THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

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

Winter 2014

20 YEARS MAKING A DIFFERENCE

THE TRANSVERSE MYELITIS
ASSOCIATION

INDEX

THE EDITOR'S
COLUMN

Sandy Siegel, PhD

The birthdays and anniversaries that end in zeroes and fives are generally given more significance in our culture and many cultures because they are landmarks and evoke more self-reflection. The year 2014 is certainly that for Pauline and me and it is so for The Transverse Myelitis Association. In July of this year, Pauline and I will be doing some serious ruminating about this being 20 years since she had the inflammatory attack in her spinal cord, and just how much that event has changed our lives. We will also be reflecting on the existence of The Transverse Myelitis Association for the past 20 years, the service this organization has provided to our members for the past two decades, and also about how the TMA has changed our lives. For Pauline and for me, the story of Pauline's getting TM and the spinal cord damage she experienced is the same story as the history and development of the TMA. Both are incredibly personal stories. Both of these monumental events will be recognized and they will both evoke intense reflection. There won't be any celebrations.

That Pauline got TM and that she suffered permanent damage to her spinal cord impacts everything about our lives, large and small. How we think about our financial resources and insurance, how we think about and plan for health care, how we make decisions about the vehicles we're going to purchase, what we do for entertainment and vacations. The large things can be very large and very expensive. Pauline and I put a lot of time and effort into deciding how we were going to create a living space for us that was totally accessible for Pauline. After weighing all of the options, we landed on remodeling our current home. We moved all of our living space to the first floor of a two-story house. I can summarize the extent of this endeavor by telling you that we transformed our existing kitchen into a master bedroom, our living room into a study and walk/roll in closet, and a family room into a laundry room and pantry. There isn't a single step or stairway in Pauline's home, the entrances to our home are ramped, and Pauline has a totally accessible kitchen and bathroom… CHA CHING!

And there are a gazillion small things. These small things have become a part of our everyday lives, and more often than not, Pauline and I don't ruminate about them aloud. Sometimes they are difficult enough to just think about. Pre 1994, one of Pauline's and my favorite activities was taking walks; we did a lot of hiking. And more often than not, we would hold hands. Today, Pauline walks very short distances using two canes or a walker with wheels (Pauline calls this device her wheelie walker) and anything longer than that, she is in her wheelchair or scooter. None of those modes of locomotion facilitate any kind of handholding. I think about this loss all the time, because it reflects a greater loss of intimacy that we have experienced over the years, and there are just so many different factors that contribute to this problem, from nerve pain to fatigue. It is difficult and the complexity of these issues boggles the mind.

Another example of one of the small things. Pauline and I have been blessed with three beautiful and brilliant grandsons. And we have a granddaughter on the way in May. Pauline and I just love being grandparents and we love the time we get to spend with Maceo, Leo and Van. If Pauline hadn't experienced TM, she would have spent the past two years carrying those beautiful babies all over the place and she would have been dancing with them. None of those activities were possible. Pauline can barely stand let alone try to hold the babies and try to walk with them. You can see the sadness on her face when she is with the kids … I know what she's thinking about. We get to see Leo a lot as they live very close to us. When we have the opportunity to care for Leo and it is bedtime, I make sure that Pauline is the one holding Leo on her lap and reading to him before bedtime. I get my share of holding Leo. This is prime cuddling time for Leo and I want Pauline to have every opportunity to be with him in this way. Not being able to care for the babies alone has been a horrible loss for Pauline.

Thus, one might conclude that there are no small things. The losses from TM are all significant and they just totally suck. The 20 years with TM will not be a cause for celebration of any kind by Pauline and myself.

The Transverse Myelitis Association has also been a very personal experience for Pauline and me. Between 1994, when we started working on the Association with the Gilmurs, until January 1997, the TMA grew to a whopping 187 members. We had spoken to many of these people and we were getting to know some of them fairly well. We gathered in Columbus in 1997 for a meeting with the National Organization of Rare Disorders and the rare disease organization, the International Fibrodysplasia Ossificans Progressiva Association. We also had the opportunity to spend time with Dr. Chuck Levy who sponsored the meeting, and with Dr. Joanne Lynn. Both physicians became the first two doctors on our medical advisory board. The people from the TMA who attended that meeting were Deanne, Debbie, Paula, Drema, Heather, Maureen, Gunny, Phil, Pauline and myself. I don't have to check notes to remember who we spent time with that weekend … it was like being with family. Sadly, Phil passed away last year. His memory should be a blessing. We gathered for our first exclusive meeting of the TMA in 1999. There were about 100 people who attended that meeting. I remember almost all of them, and we have stayed in touch with most of them. Many of these people have become our closest friends.

Running the TMA is and has always been a very personal experience for me. Our home telephone has been ringing for almost 20 years, and the people who are calling are all seeking help and guidance. I listen to the most horrible, troubling, confused, anxious and challenging stories almost every day of the week. And now that we have this email thing, we get similar stories via email. And Facebook and other social media only intensify and magnify the conversations. For almost everyone, getting TM or ADEM or NMO is the worst thing that has happened to them in their lives. And if I'm talking to a parent of an infant or a young child, we're talking about the worst thing that is going to happen to an entire family. For years, I would cry after hanging up the telephone. With some of these parents, I've started to cry before I hang up the phone. I've met people over the years who have gone through the most horrendous experiences. Often times, I'll look at them, hold them, and cry uncontrollably. And then I apologize for falling apart at the seams and freaking the crap out of them. It is personal. It is the only way I know how to deal with all of this. It is sad and it is incredibly painful. Thinking about a 6 month old who has become quadriplegic and ventilator dependent … and is still in this same situation 9 years down the line is just a challenge to think about. Thinking about Jim being quadriplegic and ventilator dependent for more than 20 some years is difficult for me to wrap my head around. It makes me so very sad to think about all of what people have lost because of transverse myelitis... and ADEM and NMO.

And the losses include having some very close friends pass away. Some of the secondary complications from these disorders can be very serious. We've lost too many friends. And we've lost some really young children, including infants. The sadness from this work is inescapable. And I don't know how to offer help and not get involved in some way emotionally. It has most definitely taken a toll on me.

I have been surrounded by this mayhem every day of my life for going on 20 years. The desperation, the frustration, the bitterness and anger, the resignation – there are people who do choose to give up – and I'm not confused as to why. There are people outside of the US who don't have access to any medical care. There are people in the US who do not have access to any medical care. Can you imagine being paralyzed, in extreme pain, no bowel and bladder function, horrible spasticity and not having access to decent, or even ANY medical care? I have to think about it every day because that terrible reality shows up in my inbox and voice mail regularly.

In my next life, I'm going to volunteer to read novels while lying in a hammock under a tree near a beach while eating a chopped liver with egg sandwich on rye mit seeds (because in my next life, I won't have to be concerned about my cholesterol).

I likely understand as well as anyone just how much work we have in front of us. In the way of research, we have so much that needs to be done to develop even the most basic understanding of TM and ADEM. NMO is better understood, but there remains much to be learned about NMO as well. From acute therapies to better symptom treatment to more effective rehabilitation programs to restorative therapies, there is a ton of work that needs to be done. I speak to people every day who don't understand nearly enough about what happened to them or about what medicine can do for them. We have so much to do to better educate our community and to also better educate physicians. I speak to people every day who are not getting good medical care – at every stage, from the acute attack through long term symptom management to disease management for people who have recurrent variants of these disorders. We have so much work to do to grow the discipline so that people have better access to good clinicians. And these are the issues we work on every day. We know we've made a difference in people's lives. I don't think about these differences every day. Being immersed in the sadness machine doesn't foster lots of opportunities for patting oneself on the back. But as we move into two decades of this work, I am in a pretty good position to evaluate our progress, and my measure is as personal as the reasons I remain involved in this work for almost 20 years. I know what this experience was like for me and Pauline when she got TM almost 20 years ago. And I know what that experience is going to be like for the person who has this attack in their spinal cord this afternoon. The odds are better for them that they're going to get diagnosed more quickly and that they are going to receive aggressive acute therapy. The odds need to be even better than they currently are, but as compared to 20 years ago and before we had TM and NMO Centers, and numerous education programs, and a physician network and research and publications in the medical literature, this person has the opportunity for a better outcome. And they can and likely will eventually find the TMA, join the Association, spend many hours on our web site, connect with people through our support groups and/or social media, and they might give me a call or attend one of our symposia or family camps. Twenty years ago, Pauline just had me, and I didn't have a clue and was totally overwhelmed by ALL of it.

One of the most profound measures of our progress is that Dr. Allen DeSena will become a TM, ADEM and NMO specialist this year and will open a new center in a new city. People who did not have access to a specialist will, literally overnight, have access to the best medical care available for these rare disorders. And not only will all of these people have access to the best medical care, our community of researchers will have a new center for research. As these are such rare disorders, almost every research project we are involved in requires multi centered studies, because no one center attracts enough patients to have good numbers for research. This is the case for almost every type of study. Dr. DeSena will create another important center for our clinical care and research network. So, this is what totally blows my mind. Dr. Kerr trained Dr. Greenberg who trained Dr. DeSena... and so on. There is nothing more important for us to do than grow this network. It will create the greatest impact on the quality of care that is being offered to our members and the amount of research that we can accomplish. My wish would be that we could have more than one doctor receive a James T. Lubin Fellowship every year. And we could do that, if we had the money to fund it.

And it is a fact. The difference between how much research is getting done and the amount of research we need is money. If we had the money, we would be getting more critical research done. If we had the resources, we would fund the training of more doctors to become specialists in ADEM, NMO, ON and TM.

When I first got involved in doing this work, I avoided dealing with the money part of this thing like the plague. The whole asking for money part of this gig just made me feel yucky. If my children were selling something for a fundraiser of some sort, I preferred buying all of what was being sold before I went about asking family, friends and neighbors to get involved. Twenty years of my involvement in this work has totally changed me. I'm evolving at an alarming rate. I know the work that needs to get done, and I also know that none of this work is going to happen unless and until we raise sufficient funds on a regular basis to support the work. I can't provide medical care to anyone, because I'm a cultural anthropologist. I can't perform medical research or train physicians, because I'm retired, I live on a fixed income, and I'm also losing neurons at the same alarming rate that I'm evolving. What I can do is raise money so that the people who are better equipped to do so can get this critically important work done. Thus, for the duration, I am going to be all about the money. Fact is ... we all need to be all about the money. And frankly it is naïve to think otherwise.

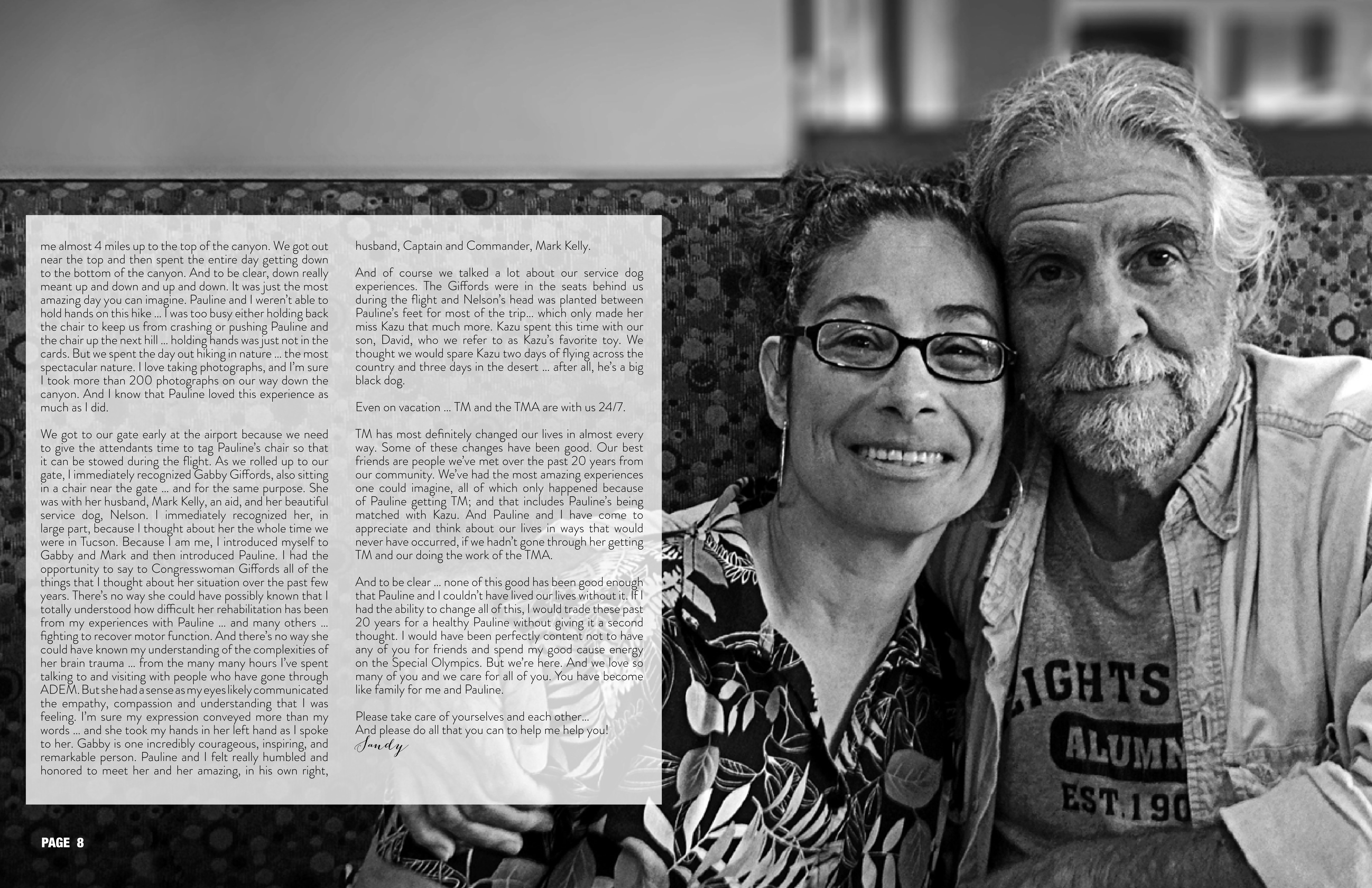
We want to recognize that this 20th year of the TMA is an amazing accomplishment. I think the best way to do this is recognize that what we have done in the past 20 years has created the foundation for us to begin to really make the difference for the wonderful people in our community. I am asking you to help me; I am imploring you to help me raise the money that will accelerate and intensify research on all of these rare disorders and also grow our discipline so that more research is possible and more people have access to good clinical care. I have two ideas to help make this happen while recognizing our 20 years of service.

We are a relatively small group of people who are connected by these rare neuro-immune disorders. Acting alone, it is a challenge to raise the money needed to accomplish all of our goals. I am asking each of you to approach your family, friends, neighbors and co-workers ... these are the people who best understand how having ADEM or NMO or ON or TM has impacted your lives and your family's lives. Find 20 of these people who will make a commitment to making a donation to the TMA and make our organization and YOUR CAUSE a part of their regular generous giving.

I am also asking you to help us recognize this special 20 year anniversary of the TMA by making a commitment to make a monthly donation of $20 each month during the year. If you can afford $200 a month, that would get us even closer to helping us achieve our/your important goals.

I've been doing this work long enough to realize that the only way we could possibly ensure the long term viability and success of our organization was to professionalize our staff. This is something that Jim, Debbie and I discussed many times through the years, and while we knew this was an important goal, we really didn't know how we were going to get there. Well, we're there. If you read my editor's columns and articles about Johns Hopkins or you visited the TM Center while Dr. Kerr was practicing, or you read the medical literature about TM, then you know all about Chitra Krishnan. That we have Chitra for our executive director might be my most dramatic and meaningful accomplishment over the past 20 years. Why ... because Chitra guarantees that the TMA will have a bright future... which means that there should be great hope in our community; and Chitra guarantees that the TMA will have a future. She has developed our relationship with Roberta who does incredible work for the TMA and she is also growing the Association. Our Board of Directors has become more dynamic, more engaged and more dedicated to helping the TMA move forward to make a meaningful difference in our community. When I think about how we got from there to here, it really does sort of boggle my mind. What a journey.

Twenty years is a long time. Transverse myelitis and now also ADEM, NMO and ON, have become a part of Pauline's and my life in almost every conceivable way. Our recent vacation to Tucson encapsulates just how this has become the case. We had never been to Arizona and we thought that a vacation to the desert would be a great way to spend the days between Christmas and New Year's. We spent our first day in Tucson with our dear friends, Barbara and Kenney. We went to the desert museum, had a lovely lunch at the museum and walked around in the desert as much as we could. The Sonora Desert just isn't all that accessible (what's with that?), and especially with the small casters on Pauline's chair. Barbara got TM in 2001, she's our support group leader in Tucson and she serves on the TMA Board of Directors. We spent the next day with the Ziemba family. We visited the Saguaro National Park and then had lunch at an awesome Mexican restaurant. I met Lauri about ten years ago when a loved one got a TM diagnosis. We had stayed in touch with each other over the years and became good friends. We met Lauri for the first time on this vacation ... after writing each other and speaking to each other on the phone for the past decade. Later that day, per Curtis' great instructions, Pauline and I drove up through the Santa Catalina Mountains. What a spectacular ride. We stopped toward the bottom of the mountains to enjoy the sunset over the desert below us.
For our last day in Tucson, we went to Sabino Canyon. The park has a wheelchair accessible tram that took Pauline and



me almost 4 miles up to the top of the canyon. We got out near the top and then spent the entire day getting down to the bottom of the canyon. And to be clear, down really meant up and down and up and down. It was just the most amazing day you can imagine. Pauline and I weren't able to hold hands on this hike ... I was too busy either holding back the chair to keep us from crashing or pushing Pauline and the chair up the next hill ... holding hands was just not in the cards. But we spent the day out hiking in nature ... the most spectacular nature. I love taking photographs, and I'm sure I took more than 200 photographs on our way down the canyon. And I know that Pauline loved this experience as much as I did.

We got to our gate early at the airport because we need to give the attendants time to tag Pauline's chair so that it can be stowed during the flight. As we rolled up to our gate, I immediately recognized Gabby Giffords, also sitting in a chair near the gate ... and for the same purpose. She was with her husband, Mark Kelly, an aid, and her beautiful service dog, Nelson. I immediately recognized her, in large part, because I thought about her the whole time we were in Tucson. Because I am me, I introduced myself to Gabby and Mark and then introduced Pauline. I had the opportunity to say to Congresswoman Giffords all of the things that I thought about her situation over the past few years. There's no way she could have possibly known that I totally understood how difficult her rehabilitation has been from my experiences with Pauline ... and many others ... fighting to recover motor function. And there's no way she could have known my understanding of the complexities of her brain trauma ... from the many many hours I've spent talking to and visiting with people who have gone through ADEM. But she had a sense as my eyes likely communicated the empathy, compassion and understanding that I was feeling. I'm sure my expression conveyed more than my words ... and she took my hands in her left hand as I spoke to her. Gabby is one incredibly courageous, inspiring, and remarkable person. Pauline and I felt really humbled and honored to meet her and her amazing, in his own right, husband, Captain and Commander, Mark Kelly.

And of course we talked a lot about our service dog experiences. The Giffords were in the seats behind us during the flight and Nelson's head was planted between Pauline's feet for most of the trip... which only made her miss Kazu that much more. Kazu spent this time with our son, David, who we refer to as Kazu's favorite toy. We thought we would spare Kazu two days of flying across the country and three days in the desert ... after all, he's a big black dog.

Even on vacation ... TM and the TMA are with us 24/7.

TM has most definitely changed our lives in almost every way. Some of these changes have been good. Our best friends are people we've met over the past 20 years from our community. We've had the most amazing experiences one could imagine, all of which only happened because of Pauline getting TM; and that includes Pauline's being matched with Kazu. And Pauline and I have come to appreciate and think about our lives in ways that would never have occurred, if we hadn't gone through her getting TM and our doing the work of the TMA.

And to be clear ... none of this good has been good enough that Pauline and I couldn't have lived our lives without it. If I had the ability to change all of this, I would trade these past 20 years for a healthy Pauline without giving it a second thought. I would have been perfectly content not to have any of you for friends and spend my good cause energy on the Special Olympics. But we're here. And we love so many of you and we care for all of you. You have become like family for me and Pauline.

Please take care of yourselves and each other...
And please do all that you can to help me help you!
Sandy

HIGHLIGHTS FROM THE 2013 ANNUAL REPORT OF JOHNS HOPKINS TRANSVERSE MYELITIS CENTER

The JHTMC was established in 1999 as the first clinical center in the world to facilitate the diagnosis and treatment of patients with transverse myelitis (TM). The JHTMC is part of the Division of Neuroimmunology and Neuroinfectious Disorders, Department of Neurology at Johns Hopkins Hospital, and is supported in part by **Johns Hopkins Project RESTORE**. Four years ago, under the leadership of Dr. Carlos Pardo, the JHTMC was revamped with the support of an outstanding team of neurologists and consulting physicians with expertise in neuropsychiatry, neuro-rehabilitation, neuroradiology, urology, neuro-opthalmology as well as physical therapists and occupational therapists. The Center works with **Kennedy Krieger Institute (KKI) International Center for Spinal Cord Injury** and the **International Neurorehabilitation Institute (INI)** who have a focused interest in TM.

2013 ACCOMPLISHMENTS OF THE CENTER ARE HIGHLIGHTED BELOW!

- The first-ever **JHTMC Regional Transverse Myelitis Clinical Care Symposium** was held on June 15th, 2013 at the Johns Hopkins Hospital with overwhelming success! Thanks to the support of the **Bart McLean Fund for Neuroimmunology Research** and in collaboration with **Project RESTORE** and **The Transverse Myelitis Association (TMA)**, over 90 participants, patients with TM, myelopathies, or NMO and their family members, all of whom are impacted by these disorders on a day-to-day basis were in attendance for this one-day symposium. The event was such a success that it was decided that a second symposium will be held in June 2014. All of the talks can be viewed at http://myelitis.org/portfolio-view/2013-regionaltm-clinical-care-symposium.

- As part of the Center's educational efforts to train physicians on issues related to rare neuro-immunologic disorders including transverse myelitis, the Center facilitated the training of Dr. Jorge Jimenez Arango, a neurologist from Colombia (South America) who completed a one-year fellowship at the Division of Neuroimmunology at Johns Hopkins. Dr. Jimenez Arango will establish a clinic that will focus on transverse myelitis and other neuro-immunologic disorders at the University of Antioquia Hospital, the first of its kind in that region of South America.

- A close collaboration with colleagues at **Johns Hopkins Interventional Neuroradiology** led by Dr. Philippe Gailloud has allowed a refinement in the diagnosis and treatment of patients with vascular myelopathies that are often misdiagnosed as "transverse myelitis". Many patients who failed previous anti-inflammatory treatments have been able to recover and return to their normal activities of life.

- In 2013, the Center received over 250 referrals from which 208 patients were seen in the outpatient clinic. These new patients came from 44 different states across the country, as well as Washington DC and Puerto Rico (see Figure 1), and internationally from such countries including Bermuda, British Virgin Islands, Canada, China, Colombia, France, Greece, Ireland, Italy, Jordan, Kuwait, Mexico, Peru, Saudi Arabia, Spain, South Africa, United Arab Emirates, and United Kingdom.

- The JHTMC consultation service, which is provided at no cost, continues to be available for those patients unable to get to the TM Center or travel to Baltimore. To date, approximately 350 such consultations have been offered, either via telephone or by e-mail. These patients and practitioners contacted the JHTMC from 38 different states around the country (see Figure 2) and from 25 countries in the world.

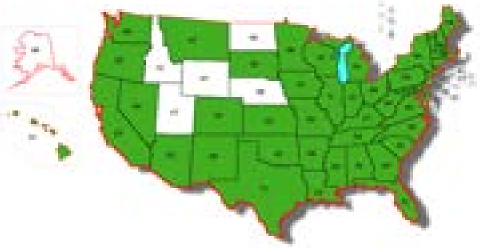


FIGURE 1. Origins of Patient Referral by State (2010-2013)

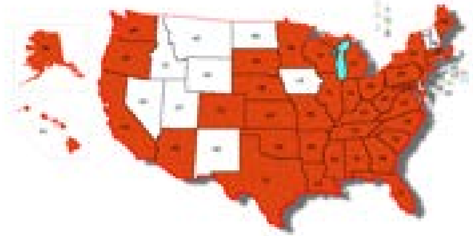


FIGURE 2. Origins of Urgent Remote Consultations (2010-2013)

- The Neuromyelitis Optica Clinic under the leadership of Dr. Michael Levy and Maureen Mealy currently manages nearly 200 patients, many of whom are actively involved in research endeavors to provide a better understanding of the disease, from participating in pain and biomarker studies to receiving novel medications for treatment of the disease.

- Research continues to be a major focus at the JHTMC. Members of the JHTMC team presented several posters at the annual **American Academy of Neurology (AAN)** meeting on subjects related to TM, including (1) an investigation of how to better differentiate vascular myelopathies from TM and (2) a look at TM in neurosarcoidosis. A recent study of biomarkers for chronic myelopathy in neurosarcodiosis was presented at the **American Neurological Association** conference in New Orleans this past October, which demonstrated a candidate protein, soluble amyloid A, to be a potential cerebrospinal fluid marker for this disorder.

- Recruitment continues for several clinical trials which can be found on the TMA website - https://myelitis.org/research/clinical-studies-trials.

- The JHTMC and its dedicated NMO Clinic has established national epidemiologic data, as well as a look at the efficacy of treatments commonly used in the disease, in collaboration with the **Guthy Jackson Charitable Foundation (GJCF)**, the University of Texas Southwestern Medical Center and **Mayo Clinic**. They have also been involved in research investigating brainstem involvement in NMO. These efforts have yielded recent publications, as listed: http://archneur.jamanetwork.com/article.aspx?articleid=1190816 and http://msj.sagepub.com/content/early/2013/10/05/1352458513507822.full.

- Studies of retinal and macular pathology have been performed in patients with TM, NMO, and MS, and. Dr. Peter Calabresi and other members of the JHTMC have been using techniques such as Optical Coherence Tomography (OCT) testing on patients with neuromyelitis optica in an effort to better understand visual disability by measuring the nerve fiber thickness in the eye. The study compares the retina and optic nerve pathology in NMO, TM with other neuroimmunological disorders such as multiple sclerosis. Findings of these investigations can be found http://www.neurology.org/content/80/15/1406.

- Studies of cerebrospinal fluid and blood biomarkers are underway in the Neuroimmunopathology Laboratory. With the support of the Bart McLean Fund for Neuroimmunology Research, Dr. Pardo's lab is actively investigating the use of cytokine and chemokine profiling, as well as the identification of micro RNAs in these biofluids for the exploration of potential biomarkers of pathogenesis and outcome. Banking of biological fluids obtained from patients with TM and other neuroimmunological disorders is actively pursued at the TM and MS Centers and serves the purpose of biomarker identification.

- Neuropathological studies are currently carried out for the characterization of the molecular and cellular neuroanatomy and neuropathology of the normal and inflammed human spinal cord. These studies will help to understand the pathophysiology of TM and other neuroinflammaptory disorders such as MS and NMO.

WHAT'S COMING IN 2014

- The JHTMC is planning an initiative to better educate practitioners on early diagnosis and continued care in TM in the future by actively participating in national and international conferences, as well as by continuing our investigator-initiated investigations.
- The NMO Clinic has begun investigating neuroimaging in patients with NMO, in an effort to better differentiate features of this disease from other neuroinflammatory diseases; finding new biomarkers may contribute to the diagnostic work-up. Also, they are working on researching what factors may influence adequate versus ineffective response to plasma exchange at the time of acute inflammatory attacks.
- New medication studies for the treatment of NMO and/or with TM associated with longitudinally extensive lesions will be launching in the coming year. Among them will be the use of Bevacizumab in acute NMO and TM with LETM and Eculizumab as a use for chronic immunosuppression in NMO.
- Funded by the **Guthy Jackson Charitable Foundation**, there is a new collaborative longitudinal biorepository launching called **CIRCLES (Collaborative International Research in Clinical and Longitudinal Experience for NMO Studies)**. Its goals are to facilitate prospective longitudinal observational studies that will improve understanding of the etiology, pathogenesis & biomarkers of NMO, and support industry efforts to develop improved therapeutic agents and strategies that benefit patients with NMO.

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The TMA provided Clinical Support Funding for Clinical Program Manager, Maureen Mealy, RN, BSN, MSCN, at The Johns Hopkins Transverse Myelitis Center under the mentorship of Dr. Carlos Pardo through a one-year grant in 2012-2013.

TMA ASK THE EXPERT PODCAST SERIES

Thank you to those who joined the podcast on "Children with rare neuro-immune disorders: understanding medical, educational and social considerations" as part of TMA's Ask the Expert podcast series on December 16, 2013. The physician-experts on the panel were Drs. Benjamin Greenberg and Lana Harder from University of Texas Southwestern in Dallas.

The podcast recording has been made available on our website https://myelitis.org/education/podcasts.
A transcript of the session will follow soon.

Stay tuned for more details on upcoming podcasts on our website!

AQUAPORIN 4 IGG SEROSTATUS & Outcome IN RECURRENT LONGITUDINALLY EXTENSIVE TRANSVERSE MYELITIS

Neuromyelitis Optica is an autoimmune disorder that affects both adults and children commonly causing severe recurrent bouts of optic neuritis and transverse myelitis. Patients often present with either optic neuritis or transverse myelitis only to have future relapses confirming the diagnosis of NMO. In 2004 an antibody was identified in a large number of NMO patients. This antibody recognized the AQP4 protein in astrocytes (a specialized cell in the central nervous system). Patients with this anti-AQP4 antibody have been shown to develop NMO when followed over time, but initially many patients tested negative for this antibody. In this scenario, scientists often question, do patients who test negative lack the antibody or is the test not sensitive enough to identify them?

Dr. Pittock's group from Mayo Clinic recently published their original work focused on recurrent longitudinally extensive transverse myelitis (rLETM). The goal of the study was to study AQP4-IgG, a known clinical biomarker of NMO spectrum disorders, from patients with rLETM using a recombinant human AQP4 based assay who were initially classified as negative for this antibody based on an assay known as IIF. The authors did a search of the Mayo Clinic database based on diagnosis from Oct 2005 to Nov 2011 and identified 48 patients with rLETM, 75% of whom were positive for the NMO signature of AQP4 IgG using the IIF method with serial serum specimens. On retesting those that were negative using the recombinant human AQP4-based assays, the overall AQP4-IgG seropositivity increased from 75% to 89%.

The authors also set out to define the clinical characteristics and motor disability outcomes in those who were positive for AQP4 IgG. This study showed that 36% of rLETM patients who were seropositive will likely need a cane to walk within 5 years after onset, and the median time from onset to first optic neuritis attack was 54 months in those who went on to be diagnosed as NMO. The median number of acute attacks was 3 in those rLETM patients who were seropositive (ranged from 2-22 attacks). Immunosuppression reduced the relapse rate in both seropositive and seronegative rLETM patients.

The authors concluded that recombinant antigen based assays can better detect AQP4-IgG in rLETM patients and generally adults with rLETM are seropositive, and are likely to go on and be diagnosed as having NMO. For rLETM patients who are at higher risk to convert to NMO, testing for this antibody AQP4 using more sensitive assays is the recommendation of the authors if less sensitive tests show negative results.

This original research was published by Yujuan Jiao, MD; James P. Fryer, MS; Vanda A. Lennon, MD, PhD; Andrew McKeon, MD; Sarah M. Jenkins, MS; Carin Y. Smith, BS; Amy M. L. Quek,MBBS; Brian G. Weinshenker,MD; Dean M. Wingerchuk,MD; Elizabeth A. Shuster, MD; Claudia F. Lucchinetti, MD; Sean J. Pittock, MD in JAMA Neurol. 2014;71(1):48-54. doi:10.1001/jamaneurol.2013.5055

JAMES T. LUBIN FELLOWSHIP UPDATE

Dear Members of The Transverse Myelitis Association,

Happy 2014! This past year was an exciting learning opportunity for me through this fellowship. I consider myself extremely fortunate to have had this opportunity, and I am so grateful to the TMA and the rest of the TMA supporting community. It seems like my fellowship just began, and now it is coming to a conclusion. However, I have garnered so much experience and tools to carry forward into the next phase of my career, and I look forward to helping the TMA in the future in any way that I can.

From a clinical experience, I have continued to see both inpatients and outpatients with TM and related neuro-immune disorders. During the second phase of 2013, we reduced my clinical responsibilities by one day to allow for more time for research endeavors. I know that I have seen more acute TM cases than most neurologists will see in a lifetime, and, this has allowed us to gain a unique perspective about reclassification and how we look at TM in the future. We have also been following individuals diagnosed with NMO, ADEM, and MS in our children's clinic, and I am confident that I can contribute positively both from a clinical and research perspective to our understanding of TM and other neuro-immune disorders. Furthermore, we have also been managing patients with autoimmune encephalitis, and I certainly feel that improving our understanding of all of these disorders will provide potential collateral benefits across the board. I am also planning on visiting Kennedy Krieger Institute in the next few months, and I hope to learn as much as I can about optimal rehabilitation, which is clearly a dire need in the TMA community.

With regards to research endeavors, I have had 3 articles accepted for publication. A paper entitled, 'Light switch' mental status changes and irritable insomnia are two particularly salient features of NMDA (N-methyl D-aspartate) receptor antibody encephalitis" was accepted for publication in Pediatric Neurology. Two papers we have written were accepted for publication in JAMA Neurology. The first is entitled, "Transverse Myelitis Plus Syndrome and Acute Disseminated Encephalomyelitis Plus Syndrome: A case report of 5 children." The second is entitled, "HSV Encephalitis as a Potential Cause of NMDA Receptor Antibody Encephalitis: Report of Two Cases." In addition, I also presented a poster at a national meeting, Child Neurology Society, in Austin, TX entitled, "Three distinct subtypes of non-neoplastic NMDA receptor antibody encephalitis in children: why symptom presentation may have a bearing on prognosis." I am in the process of submitting this work for formal publication.

We have 4 IRB (Institutional Review Board)-approved research projects underway:

1. A retrospective review of idiopathic transverse myelitis and classification according to MRI features. We are hoping this can help us and others better target therapies and interventions based on the type of TM that patients have. We know everyone is different, and we feel strongly that our understanding of this disorder must reflect those differences.
2. Assessment of the prevalence based on location of MRI spinal cord lesions in patients with and without MS and other demyelinating disorders that have mild-moderate vertebral body disk disease compared to those that have no disk disease.
3. A retrospective review of medications used for agitation and immunotherapy interventions in anti-NMDA receptor antibody encephalitis.
4. A prospective study of the Agitated Behavior Scale on first hospitalization for patients with anti-NMDA receptor antibody encephalitis.

We have been making strong efforts to advance our research endeavors alongside patient care. I feel strongly that a complete TM-specialized physician must advance our understanding on both fronts. For clinical care, we are constantly educating other physicians and helping families cope with difficult diagnoses. For research, we are focusing our efforts on new and novel ways to look at TM and related disorders.

Lastly, I am excited to announce that when I depart UT Southwestern, I will be establishing a Neuroimmunology Center at Cincinnati Children's Hospital and Medical Center in Cincinnati, Ohio. My wife and I feel that Cincinnati offers unique opportunities and support to help further build our knowledge and understanding of TM and related disorders. It is with some sadness that I am leaving Dallas, but I am excited to be part of Cincinnati, and the Pediatric Neurology Department at Cincinnati Children's is committed to helping me and others grow this field further.

Without the TMA, I could never have achieved this much. I am so eternally grateful to everyone in the TMA community. This truly has been the opportunity of a lifetime, and I am confident that good things will come in our endeavors as a team in the future. Thank you so very much.

Sincerely,
Allen D. DeSena

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, dinner and silent auction 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

HELP INCREASE OUR PHYSICIAN NETWORK!

One of the most frequent requests we receive at the TMA is a referral to a specialist who understands TM, ADEM, NMO or ON. Finding these specialists is critical and also a challenge. It is a challenge because these disorders are rare and there are few centers and physicians who focus their specializations on these disorders.

Last fall, we launched a web-based resource, the Physician Network, to address this critical need in our community. The network (www.myelitis.org/resources/physician-network) resource allows anyone to browse through a list of experts in the field of rare neuro-immune disorders. You are able to search based on disease expertise (ADEM, NMO, ON, TM) and by specialization (ranging from pediatric care to psychiatry to urology). The physician network is organized geographically so that you are able to search by location, as well.

We need your help to expand and grow our network of physicians. If you would like to share information about your physician or medical professional in your area who has been able to offer you excellent care through your journey with one of these rare neuro-immune disorders, please add them to the network and help us expand it. The link is www.myelitis.org/resources/physician-network. Please don't forget to ask your doctor for his/her permission to be added to network. The TMA will check the accuracy of the information that is provided and will confirm that the physicians and specialists added to the network have an open practice and are seeing new patients. Thus, there will be some time between the submissions from our community and when they are posted on the network.

Please help us by sharing your experience so others might benefit. If you have a physician that you think should be on our network, please add them to the list by going to www.myelitis.org/resources/physician-network. We look forward to hearing from you and are excited about the potential to improve medical care!

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.

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.

A YOUNG GIRL'S DETERMINATION TO HELP CHILDREN ATTEND THE TMA FAMILY CAMP

This is a story of a young girl who was affected by a rare neuro-immune disease called Transverse Myelitis in 2006 when she was 4 years old. Her mother sent us this story with a very generous donation to support our mission.

Abby was looking for a way to raise money for the TMA to help send kids with TM to camp. She constantly makes different items out of duct tape. She came up with the idea of making wallets, coin purses, iPod holders, purses, recorder holders and flower pens and then selling them at the Christmas Store at her elementary school. Students come in and buy gifts for their parents, grandparents, siblings and special people. The PTO sponsors the event. They waived the entry fee for Abby since she was donating all of her proceeds to the TMA.

Abby worked hard in the months prior to the sale to make enough inventory. She also enlisted her brothers, cousins, grandma, uncle and parents to help make all of her items. The day of the sale, her grandma worked her table since Abby had to be in class. Abby and her little brother, Drew, also made Rainbow Loom bracelets to sell. She ended up selling 30 flowered pens, 32 wallets, 24 coin purses, 35 bracelets and 10 pens and made just over $300.

Abby and her family come to camp every year and experience this very special place with other families with children with TM, ADEM and NMO. We are thrilled to make this experience available to families around the world. This opportunity is made possible because of the generous spirit and kindness of people like Abby. If you are looking for a worthy cause, helping to get these kids to camp is a great one. We encourage you to get involved. To learn more about camp, please visit our website http://myelitis.org/education/camp.

AMERICAN PARALYMPIC MEDALIST DR. ANJALI FORBER-PRATT JOINS THE TRANSVERSE MYELITIS ASSOCIATION'S BOARD OF DIRECTORS

The American Paralympic Medalist and Assistant Research Professor at the University of Kansas, Anjali Forber-Pratt, has recently joined The Transverse Myelitis Association's (TMA's) Board of Directors.

The connection between the young athlete and The Transverse Myelitis Association deepened during the TMA Family Camp held last year from July 24 – 28, 2013 at the Center for Courageous Kids in Scottsville, KY. Anjali gave an inspirational presentation about her personal journey and encouraged the TMA community, particularly the children that suffer from rare neuro-immune conditions to reach for their goals.

Anjali recently attended the 2013 Rare Neuro-Immunologic Disorders Symposium in Dallas, TX on October 25-26, where she gave the Keynote Address.

Dr. Forber-Pratt epitomizes courage and persistence and that dreams can come true when you work to make those dreams into a reality. She is a wonderful role-model for all those people affected by a rare neuro-immune condition.

"I have been living with transverse myelitis for 29 years. Part of my own mission in life is to show others what is possible and help them reach their fullest potential. I am honored to join the advocacy and education efforts of the Board of the TMA. To me, there is power in seeing someone like you. This is an incredible opportunity for me to be that person for others and help encourage them to live an active and healthy life despite their challenges."

The TMA is delighted to have Dr. Anjali Forber-Pratt join the TMA's Board of Directors, where she brings her leadership, academic excellence and, above all courage, to this new endeavor. *"We are so proud to have Dr. Forber-Pratt elected to the TMA Board of Directors. Her intellect, determination, and passion will help us achieve the important goals we have to improve the quality of life for people with these rare neuro-immune disorders. Anjali is an inspiration to everyone. We know that she will make an important and very positive difference for our organization and for our community,"* shared Dr. Sandy Siegel, President of The TMA.

OUR COMMUNITY'S FEEDBACK ON CLINICAL TRIALS

Summarized by Samuel Hughes

University of Texas Southwestern Medical Center – Dallas, TX

Last summer, the TMA reached out to the community to learn and gain feedback from patients and caregivers about their interest in clinical trials, specifically the ever-controversial placebo-controlled trials, and there was a great response to the survey. There were 1,231 responders, with 77% being patients and 22% being caregivers. All of the diagnoses for which the TMA advocates for were represented, the majority being TM patients with NMO patients coming in second. Some of the questions asked were about disease history, like: "How many attacks have you had?", "Have you had an attack in the last year?", "Do you take any immune-modulating therapy?", and, "Have you had an attack while on an immune-modulating therapy?" Since many of the respondents were idiopathic TM patients, the majority had had a single attack, but about 28% shared that they had had more than one attack during their disease course. These were predominantly the NMO patients, and we learned a lot from them through this survey. Of the 84 NMO patients who answered these questions, 25% had a single attack, 52% had between two and five attacks, and 23% had five or more attacks. Of these, 33% had had an acute inflammatory attack within the last year.

Some of the very interesting information we learned from this survey was the community's interest in clinical trials, specifically in placebo-controlled drug trials. There's a lot of rumbling within the NMO research world about the need for Food and Drug Administration (FDA) approved therapies for NMO considering its relapsing nature. For that matter, as new drugs are developed, this is relevant for Transverse Myelitis, ADEM and all rare neuro-immune diseases. There are many NMO patients who are currently taking medications to prevent attacks. According to our survey, about 87% of the NMO patients were on a therapy to control their NMO, but of that 87% of NMO patients, 43% also said they had a relapse while on their prescribed therapy. While many NMO patients have found success with the standard treatments, seeing numbers like this can be startling; it's a reminder to us all that these drugs have not been formally tested and approved to treat NMO, rather they are used off-label. When a drug is used "off-label" it means that the FDA has not approved the drug to be used for the purposes for which it has been prescribed. This is a common practice with many types of medications. Physicians will use certain drugs off-label for many reasons, many times based on anecdotal experience or theory as to how certain drugs can work to mitigate different disease processes. This has been the case with NMO and the use of immune-suppressing therapies.

There has been a surge recently in the world of NMO research to create new therapies targeted specifically to this disease process. Pharmaceutical and biotechnology companies are showing a great interest not only in creating therapies based on new basic science research, but also in funding full-scale clinical trials to test these drugs. This is when we come to the discussion of placebo-controlled trials, meaning trials where we test an experimental drug against no drug at all. Many of you are wondering, "But why does it have to be placebo-controlled? Why can't they compare these new drugs to the drugs that the doctors prescribe now?" These are great questions, questions that even the research physicians are asking the FDA. Many drug trials are designed to compare a new drug to an existing drug, but in these trials the existing drug that is used as the comparator is already approved by the FDA to be used for that purpose. With NMO, none of the drugs that are currently used are approved by the FDA to be used in NMO, therefore the FDA would be unable to properly interpret any data that came from a trial that used these existing drugs as comparators. The FDA must be able to see that patients taking a therapy have better outcomes than the natural history of the disease, otherwise there's no way for them to compare one drug against another drug. The need for placebo-controlled trials is purely scientific, but it does inherently raise concerns from many groups of people, including and most especially the patients.

Within the NMO patient group who responded to the survey, 35% said they would participate in a placebo-controlled trial, 15% said they would not, and 49% said that they were not sure. It was very interesting (although not surprising) to see that about half of the NMO patients who took the survey were on the fence about their willingness to participate in this kind of treatment trial. Even more interesting than the numbers were the personal answers that were given when asked what they would need in order to participate in such a trial. Of course many expressed concern about the risk of relapse, and that their participation very much depended on the design of the trial. Others said they would only consider it if their current therapy were not working, or if their treating neurologist approved of the research. All of these are valid concerns, concerns that the TMA is voicing on your behalf.

It is only a matter of time before many of you are approached about a clinical trial testing a new treatment for NMO, a trial that could very well be placebo-controlled. The research physicians, industry sponsors, and patient advocacy groups are assuredly doing everything they can to make these upcoming trials scientifically rigorous while still being safe through designing a clinical trial that has several checks and balances with the patient's safety and health in mind. At the end of the day, it will not be the researchers, or drug companies, or even the FDA that approves a new therapy for NMO, it will be you – the person living with the disease – to decide if the risk is worth the benefit.

IN THEIR OWN WORDS ARTICLES

In each issue of the Journals and 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 and journals 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.

FACEBOOK

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.

HOPE

Allen Rucker

I am not a doctor, but I play one every time I attend a conference of experts focused on the state of transverse myelitis. The most enlightening such conference I've ever experienced happened a few weeks ago in Dallas, Texas. The title is a little scary: the 2013 Rare Neuro-immunologic Disorders Symposium, or RNDS, if you can remember that. Hosted by the TMA, Dr. Benjamin Greenberg of UT Southwestern Medical Center and the Johns Hopkins Transverse Myelitis Center, this was a gathering of some of the best research doctors in the world who specialize in our little group of "orphan" neurological disorders like transverse myelitis, neuromyelitis optica, acute disseminated encephalomyelitis (ADEM), and optic neuritis. The two-day conclave was geared to these disorders but had implications for a much larger group - those with spinal cord injury in general. I have one of those – I'm a T-10/12 para – and the fact that it derived from TM doesn't make the paralysis much different. Different source, same injury. As one of the guest lecturers pointed out, in many cases, "TM = Spinal Cord Injury."

This version of the recurring RNDS was dedicated to an angle of research that is dear to all of us that fit the brackets above: rehabilitation, repair, and recovery. Yes, recovery, the impossible dream, the unreachable star. The goal is restoring nerve function in the spine. And if you listen to this group, we are well on the way to getting there.

Here was the big message everyone in attendance walked away with: neural restoration is possible. This is actually a mantra we all should learn and repeat daily. To quote Dr. Cristina Sadowsky of Johns Hopkins and the Kennedy Krieger Institute, we are capable of "achieving significant, incremental improvement at any time following injury." I repeat: at any time. Whether you were injured yesterday or like me, seventeen years ago, you can improve.

How many of you long ago gave up on the idea your condition would ever change? That's what the doctor no doubt told you soon after your injury. "I'm sorry, son, there is no recovery from this." Before this conference, I believed that almost as a matter of doctrine. This paralysis is it, I figured. It could only get worse, not better. My sole focus, outside of exercise, has been trying to avoid nasty falls, skin breakdown, and infection. Every time I read in the newspaper about a "breakthrough in paralysis" or some such miracle on the horizon, I turn the page. Years away and too late for an old-timer like me, I'd tell myself. I don't tell myself that anymore.

One problem, for instance, I thought was intractable: severe contracture, or shortening of the knee muscles, in both legs. My legs are bent at close to 90 degrees and won't bend back. I have repeatedly been told, "Tough luck, you can't change that." Not so, said Dr. Sadowsky and others. Depending on the nature of the contracture, there are both physical and surgical ways of dealing with it. All of a sudden I can imagine my legs being straight again. To me, that would be a miracle.

Straight legs would allow me to leap into many of the other restorative therapies outlined at the symposium. You can lump many of them under the mantle of Activity- Based Rehabilitation Therapy (ABRT). The simplest such therapy, strongly recommended by every doctor in the room is exercise itself. Mood stabilization, pain, tight joints, overall strength and endurance – all are enhanced or relieved by exercise. This relentless drumbeat – "exercise, exercise, exercise" – drives many people nuts. It's like telling someone overweight to eat less food or an alcoholic to drink less Scotch. But, all whining aside, exercise is critical to your health. It's an obvious truth and something that will only make you better. In some cases, says Dr. Sadowsky, exercise has been known to "promote functional recovery."

This leads to a specific kind of activity-based therapy called gait training. Gait training is rehearsing the act of walking by actively simulating it over and over and over again. This can run the gamut from treadmill training, if you are capable, to the complex mind/motor/computer contraption that is used in locomotor training, a whole other conversation. Gait training stimulates the right nerves and teaches you how to walk again without contact with the brain. It all begins with what Karen McCain of UT Southwestern identified as the Central Pattern Generator (CPG). These are neural networks that can produce patterned outputs, like walking, without the brain being involved. Dr. McCain also explained the idea of "learned non-use." If you don't use your paralyzed muscles, they figure that non-use is their natural state. Is this reversible? Yes.

In addition to reinvigorating the CPG one way or another, there are also gait improvement experiments involving the much-talked-about drug called Ampyra. Ampyra is already in use with MS patients to improve motor skills. For the first time, there are trials in motion that will judge the effect of Ampyra on TM patients. Here's where I got a little lost. I know that this has something to do with inhibiting potassium and rearranging the biochemistry of demyelination, which is probably all I need to know. If the pill works, I'll be down at CVS to pick up my order.

I'm also excited but a little vague about the benefits, some of them mind-boggling, of FES, or Functional Electrical Stimulation. FES, according to Dr. Daniel Becker at Johns Hopkins, can actually stimulate stem cells, which can, in turn, give rise to new neural cells to replace the damaged ones in your spinal cord. Nerve restoration using electrical stimulation? Think about it. Sounds like something out of a Frankenstein movie. Nonetheless, in competent hands, it can produce real change. Even on a physical level, FES combined with exercise can improve muscle strength and flexibility.

ABRT, CPG, FES, plus acronyms that flew right by me, like LINGO – it got a little overwhelming over two days. An English visitor to the conference showed me his ringed notebook, each page stuffed to the edges with single-line scrawling. It was like he was in med school. I'm sure he went home, looked at his frantic notes, and asked himself, "What is this gobblygook?"

I feel remiss in not being able to adequately do justice to half the people on stage and their research and discoveries. It's not out of disinterest, just limited brain capacity. Worth noting is a here-and-now study, led by Dr. Michael Levy, involving the direct surgical transplant of stem cells into a damaged spinal cord. Also, there is an antibody compound called rHIgM22 that might promote remyelination. Plus, there was a lot of enlightened talk about how to deal with fatigue, bladder problems, and cognitive rehabilitation. Got bladder leakage problems? Ask your urologist about Botox. Yes, the same thing that disfigures celebrity faces could help you.

The immediate things I didn't forget involved the least amount of specialized expertise. I now take Vitamin D daily and immediately asked my urologist about Botox (he said I wasn't a candidate). The more involved restorative therapies that seem so promising are not readily accessible, at least to me, and no doubt involve a commitment of time and money that many people can't make. That's often the frustration of a gathering like this. With the help of some very bright and caring people, you can see over the horizon. You just don't know how to get there.

But back to the easily-understood main point: functional improvement is possible. None of these therapies are a magic pill that will get you up and walking tomorrow, but taken as an aggregate, they produce something right now that in and of itself can help you progress: hope. Think of hope as an exercise you must commit to on a daily basis. It may be the beginning of your way back.

2013 RNDS PRESENTATION VIDEOS ARE NOW ONLINE!

The 2013 Rare Neuro-immunologic Disorders Symposium was hosted by The Transverse Myelitis Association, University of Texas at Southwestern, Children's Medical Center and The Johns Hopkins Project RESTORE on Oct 25-26, 2013 at University of Texas Southwestern in Dallas. All presentations are now available to view online! The link to watch them is https://myelitis.org/portfolio-view/2013-rare-neuroimmunologic-disorders-symposium.

This symposium focused on current strategies and research projects addressing opportunities for recovery of function after CNS damage.

IN THE MIDDLE

By Renee Elton

Any case of transverse myelitis results in more questions than doctors or the individuals with the disease can answer. How your family deals with the disease can be even less predictable. I have a wonderfully supportive spouse and two darling daughters. I have an extended Sicilian family and an extended Norwegian family. Each day I travel back to the mother lands, back to languages and customs of enormous wealth and humor.

My father calls every day and asks, "How are your legs?" I contracted transverse myelitis months ago, back in May 2013. He has called every day with the same question. Then he asks what I am cooking. He is cooking the greens and cannellini beans. Maybe tomorrow he will make the escarole and penne. Yesterday, he made the veal meatballs and sauce. We discuss the price of "good" pecorino cheese in Ft. Myers. Next, he tells me about his damned brother who made the wine and stole his recipe. My Uncle Pete is sitting there with him, drinking wine. They begin to swear at each other, and he hangs up. They will go to the track today and lose ten bucks each, then come home for meatballs. How can I explain to him my legs belong to an extraterrestrial addicted to delayed-release capsules that cost as much as space travel? I just tell him what I am cooking. Thanks to the capsules, my diet must include any food that helps exfoliation. My loving spouse asks me every day, did you "EXFOLIATE?" Good thing flax seed is a staple on my home planet, Colacia. Thank goodness, I love all greens and know how to cook them with Uncle Pete's wine. My health insurance company does not allow me to purchase the "good" pecorino, so I use a variety made from corn oil. They assure me the side effects are no worse than with the original formula, and my short-term memory will return at a later date. Where was I...?

My mother-in-law calls less frequently, as she has her church singing group eight times a week, twice on Sunday. They sing after the dessert and before the wine. She does not ask about my legs, not because she does not love and adore me, but because I have no visible, or outward signs of disease. In Norway, this means you are able to withstand the blizzard and bring in the cows. At my age, 53, she was more than able to square dance the night away and travel to China with her husband. She can shoot a rifle. She is 83 now, and clearly remembers calling her horse to the fence in northern Montana, leaping on bareback, and delivering homemade beer to the landless Chippewa Indians sleeping in her father's barn in 1938.

How can I tell her that I face real danger when malfunctioning smoke alarms go off in the house at 1 AM, and I leap out of bed and start to run out the front door? I need a "comfort horse" (not "comfort dog") to land on! How can I explain to her that airline travel is physically comical? I look perfectly able to stand in line for an hour, take off my shoes, and stand on the little feet in the gamma-gamma machine. When I stagger a bit and can't get my shoes off, I see other travelers stare—is this lady tipsy? I never could sing or dance, so at least I have no regrets there. Actually, buzzing feet may improve my dance moves. So I plan on making some homebrew at my local brewery co-op real soon. I can only imagine how it will react with the Cymbaspirovia, so I will avoid signing up for Swing Dance.

Transverse myelitis is like that, a crazy family of stories shifting and morphing over the days, months, and years of the condition. Every year I write a family newsletter at Christmas, and this year was no different. But when I started writing the usual bragging, happy, sad, jumbled missive, I realized I was not able to tell my friends and family what TM has done to me. So instead, I sent a Christmas Buffet Menu, shaped like a pine tree, filled with the Sicilian and Norwegian specialties my girls make each year. The dinner was sumptuous and wonderful, replete with krumkaka, pizzelles, struffoli, and lefse.

Few people, aside from the readers of this newsletter, will ever understand our TM travails. Few people can understand that neuropathic pain is real pain, buzzing feet are not "happy feet," and exfoliation is not covered by insurance. So, learn to make wine. Save for a trip to China. Answer the phone and laugh and cry.

ANNOUNCING A NEW ADDITION TO THE TMA STAFF

Rebecca Whitney, whom many in the community know and who has been a volunteer with the TMA for a while now, has recently joined the TMA in a part-time role as Pediatric Programs Manager. In this role, Rebecca will be working closely with our TMA staff, Board and community to build a strong and engaged community presence for pediatric neuro-immunologic diseases. Rebecca will also be the point person for our recently funded pediatric outcomes CAPTURE study in partnership with UTSW, JHU, Children's Hospital of Philadelphia (CHOP), SickKids Toronto funded by Patient Centered Outcomes Research Institute (PCORI). We are thrilled that Rebecca has agreed to join us and look forward to a focused program for children and families affected by these diseases.

My path to coming to work with the TMA is not one that I could have ever foreseen nor would have necessarily chosen. It still seems so surreal at times when I think about how my family's life has changed over the past 6 years, 1 month, and nearly 1 week, all because of transverse myelitis. Our son was born on a nearly 80-degree day in the summer of 2007. He was a perfect baby; happy, healthy, bouncy, just the light of our world. He was healing to my heart after a difficult time with our second child who struggled with various medical issues through his infancy. We had just started getting back into the swing of a different daily routine, having returned to work from maternity leave and now parents of three young children. It was a balancing act that sometimes felt more like a circus act, but it was working!

I will never forget the days immediately preceding and the date of December 13, 2007 when we suddenly found ourselves in the ICU with our infant son with no idea as to why he was no longer moving and struggling to breathe. Our life as a family, our lives as individuals, were turned upside down by an unheard of disease called transverse myelitis. My heart was broken. It was shattered into pieces and seemed they could never be put back in place. I had no idea what the future held for us; for my baby that was motionless, taking only a small, shallow breath every so often with the ventilator, for my other two children that couldn't grasp why their mom and baby brother couldn't come home, for my husband and I as partners and parents; we had just been through enough with our other son, what was this going to do to us?

Our lives since our son's diagnosis has not been easy. We've been so busy trying to live our lives as "normal" as possible while learning about TM and making sure that our son has what he needs in terms of medical care and rehabilitation. We felt so alone and would become so frustrated trying to explain what the disease was until 2012 when we met another family and young boy who also had TM. We had found our extended family and through them, became more closely acquainted with the TMA. Since then, I've had a passion to help further the TMA's mission. I firmly believe in them and their goals. I see a brighter future for my son through the work they have set out to complete.

As I move into the role of Pediatric Programs Manager for the TMA, I look forward to working with the executive team, the physician network, families and patients, to expand what we know about TM, ADEM, NMO and ON in the pediatric population. I hope to be an advocate for and provide support for the children and families who have never heard of such diseases but have found their lives upended as ours was in 2007. I hope to connect them to one another so they don't have to experience this journey of navigating these rare neuro-immune diagnoses alone. I most sincerely want my son, your daughter, your grandchild, you as parents, to have hope for the future and to know that we are working towards eliminating the debilitating effects of TM. I am truly humbled by the offer and trust of this position with the TMA. This is a matter that is deeply personal and of my heart. I am committed to doing my best for each of our children.

While my heart has started to heal, it still aches where it has started to come together and I swear that there are pieces of it that will remain forever in that pediatric ICU room. It will never be the same. I remain hopeful yet still struggle, especially with trying to hold back and sort my mixed emotions. As I type, I am able to watch out the window as my daughter runs by on her fourth mile with ease, my older son trots through the snow without any mishap heading back to their fort, and my youngest, determined to let nothing stop him, struggles to stay up on his feet. He's trying diligently to carry a large snowball, a "diamond" that he has found to house in their fort. It hurts to see him struggle while the other two move with such ease. But he doesn't give up and has even managed to find "diamonds" in this cold, harsh winter. I'm not giving up either and will look for the diamonds, too.

- Rebecca Whitney

APPLY FOR THE 2014 TMA FAMILY CAMP

The TMA Family Camp will be held at The Center for Courageous Kids in Scottsville, KY from July 23 - 27, 2014! Applications are now open. Please apply by going to http://www.thecenterforcourageouskids.org/camperapp.html and select Family Retreat Application. We have limited space, so we encourage you to apply early! The camp will accept the first forty completed applications from our members for review. The application must be completed - both the electronic, online portion and the medical portion in order for camp to consider it a completed application. The subsequently submitted applications will be placed on a waiting list. Please apply early!

We cannot wait to experience the magic of camp at CCK with you in 2014!

You can view highlights of the 2013 TMA Family Camp and download our brochure by going to http://bit.do/tma-camp-2013.

DEBBIE CAPEN RECEIVES

2013 TMA DISTINGUISHED SERVICE AWARD

It was an honor for the TMA Board of Directors to recognize Debbie Capen as the 2013 Distinguished Service Awardee. She was given the award at the 2013 Rare Neuro-immunologic Disorders Symposium held in October in Dallas. Debbie has been an Officer and Board member of the Association since nearly the founding of our organization. I found Debbie on the Transverse Myelitis Internet Club, shortly after Jim established this list serve group in 1997. When the Internet was first developed, the TMA was a very small group, and most of our members knew each other fairly well and had created many personal relationships. We asked Debbie to be the Secretary of the TMA.

There is an amazing amount of work involved in running an organization like the TMA. And for most of our 20 year existence, all of this work was being performed by volunteers. And Debbie is one of the volunteers who also has TM with all of the very complicated and difficult symptoms. Debbie was also diagnosed with Lupus after receiving a TM diagnosis, so she has more than her fair share of issues to manage. In spite of her physical challenges, Debbie has been a dedicated, remarkably consistent, dependable and loyal volunteer of our organization.

In doing the work of the TMA, we experience some really amazing opportunities such as our family camps and symposia. There are also some mind bogglingly difficult and sometimes horrible experiences, because running an organization can cause mayhem, and because doing this work exposes us to thousands of people who have complicated health issues and sometimes bad things happen. And often times the challenges are intensely difficult emotionally. It is hard work.. very hard work. But it is not just these highs and lows that define the nature of Debbie's involvement with the TMA over all of these years; it is the day to day tedious, energy and time intensive chores that we need to get accomplished in order to be a transparent, responsible and accountable organization. Debbie spends many hours a day, often seven days a week, all year long participating in getting our work done. And she is involved in everything, from managing donor recognition, to planning camps and education programs, participating in the publication of our newsletters, as well as numerous other activities involved in the day to day operations of any organization. Debbie also is available to people in the community who are seeking guidance about a myriad of issues in navigating the health care system and finding as many answers to their medical questions from the information we offer on our web site. And if that were not enough work, Debbie is also very actively involved in the Southern California Support Group that she helped to start many years back with Cindy McCleroy.

Her greatest supporter and her best friend is her husband, Michael. Michael not only supports the work that Debbie does for the TMA, he is also an active participant. Michael has been involved in our work since the beginning when he was a caregiver at our first Children's Workshop in Columbus in 2002. Debbie and Michael continue to tirelessly volunteer for the TMA at our family camps transporting families to camp from the airport in Nashville. Michael and Debbie are there to help these families during the entire week of camp. They are a wonderful team, and we have all benefitted greatly from their involvement.

Over these many years, Debbie has been a wonderful colleague and has become a great friend. She so deserves this recognition as the Distinguished Service Awardee, and we look forward to Debbie's incredible contribution for many years to come. She has made a positive difference in so many people's lives, and mostly for those of us who are honored and grateful to be working with Debbie closely every single day.

Life as I knew it ended on December 30, 1996, and my new life adventures began as a victim of transverse myelitis. I was desperate for answers, and when I returned home from the hospital, the first thing I did was get on my new computer and search for "transverse myelitis". First, I met Jim online, then I began communicating with Deanne, Sandy and Pauline and the others who were searching for the same answers. Over the years, I have come to love each and every one of these people as members of my family. I am so honored to know that they love me as much as I love them. The course of my life changed – from being a contractor and decorator to advocating for my own health care and helping others do the same. What a change in lifestyle! As a recipient of the Distinguished Service Award, I thank you all for this honor, thank you all for being in my life.

– Debbie Capen

JOIN THE TMA'S WALK-RUN-N ROLL CAMPAIGN

Last year in April, the TMA launched an ambitious nationwide Walk-Run-N-Roll campaign to increase awareness and funds for research and programs that the TMA offers under the "10 cities-1000 people-$100,000" slogan.

Six cities participated, more than 1000 people joined the campaign and helped raise more than $100,000 for research and education efforts!! The walks were led by amazing, passionate and committed volunteer leaders and held in South Jersey (NJ), South Park (PA), Douglasville (GA), Cocoa (FL), Holland (MI) and Downer's Grove (IL). It was our first year and all expectations were surpassed!

We want to be more ambitious this year! Would you like to lead or volunteer for a Walk-Run-N-Roll event in your area? Do you want to raise awareness for these rare neuro-immune diseases that so unexpectedly rob so many people of their normal lives? Please join us in this effort in 2014! We have created a website for the walk - http://myelitis.org/get-involved/walk-run-n-roll-campaign - where you can learn from the walks of 2013.

We know it can be intimidating and overwhelming to think about leading an effort like this. If you are wondering, "where do I start?" – we have provided you with all the tools on the website as to how to get started! Please begin by sharing more about yourself and why you would like to become involved in a walk in your city or volunteer and be part of a Planning Committee. All forms are available online to complete and send to us.

We look forward to hearing from you and more importantly working with you in making the 2014 TMA Walk-Run-N-Roll Campaign a great success!

Go to http://myelitis.org/get-involved/walk-run-n-roll-campaign for more information.

SUPPORT GROUP IN DALLAS-FORT WORTH AREA, TX

Barbara Nichols, who is living with NMO, reached out to the TMA in the summer of 2013 to start a support group in the Dallas-Fort Worth area. Thanks to her leadership, the first meeting of the Dallas-Fort Worth support group was held on Sept 14, 2013, which 27 members attended. Dr. Benjamin Greenberg, Director of the TM and NMO Center at University of Texas Southwestern and Martha Mann, a clinical research nurse also at UTSW joined the group and shared about what is happening in the world of NMO. Caregivers and individuals living with these rare neuro-immune diseases attended, got to ask questions and learn from each other's experiences.

A second meeting was held in November 2013 and Martha Mann shared updates on the latest research and developments from the Rare Neuro-immunologic Disorders Symposium in Dallas, which was held on Oct 25-26, 2013.

The group is planning the next meeting in February. If you are in the Dallas-Fort Worth area and would like to join and meet others, please email Barbara Nichols at nmofamily@att.net. Although the group started out initially as focused on NMO, the support group is focused on both individuals living with TM and NMO. Future meetings will be focused on specific symptom management and also keeping up on the latest research and discoveries.

In loving memory of

JOAN FINK

February 17, 1940 – December 20, 2013

While I am incredibly sad at the passing of my friend, Joan Fink, she is celebrating the New Year with her Lord and Father. Joan passed away in the evening of 12/30/2013. Back in about 2000 Joan, Debbie Capen, Teri Apodaca and I met at the Abilities Expo in Long Beach, CA. We all had TM, and for Joan and Teri it was the first time they had met others with TM. We all became friends and belonged to the TM support group in Southern CA that Debbie and I had started.

Joan and I went to many Angel baseball games together. The Angels along with the New Orleans Saints were her two favorite sports teams. One of Joan's favorite memories of the Angels was the day Arte Moreno, the Angels owner, invited us to watch the game from his suite along with some baseball greats. It was a thrill for both of us.

When I spent a year in the hospital (all of 2011), Joan took my dog into her home and loved her like I did. She took Missy (my dog) to the vet, to get her nails done, and walked her several times a day. It was so hard for her to return my Missy dog to me. However, about two weeks later one of her friends found a scruffy little terrier wandering the streets. A bath, food and lots of love and this little stranger became her best friend.

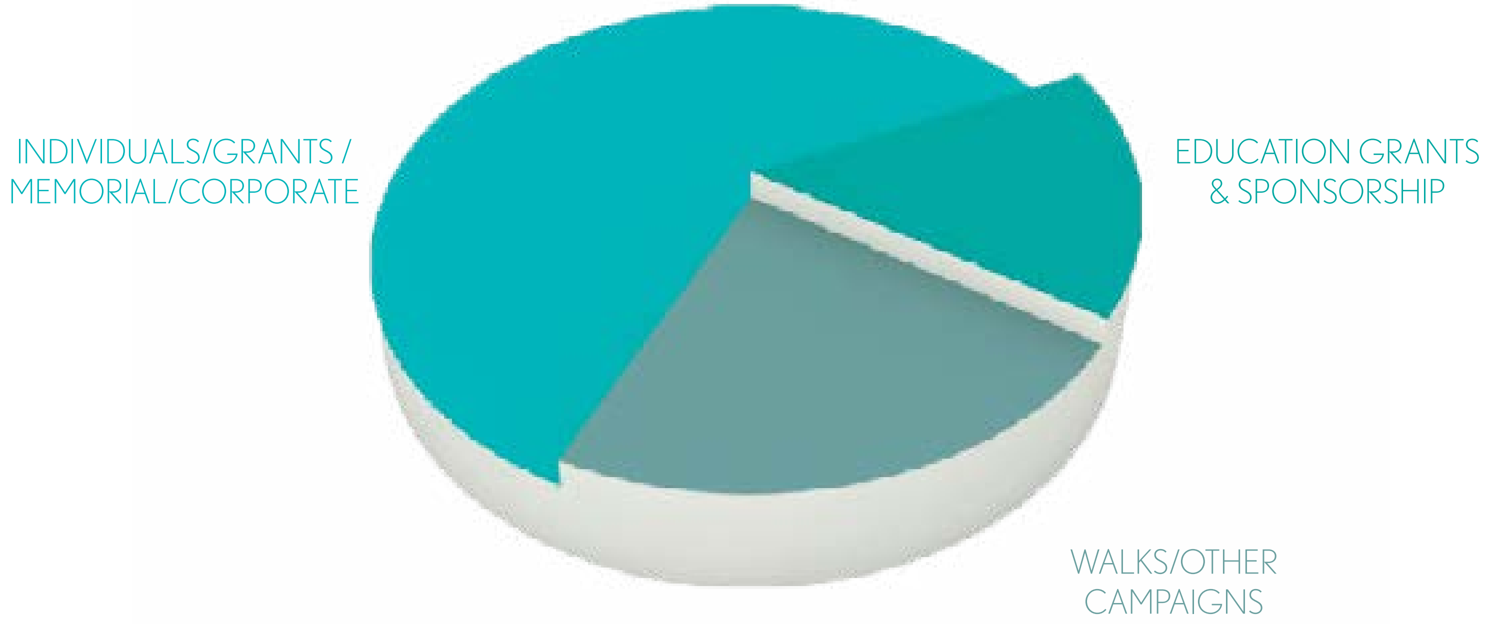
Joan had many friends that she was always there for, supporting them emotionally. She loved her family so very much. She threw herself into all that she did and succeeded in giving the best of herself to all she knew. She was always there when I needed her advice or just to talk, no matter the time of day or night.

There are so many wonderful things to say about Joan. I miss her and she will always be a wonderfully remembered friend. Transverse Myelitis has lost a great friend and our TM group missed her so very much at our last meeting on January 18, 2014. Joan always brought much advice, many helpful suggestions learned from her past medical career, and a lot of humor to all the meetings. Rest in peace my dear friend.

- Cindy McLeroy

THANK YOU TO OUR SUPPORTERS!

The TMA had an incredibly successful fundraising year in 2013. We are so thankful for your generous support of the TMA that enabled us to raise more than $385,000! Below is a breakdown of funding sources for 2013:



The TMA 2013 Walk-Run-N-Roll Campaign, which built on the success of a walk that was held in NJ in 2012, has been a huge success in increasing awareness of the TMA and building community support among local TMA members. Events held in New Jersey, Pennsylvania, Georgia, Florida, Michigan, and Chicago, along with a silent auction in Minnesota raised over $110,000 this year. Other events organized by members and their families and friends helped raise significant contributions for the TMA. Many thanks to the organizers, participants, sponsors, and supporters of these events!

The TMA continues to pursue institutional grants that support specific member programs. We are grateful to our members and donors who supported us with several gifts through the year. We thank those who chose to honor the memory of their family and friends by donating to the TMA – we are humbled by your generosity.

A complete list of 2012 and 2013 donors is included in the newsletter. Once again, a sincere thank you for your support!

A full financial report for 2013 will be available on our website after our 990 tax form is filed.

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