their names and phone numbers on a list. Then, I look at it. After a while, I call one. Whew, that wasn't as hard as I thought. Progress is slow. I've made casual friends in the pool—but none that carry outside the water, with last names and phone numbers. I avoid going outside, fearing mosquitoes.  
*Social interaction will take time.*





## MY WISH LIST AS OF MAY 2014

1. **One FDA-approved medication for TM.**
2. **Medication for spasticity** – something more effective than Baclofen; something that doesn't cause muscle weakness and doesn't require a pump to be installed in the spine.
3. **Comfortable seat for power wheelchairs** – not hot, not slippery – with guaranteed 12-hours of comfort.
4. **Kitchen faucet I can reach**—spout and handles included.
5. **Reacher for paper.** “Squeeze and grab” reachers don't work on paper.
6. Good **shock absorbers for power wheelchairs.**
7. **Wheelchair Feature and Comparison Guide.** The best resource I have found to date is a book by Gary Karp titled, Life on Wheels: The A to Z Guide to Living Fully with Mobility Issues. A more complete comparison of wheelchair features is needed.
8. **Survival-to-Living Guide** written for and by people with SCI/TM.

## WHO AM I TODAY?

I am more satisfied, rarely fearful, more trusting of my husband and caregivers to take care of me, happy to be creating art, delighted to be working out, moving, stretching and strengthening my body four times a week, enjoying being mobile and getting out of the house a few times a week, feeling a little more independent but a LONG way from where I'd like to be, having moments when I am sick and feel sad to be like this and moments when I forget that I am like this, and learning to ride out the good and bad rhythms of each day. ***I plan not only to survive, but to live a happy, meaningful, productive and loving life. For my husband and me, there ARE and WILL BE celebrations every day.***

## COULD WE CREATE A SURVIVAL-TO-LIVING GUIDE?

Yes, we can! Please share your survival-to-living stories or tips with me: [jeannelazo@aol.com](mailto:jeannelazo@aol.com).

Jeanne Lazo, MBA, and Carol J. Amato, MA, co-authored ***Persistence is Power! A Real-World Guide for the Newly Disabled Employee***, a nationwide guide to help people obtain disability benefits through Social Security, disability insurance and workers' compensation.



It is 9:22 am on Sunday, June 22, and the blast of a horn signals the start of the first Maryland Walk-Run-N-Roll for The TMA. Children and adults from age three to eighty-three are off on a 1.4-mile walk around the tree-lined campus of Goucher College in Towson, MD. The day was finally here! You could feel the energy and the enthusiasm in the air. From the minute participants put on their Walk t-shirts until the last good bye, we were pumped. Even through the warm up exercises led by Brick Bodies, it was hard to miss all of the smiles. What a site it was to behold, a sea of yellow. Family, friends, medical professionals, caregivers and patients were together for the first time in Maryland to join in the celebration of this TMA event.

Volunteers were on hand to direct traffic, register participants and accept donations. Local merchants donated orange juice, bagels, apples and assorted chips. Blue goodie bags filled with protein bars, pads, pens, coupons, purple and blue water bottles were made available to each of our participants, compliments of local businesses. Homemade team signs were displayed with pride. The weather and music were pitch perfect. Everything was going perfectly.

After the Walk, we posed for group and

team pictures. Then we started the “meet and greet” part of the day. While children buzzed around the face-painting table picking out their favorite pictures, we listened to stories from those who were affected by these rare neuro-immune diseases. We were fortunate to have Cody Unser from the Cody Unser First Step Foundation start us off and speak about her positive efforts in scuba diving with the disabled. By noon, the events were winding down and it was time to say goodbye. It had been a very long day for many of us, but, as they say, all good things must come to an end. At least for now that is ... because soon it will be time to start planning for an even bigger and better celebration for 2015.

There is so much to think about in planning one of these events. For starters, there is the venue, the food, the t-shirts, the music and the entertainment. For 2014, we only had a handful of volunteers to take on this monumental task, and with our time frame already cut short, we knew this would be a huge challenge. But we were ready. First, we needed the perfect venue and everywhere we looked, the terrain was not suitable or we needed to pay a fee. We finally agreed upon Goucher College and successfully negotiated a reduced fee. Then it seemed to be one delay after another with getting

the contract signed. In the midst of our waiting, however, a donor came forward offering to pay the fee. What a great surprise and a relief! Now it was time to rock and roll. With little more than 90 days to go, we needed to aggressively find more volunteers, sponsors, donors and fundraisers. We immediately set up a Facebook page and invited friends and family to help with the planning. Our local TMer's were first to sign up and then our friends from Kennedy Krieger stepped in. They offered their time, their expertise and even their monetary resources. GO TEAM KKI! Anything that needed to be done, they were there. Thank you to Dr. Becker and his team from The International Rehabilitation Institute, and Dr. Pardo and The Johns Hopkins Transverse Myelitis Center for their support and for joining us at the walk.

There are so many people to thank for helping to make this event such a huge success and we are grateful to each of them. We received so many compliments and expressions of gratitude. I hope that the rest of the volunteers feel as humbled and grateful as I do because this was a truly rewarding experience.

The planning committee for 2015 better get ready because they have big shoes to fill!

~ Laurie Lissimos





# FIRST ANNUAL GOLF OUTING

## THE TRANSVERSE MYELITIS ASSOCIATION

### RECOGNIZING 20 YEARS OF SERVICE

*Chippin' in against Transverse Myelitis*

#### WHAT

A four-person, best ball scramble and dinner to benefit The Transverse Myelitis Association (TMA). Greens fees are \$150 per person and include unlimited use of the range, 18 holes of golf, including cart, lunch, dinner, participation in contests for prizes. Dinner-only tickets are available for \$30. Bonus: The greens fees include a voucher for one free additional round of golf at either Scioto Reserve or Kinsale Country Clubs (cannot be used on the weekend and does not include a cart).

#### WHEN

Monday, September 29, 2014

9 – 11 a.m. Registration

11 a.m. Shotgun Start

5:00 Dinner, Awards Ceremony, Guest Speaker: Dr. Benjamin Greenberg

#### WHERE

Scioto Reserve Country Club, 7383 Scioto Parkway, Powell OH 43065

#### GUEST SPEAKER

Dr. Benjamin Greenberg, Director of the TM and NMO Center at the University of Texas Southwestern in Dallas will share the latest updates and progress in rare neuro-immune disease research.

#### WHY

To raise funds and awareness for The Transverse Myelitis Association. TMA advocates for and supports people and families affected by rare neuro-immune diseases, including Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON), Transverse Myelitis (TM) and Recurrent Transverse Myelitis. These disorders occur when a person experiences an acute inflammatory attack in the spine, brain or optic nerve, causing disability and paralysis, depending on the extent of the injury. These diseases affect children and adults at any age.

#### REGISTER

Please join us by registering online at <https://myelitis.org/register/golf-outing-registration> or by mail using the registration form. Invite your friends and family and you can register for dinner only as well!

#### HOW TO VOLUNTEER

Contact Sandy Siegel, (614) 766-1806 or [ssiegel@myelitis.org](mailto:ssiegel@myelitis.org)

# THE SUCCESS OF OUR FIRST TMA ANNUAL GOLF OUTING

## IS YOUR SUCCESS!



HELP US MAKE THIS A SPECIAL EVENT WORTHY OF OUR SPECIAL COMMUNITY

*Here's how you can help us!*

BE A SPONSOR OR ASK YOUR COMPANY TO SPONSOR YOUR CAUSE

Information is available on our web site at <https://myelitis.org/golf-outing>

BE A PLANNING COMMITTEE MEMBER OR VOLUNTEER ON THE DAY OF THE EVENT

Please contact Sandy Siegel by phone (614) 766-1806 or email [ssiegel@myelitis.org](mailto:ssiegel@myelitis.org)

PLAY A ROUND OF GOLF AS AN INDIVIDUAL OR A TEAM WITH YOUR FRIENDS AND FAMILY

You can register at <https://myelitis.org/golf-outing>

JOIN US FOR THE DINNER RECEPTION, MEET OTHER MEMBERS, AND LEARN ABOUT THE LATEST RESEARCH FROM DR. BENJAMIN GREENBERG OF UNIVERSITY OF TEXAS SOUTHWESTERN!

You can register for dinner only at <https://myelitis.org/golf-outing>

*Thank you to our sponsors*

**aetna**

**THE NARDUCCI'S**







# HELPING TO MAKE A DIFFERENCE

In 2002, after seven years of marriage and three years of working hard and wishing, we were given the news we had almost given up on hearing. We were expecting our first child. Jonathan blessed our lives in October of that year. The first six months he was very happy and healthy, and then things started to change. After his four-month vaccines, Jonathan did not seem like himself. He was much fussier so off to the pediatrician's office we went. We went to the pediatrician six times over the next month with a diagnosis each time of suspected ear infections. Then Jonathan took a turn for the worst. He was not breathing well and not moving as a seven month old should. We went to the emergency room of the best children's hospital in our state and after several hours of waiting Jonathan was admitted. Doctors were still unsure at that point what was causing

his symptoms. After three days in the Pediatric Intensive Care Unit, several tests, many doctors performing examinations, adding a ventilator for breathing support and finally an MRI, the diagnosis of Transverse Myelitis was what we were given. The relief from finally receiving a diagnosis quickly turned to a flood of questions. What is Transverse Myelitis? What are the treatments? And most importantly, how quickly will Jonathan be back to feeling better? The doctors did not have all the answers, but were gathering information for us.

As any family would, we did our own research and found The Transverse Myelitis Association and Sandy Siegel. The website had so much valuable information which included Sandy's direct phone number. We called and were immediately comforted by the friendly and understanding man on the other end. Sandy understood the fear in our voices and the urgency to get Jonathan in the hands of the right people. Sandy put us in touch with Dr. Kerr, Chitra and many TM families that had similar experiences. We made outreach to get the advice needed to assist in Jonathan's recovery. After three months in an acute care hospital and eight months in a rehabilitation facility, we finally brought Jonathan back home. He is now a thriving 11 year old boy who just loves every part of life. Although Jonathan remains a quadriplegic and uses a ventilator for assistance in breathing, he has made much progress and has been fighting hard to get where he is today. Jonathan will be entering 6th grade at our local public school and is hoping one day to be an Art Teacher.

We are so grateful to the TMA and Sandy for being there for all of the TM families at these critical moments. We would not be where we are today without their compassion and tireless support. Everything the TMA does for the families with education and seminars helps us as parents and caregivers to learn what we need to do to continue to support and encourage our children to accept or adapt to life's changes. The TMA Family Camp is also an amazing opportunity for the kids to be kids and not worry about their differences. The entire TMA team goes above and beyond to be at camp, to share information and education and to support our kids. This is an amazing opportunity for parents, as well as for our children.

Every year our family has made a financial donation to TMA because we believe in everything this wonderful

group of caring people does. We want to be sure they have the financial backing needed to assist us, as well as other families who may sadly be diagnosed in the future. So we do whatever we can to help. Bonnie is fortunate to work for Aetna which is a wonderful company that is always willing to support charities. Aetna has a gift matching program so every donation we make over \$25 is matched at 50% by Aetna. When we saw the upcoming TMA Golf Outing we knew we needed to try to do more. So our family will be sponsoring the tournament at the Platinum level (\$5,000). Since we do not live close to Ohio, we are also donating our players so that Sandy can maximize opportunities that may become available. In addition to the gift match that Aetna will make for this donation, Bonnie reached out to her management team in the Connecticut office and asked if there is anything they could do for this great cause. They agreed without hesitation to also sponsor the tournament at the Platinum level. They were willing to do anything they could to give back to the amazing organization they knew helped us and Jonathan through some scary times. Aetna of Connecticut is going to reach out to their counterparts in Ohio to have them play in the tournament, and will try to bring awareness of the fundraiser to other companies in the healthcare industry that they work with. We are so grateful for their support.

If we all made an attempt to try to support the TMA with even a small donation each year we could bring in the funds needed to continue the educational programs for parents, caregivers and especially the doctors so that diagnosis and treatment can happen much more quickly. We as TM families need to motivate and educate those around about TM and how everyone can assist us in supporting the efforts to find cures and treatments for our kids and adults. Without Sandy and Pauline's dedication and sacrifice over the last 20 years, the TMA would not be where it is today or here at all. So with that in mind, we all need to do everything possible to help continue to support the TMA organization.

So as our son Jonathan always says, "Let's take a chance" and ask your employers, neighbors and friends to help you give back to those who have given our families and children the strength needed to move ahead and live life to the fullest!

~ Paul and Bonnie Narducci





# RILYNN'S JOURNEY

## A Story of *Endless Love* *Dedication* *& Hope*

April 1, 2013 was just like any other tax season day for our household. We were finally into April, which signifies the beginning of the end of my long 90+ hour weeks as a CPA. Our nine-month-old daughter, Rilynn, woke up just fine, had breakfast and was off to the daycare provider as usual. She ate lunch, went down for a nap and woke up around 4:00 p.m. She had a snack and her bottle. At 4:45, our daycare provider called Niki and said she was worried about Rilynn. Her eyes were glassy, she cried whenever she was touched and she was unable to bear any weight on her legs. Niki called me at work to let me know something was wrong with Rilynn and I told her I would meet her at home.

When Niki picked her up from daycare, Rilynn was limp. She screamed in pain as Niki tried to buckle her into her car seat. As soon as they got home and I saw Rilynn's face, I knew something was very wrong. We immediately made the decision to take her to the Emergency Room. We called Rilynn's primary care physician on the way to the hospital and he agreed that we were doing the right thing by taking her there. We entered the ER and sat in the waiting room for 20 minutes before we were taken back to be evaluated by a doctor. Rilynn was in complete misery. After finally being escorted into one of the rooms in the ER, we waited another 30 minutes before the attending doctor eventually came to our room to evaluate Rilynn. Rilynn had previously suffered from numerous upper respiratory issues from the time she was three months old. She was constantly on antibiotics or steroids every couple of weeks trying to get her lungs to clear. When we went to the ER, we fully expected this to be a worst-case scenario from the respiratory problems she had been having. We explained her history to the doctor and he ordered a chest

x-ray to look at her lungs. The x-rays came back clear. By that time, Rilynn had become extremely lethargic. The only way she was comfortable was if she was being held by Niki or me. She cried every time she was moved. Her cries were becoming softer – she was barely vocal at that point. The doctor looked her over and said that he didn't know what her issues were; that she just seemed "fussy." He immediately wanted to discharge us. We knew something was wrong, and something bad by the way she was acting. She was weak and by this time she was no longer moving her arms. We expressed our concerns to the doctor about being discharged and asked what other tests we could run to try and determine what was going on. He reluctantly agreed to run blood and urine tests.

The results from the blood and urine tests came back normal and we begged the doctor to do more. He wanted again to discharge us, stating that we were probably being over reactive parents. We again explained that something was very wrong with Rilynn. She was normally so active and since the onset of whatever this was, she was motionless. I remember asking him if maybe she broke an arm the way she was holding it. He twisted and pressured her arm, and because Rilynn showed no immediate reaction, he ruled broken bones out of the equation. He said she would be fussier if she had broken a bone. We kept pushing for more tests and he finally agreed to do a CT scan to check for head trauma. We were furious when we found out that the only reason he agreed to do the CT scan was due to a phone call he had placed to Rilynn's primary care physician, Dr. James Wigington. The ER doctor had needed Dr. Wigington's reassurance that Rilynn was normally a "very active" baby. Why he wouldn't trust our statement, as her parents, that she was not acting like herself still infuriates





us. The CT scan, of course, came back clear. The doctor told us the next step would be a spinal tap, but he did not see any reason to perform one. He discharged us with the instructions to give her Tylenol for pain and to take her to see Dr. Wigington in the morning if she still wasn't better. Rilynn was motionless at this point but we had no choice but to take her home and see how she did through the night.

As we were leaving the hospital, I called a good family friend who is also a nurse at the hospital. She gave us the best advice we had received that day. She explained that, because we are in a rural area, our hospital is equipped to "stabilize and transport" rather than to "treat and release." She strongly encouraged us to keep a close eye on Rilynn and that if she stopped nursing at any point, to get in the car and drive her to Colorado Springs and thereby circumventing our local hospital. We took Rilynn home and put her to bed. She slept in the clothes she had been wearing all day. Every time we touched or moved her, she whimpered in pain. Niki slept on the floor next to her crib that night as I went to bed, hopefully getting up the next morning to do more tax returns. At this point, our naivety was at its peak. Around 4:00 a.m., Niki told me that we had to get to the hospital. Rilynn had woken up and had tried to nurse but was unable to lift her head to do so. Her eyes were open, but she was completely unresponsive. She was not moving her body at all.

The closest Children's Hospital was two hours away in Colorado Springs. We called ahead to let them know we were coming, loaded up and rushed to the ER. We finally started the process of getting Rilynn diagnosed. We met some of the most incredibly compassionate care providers, especially in the ER, which was such a welcome relief from our experience the night before. We were rushed in, and the doctor was in our room in minutes. He went through a gamut of tests including a full body X-Ray, more blood work and a spinal tap. Each test kept coming back clear. I remember Niki asking the doctor at one point if he was going to discharge us if the tests kept showing up clear. The doctor looked at her like, "you're kidding me right?" He called the on-call pediatric doctor, Dr. Elisabeth Martin, who came down and examined Rilynn. We knew Rilynn wasn't moving, but the fact that she was paralyzed never crossed our mind. The first thing Dr. Martin did while examining Rilynn was to try and get her to sit up. She slumped over like a limp noodle. Her cries were still a whimper, but her face showed that they could have been very loud screams. After examining her, Dr. Martin stated that she felt Rilynn had one of two conditions, Guillain-Barre syndrome or transverse myelitis. An MRI on her spinal column would be needed to determine her diagnosis. Her intuition was that Rilynn had transverse myelitis or TM. We had never heard of either of these diseases, and I soon took to my smart phone to read about TM. This is when reality began to set in. The information that came up was



overwhelming and none of it showed a good, long-term prognosis. No one was able to answer questions for us regarding baselines or what to expect from this condition. We were fully admitted to the hospital and waited to go for the MRI. It took until 6:00 that evening to get Rilynn in for her MRI and very shortly after a neurologist confirmed the TM diagnosis. Rilynn had significant swelling at the "C2" level, explaining her complete paralysis. The first course of action was to begin IV steroids. She was given her first dose at 10:00 p.m., approximately 30 hours after onset. We both wish we had made the decision to head to Colorado Springs the night we were discharged from the Salida Hospital, rather than waiting 6 hours at home before we made the decision to go. We were told that we were very lucky the swelling didn't continue up her spine, or she may not have been able to breathe during that time and this could have been fatal.

We stayed several long days and nights at the hospital without Rilynn showing any signs of movement. We were told to stay strong and "hope" that the steroids were going to work. Nights were the hardest. The hospital only allowed one person to stay overnight with Rilynn in her room. Niki would stay since Rilynn was still nursing and I was forced to head to a nearby hotel. It was so hard to leave them, but even harder on Niki. Rilynn's skin was so sensitive to touch during this time and any movement caused her a huge amount of pain. During the day, it took two of us to change

her diaper – it was the only way to do it quickly and with minimal movement. At night, Niki was left to nurse her and change her on her own, all while trying to keep Rilynn as still as possible so as not to cause her any pain. Getting her out of bed was so complicated – we had to move her very carefully so that her IV would not become dislodged. She had heart and oxygen monitors attached, as well as oxygen in her nose. The room was not set-up for anyone to stay other than the patient and I specifically remember having to put a padded chair at the end of the small couch so that Niki's feet wouldn't hang over the edge as she was trying to sleep.

On the third day in the hospital without any signs of movement from Rilynn, her big sister, Nola, finally got to visit. Our parents had shown up to support Rilynn and us during this time. We have video of Nola walking into the room and Rilynn smiling so big, and then the most amazing thing happened. Rilynn got so excited she shrugged her shoulders. This was her first movement in almost four days. She did it again when Nola got closer with such a big smile, everyone in the room cried. I became obsessed with learning about TM, its prognosis and treatments. On the fourth day of the five-day steroid treatment, Rilynn was given an Intravenous Immunoglobulin (IVIG) treatment, which has been shown to help patients with TM. The effects take anywhere from two days to two weeks to appear and the neurologist felt this was the next best option for Rilynn to try and help with her recovery.

We were set for discharge on Tuesday, eight days after being admitted. Rilynn was showing minimal improvement. The sensitivity of her skin had started to diminish and she was able to handle a couple of physical and occupational therapy sessions. We requested a meeting with Dr. Martin and the neurologist prior to discharge. We explained to them our concerns – normally when you are discharged from the hospital you leave with a "healthy" child. I had done research on the Internet and had read some positive articles about the use of Plasmapheresis (PLEX) therapy on people with TM. A PLEX treatment is basically a blood exchange that takes place in numerous sessions over several days. Approximately 60% of the patient's blood is removed during each of these sessions and the plasma in the blood is separated. The cleaned blood is then put back in the body and the plasma is replaced with a man-made version. Our neurologist felt that Rilynn was too young to explore this option and immediately ruled it out. We also inquired about moving her to the Denver Children's Hospital to get her in the inpatient rehabilitation program. Again, that was ruled out by our doctors as they felt Rilynn would not be able to withstand three one hour long therapy sessions per day, which is what would be "required" of her to be in the inpatient program. We were discharged with a prescription for steroids, a neurological pain medicine and the advice to schedule four therapy sessions per week.

We came home and tried to adapt to our new life with a quadriplegic baby, not knowing if she would ever recover further than shrugging her shoulders. One of our family's best friends is a physical therapist and she came to our home daily to work with Rilynn and help us with the therapy process. We also arranged for a local acupuncturist to come to our house and work on Rilynn. After several days of this, Rilynn picked up her arms and moved them above her head during an acupuncture session. Niki's mom was recording it when it happened and you can hear us all crying and laughing with excitement. Her little hands were fisted, and we would work every day to stretch her fingers out. This was all taking place during the last week of tax season and I had no choice but to go back to work during the day. Thankfully, Niki had sick time saved up and was able to stay home with Rilynn. We also had the help of numerous family members to assist with Nola and getting her to school. At work I could not focus, and was an absolute mess.

I researched and obsessed about TM. I couldn't find many stories of full recoveries or even close to full recoveries and was at my wits end when I finally joined The Transverse Myelitis Association (TMA). I had been to their site many times reading the educational materials, but had not yet joined the association. We kept searching for the "silver-lining" approach to Rilynn's diagnosis and weren't finding it, especially for infants. I went through the process of joining the TMA and this turned out to change our lives forever. Literally within minutes of joining, Sandy Siegel, the president and founder of the TMA, emailed me to call him as soon as possible. I immediately called and we





discussed my daughter's condition. He mentioned PLEX, and I told him that we were told by our doctors that wasn't an option for infants. He explained that though he is not a doctor, he believed it could be done and may be very beneficial. Sandy took it upon himself to contact Dr. Ben Greenberg, a top neurologist in the study of children with TM. Dr. Greenberg immediately requested our approval to allow Rilynn's medical records to be released to him for review. Dr. Greenberg then contacted Dr. Teri Schreiner, the head neurologist at Children's Hospital in Denver to see if her team would be willing to perform the PLEX treatments on Rilynn. Dr. Schreiner called us at home on the Saturday after we were discharged from Colorado Springs. She told us that she was willing to do the PLEX treatment on Rilynn, but still needed to discuss it with her team on Monday morning. She would be in touch with us on Monday to let us know what her team's decision was, but to plan on heading to the hospital that next week to begin the treatments. Dr. Schreiner called us on Monday to let us know it was a go and we were scheduled to be admitted that Wednesday. We finally felt like we were headed in the right direction. On April 17, 2013, we walked Rilynn into the Intensive Care Unit of Children's Hospital. I remember the receptionist telling us how strange it was to be admitting someone who was being brought in by his or her parents, rather than through the ER. The PLEX treatment would be administered through the use of two IV lines that had to be inserted through her inner thigh. Rilynn had to be sedated to insert the lines. They told us it would take about 30-45 minutes, but it ended up taking a little over an hour and a half. The wait was excruciating, but thankfully worth it. The lines were in and we were scheduled to begin her first PLEX treatment that afternoon. We had to stay one night in the ICU before being transferred to a regular room.

Rilynn completed five PLEX treatments over a seven-day period. They were painless for her; she slept or watched movies through most of them. We immediately began discussions with the rehabilitation doctors about Rilynn's admittance to their inpatient rehab program. The information we had been given in Colorado Springs about her needing to be able to withstand three one hour long sessions per day was not correct and the rehab doctors were ready for her to begin the program. We were ecstatic as we met the PT and OT personnel, especially when we learned that they had worked with TM patients before. During Rilynn's treatment she was beginning to show great signs of improvement. Her right arm needed an IV, therefore, it was bandaged and pretty heavy, but her left was free and she would swing it around all the time. I also have footage of her giving me knuckles when she finally opened her hand for the first time and moved her fingers. After those seven days, all of the IV's and monitoring cords were finally removed from Rilynn and we were transferred over to the rehab side of the hospital. This in itself was very liberating as we could finally get her out of the room. We had therapy sessions three times per day, at roughly



an hour a session. Rilynn was very motivated, and worked very hard. The PT's and OT's were amazing. They taught us how to work with her, and the days were very busy between naps, eating, therapy, and play sessions. During this time she continued to improve, from arm and hand movements, to attempting to roll, to rolling from her belly to her back. We have plenty of pictures and video of this progression. I could literally write ten more pages on her recovery process.

We were released to go home on May 17th, 2013 with a specific plan for PT and OT for the unforeseeable future. We feel incredibly lucky at how well our insurance company has worked with us. They have deferred to the doctor's orders when it comes to therapy sessions and she has not been limited to a certain number of sessions per year. We have been extremely lucky that Rilynn has shown no bowel or urinary tract issues, though being an infant at the time she had no control over movements anyway. She has never had a urinary tract infection, or any bowel issues. Just last week, at less than two years old, she sat on the potty and went! And she has done it consistently, telling us when

she has to go. We are very hopeful that this may not be an issue going forward.

She has slowly regained what seems to be 100% of her hands, arms, shoulders, neck, and core muscles, though the core certainly needs to get stronger. During our stay in rehab, her legs began to have movements, though spastic at first. She would react to cold water when in a hot tub. She began to "army" crawl about a month after our release from the hospital and it took several months for her to be able to get onto all fours. One day in the tub, she finally began to crawl. It was labored at first, but today she crawls all over the place and is happy. She can feel, what it seems, 100% of her body by touch. She has no permanent paralysis, and she is starting to walk with help! Her little legs sometimes cross when she does, but more often than not she gets it right. She is beginning to cruise at home, using the furniture for assistance. We are currently working on her transitions from sit to stand to cruise to walk. We will walk out of the playroom and come back to see her standing. Though she is slow and fatigues pretty quickly, we, along with her doctors and therapists, are very optimistic that Rilynn will walk one day.

There is so much more we could write about Rilynn's story but to write it all would turn this into a novel, not an article. We are constantly reminded that the rehabilitation process after TM is a marathon not a sprint. We try to be careful not to let our highs get too high or our lows get too low, which is definitely a lot easier said than done. We were very blessed during our time in the hospital as both Niki and I are employed by incredible organizations and people. They understood our situation and said just be there for our daughter. We spent 41 nights in the hospital without worrying about our jobs or being paid, allowing us to focus on Rilynn's recovery. Children's Hospital in Denver encouraged family to stay with the patient as it helps so much with the recovery process. I'd sleep on the floor and finally got smart enough to bring up a cot, and Niki would take the couch. Nola made the three hour trip between Salida and Denver every weekend and was able to stay in the room with us during her visits. Those were the best days – both girls together again brought so much love to our world. Niki and I worked as a team helping Rilynn and taking breaks when we needed them. It's interesting to look back on and reflect on that time now. Niki and I both had our bad days, but thankfully, never at the same time. We were each other's strongest support team. It was awful, painful, inspirational, and amazing every day. Rilynn was so positive and worked so hard. Her motivation is the reason we are where we are today.

I remember reading a story and it started that their child has now had TM longer than she didn't have it. Rilynn is now the same, turning two years old on June 13, 2014. Just last week, while taking a bath with her sissy, she began to kick her legs. She now kicks them every time we ask her

to. She is asking to walk more and more, and has received some specialized ankle orthotics that fit on her feet to help strengthen her stance, allowing her core to strengthen. We are down from four to three therapy sessions a week. We've coordinated all of her sessions over our lunch hours. I pick Rilynn up and take her to her session. Niki meets me at therapy and takes Rilynn home, which allows us both to be at every therapy session without missing any extra work. We have been fortunate to meet the most amazing people through this experience. We have been fortunate enough to have the ability to hire in-home care providers for Rilynn and they have grown to love our daughter as much as we do. We have so many people rooting for Rilynn's success. We cannot thank them enough as their support has helped so much in Rilynn's progress. We worry that Rilynn may have another attack and that worry is always in the back of our minds. But that worry and this diagnosis have also taught us the importance of living in the moment and being grateful for every day. Some days, her progress seems to slow down and we start to panic. But those slow-downs are always followed by some break-through in her progress. The more cognitive she becomes, the more she is finding out how much she can do. We are very optimistic for the future and will not allow this disease to defeat our family. When we look at life, we feel incredibly happy and incredibly lucky.

If your child is diagnosed with TM, here are a couple points and why the TMA is SO important:

- Early diagnosis is incredibly important, therefore the more awareness of TM the better.
- FIGHT for your child. Don't allow doctors to dictate everything. You know your kids better than anyone else, therefore don't allow a doctor to think for you. If something doesn't seem right, express that. Fight for answers.
- Love, persistence, and harmony go a very long way. We did our best to never react negatively around Rilynn. If you need some time, excuse yourself, break down, recompose and come back.
- You are in for the long haul, so take it day by day. Remember that this is a marathon, not a sprint.

You are stronger than you give yourself credit for. It may feel like your world is crashing down but you can handle this. You have an amazing child who is about to show you how strong they are. They got that strength from you. Parents that have children with TM, please feel free to contact us through the TMA, as we would like to help in any way we can. We owe a lot of our daughter's progress to Sandy and this great organization.

With warm hearts and lots of Love,

~ Danny J. Stotler











# ANNOUNCING THE TMA'S **20 for 20** ANNIVERSARY CAMPAIGN

The goal of the 20 for 20 Anniversary Campaign is to recognize 20 years of service to the community and raise funds that will enable us to achieve our mission through the:

-  Creation of new medical centers of excellence that will provide experienced medical professionals to help you manage your disease and symptoms
-  Funding of education and research tailored to your needs and priorities
-  Launch of new community support programs that provide you forums for communication between yourself and other patients and their families that are experiencing many of the same issues as you
-  Advocating for you and your family and provide tools that enable you to do the same

PLEASE JOIN US AND THE TMA BOARD OF DIRECTORS WHO HAVE COMMITTED OVER \$42,000 TO LAUNCH THIS CAMPAIGN IN SUPPORT OF OUR PHASE I GOAL OF \$420,000!

[HTTPS://MYELITIS.ORG/DONATE/20-FOR-20-ANNIVERSARY-CAMPAIGN](https://myelitis.org/donate/20-for-20-anniversary-campaign)

## HERE IS HOW YOU CAN HELP MEET OUR GOAL

CREATE A TEAM AND DONATE ONLINE IN 5 EASY STEPS!

1. Go to our Campaign Page on Crowdrise - <https://www.crowdrise.com/The-TMA-20-for-20-Campaign>
2. Click on "FUNDRAISE FOR THIS CAMPAIGN" on the lower right corner and create your own fundraising page
3. Donate your first 20 dollars
4. Copy the link of your fundraising page and send it out to 20 friends & family members
5. Let the fun begin and watch your donation grow!

OR DONATE OFFLINE

Download our Donation Cards to give to 20 people (<http://bit.do/donation-cards>) and download the 20-Year Power of Giving campaign Flyer (<http://bit.do/campaign-flyer>) to give out to your friends and family!

IF EACH OF US  
**GIVES \$20**

*Then...*

**1 MEMBER CAN  
RAISE \$420**

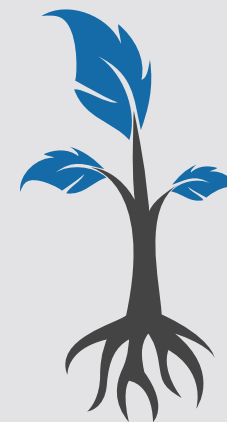
& ...

100  
MEMBERS



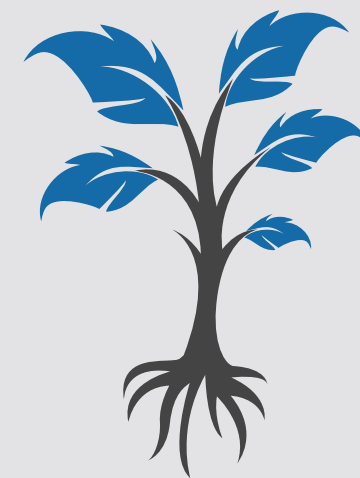
\$42,000

1,000  
MEMBERS



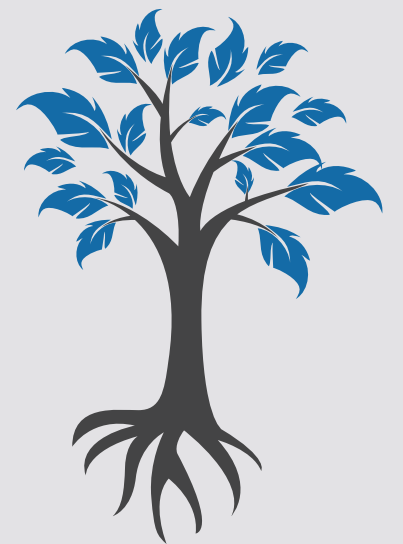
\$420,000

5,000  
MEMBERS



\$2,100,000

10,700  
MEMBERS



\$4,494,000

AND ASKS

**20 FRIENDS  
& FAMILY TO  
GIVE \$20**

## PAY IT FORWARD! HELP US HELP YOU!

*Help us help a family, child or individual diagnosed with Transverse Myelitis, Neuromyelitis Optica, Acute Disseminated Encephalomyelitis!*

ALL IT TAKES TO GET STARTED IS \$20.

*Please join us!*



# Johns Hopkins NMO Patient Day

## Save the Date

October 5th, 2014, Johns Hopkins Hospital,  
1800 Orleans Street, Zayed 2119;  
NMO patients and caregivers will have the  
opportunity to meet with practitioners and other  
patients in an effort to learn more about their  
disease, symptom management, patient advocacy,  
and standard-of-care & ongoing investigation into  
new treatments. Research opportunities will be  
available to those interested!

[www.nmoresearch.org](http://www.nmoresearch.org)

Sponsored by: Guthy Jackson Charitable Foundation



*Agnes Killough*

*1939 - 2014*



Agnes Killough was a very special friend. We met while I was the Virginia Support Group leader and she contacted me. We spent a great deal of time on the phone and the internet. She started the Eastern Shore, VA group and we began meeting regularly with this small but growing group. Agnes also received referrals from a PCP, Dr. Paschall, so that we could contact those newly diagnosed who may need our fellowship and support. Agnes and her husband of 41 years, Joe were very active in our VA group. She helped to arrange meetings, lunches and a phone tree for member support!

Agnes actually spoke regularly with my mom about recipes and favorite foods, hers and mine. Agnes went home to our Lord on June 5, this year following an illness not related to TM. She was 75 years old and proud! Agnes was such a dear, and will always be a special person in my heart. I wish there had been more time for me to become a better friend for her. She did have the "last laugh" as the electricity went off during her memorial service! I miss my friend and I am sad because everyone with TM should have an Agnes in their lives.

Below is a copy of her obituary:

*Agnes Doughty Killough, 75, wife of Joe G. Killough and a resident of Pungoteague, VA, passed away Thursday, June 5, 2014 at her residence. A native of Pungoteague, she was the daughter of the late E. Upshur Doughty and the late Lillie Ralph Doughty and the granddaughter of the late Thomas E. Ralph and the late Bessie Fentress Ralph and the late Major R. Doughty and the late Mamie Mapp Doughty. She was a graduate of Central High School class of 1956, graduate of Kee Business College, 15 year member of the Navy Wives Club of America, life member of the VFW Auxiliary, 50 year member of the Ladies Auxiliary of Fleet Reserve Branch 60 and attended Colonial Baptist Church.*

*~ Pamela New*





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

**Non-Profit Org**  
US Postage  
**PAID**  
Columbus, OH  
Permit No 2609

CHANGE SERVICE REQUESTED

## CONTACT US

Sandy Siegel | President | [ssiegel@myelitis.org](mailto:ssiegel@myelitis.org) | 855-380-3330 - extension 1

Chitra Krishnan | Executive Director | [ckrishnan@myelitis.org](mailto:ckrishnan@myelitis.org) | 855-380-3330 - extension 2

Roberta Pesce | Executive Editor (Consultant) | [rpesce@myelitis.org](mailto:rpesce@myelitis.org)

## ANNOUNCEMENTS

**2014 First Annual TMA Golf Outing:** September 29, 2014. Details inside.

## DONATE

The Transverse Myelitis Association  
Sanford Siegel, President  
1787 Sutter Parkway  
Powell OH 43065-8806  
<http://www.myelitis.org/donate>