THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

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

Fall 2014

20 YEARS

MAKING A DIFFERENCE

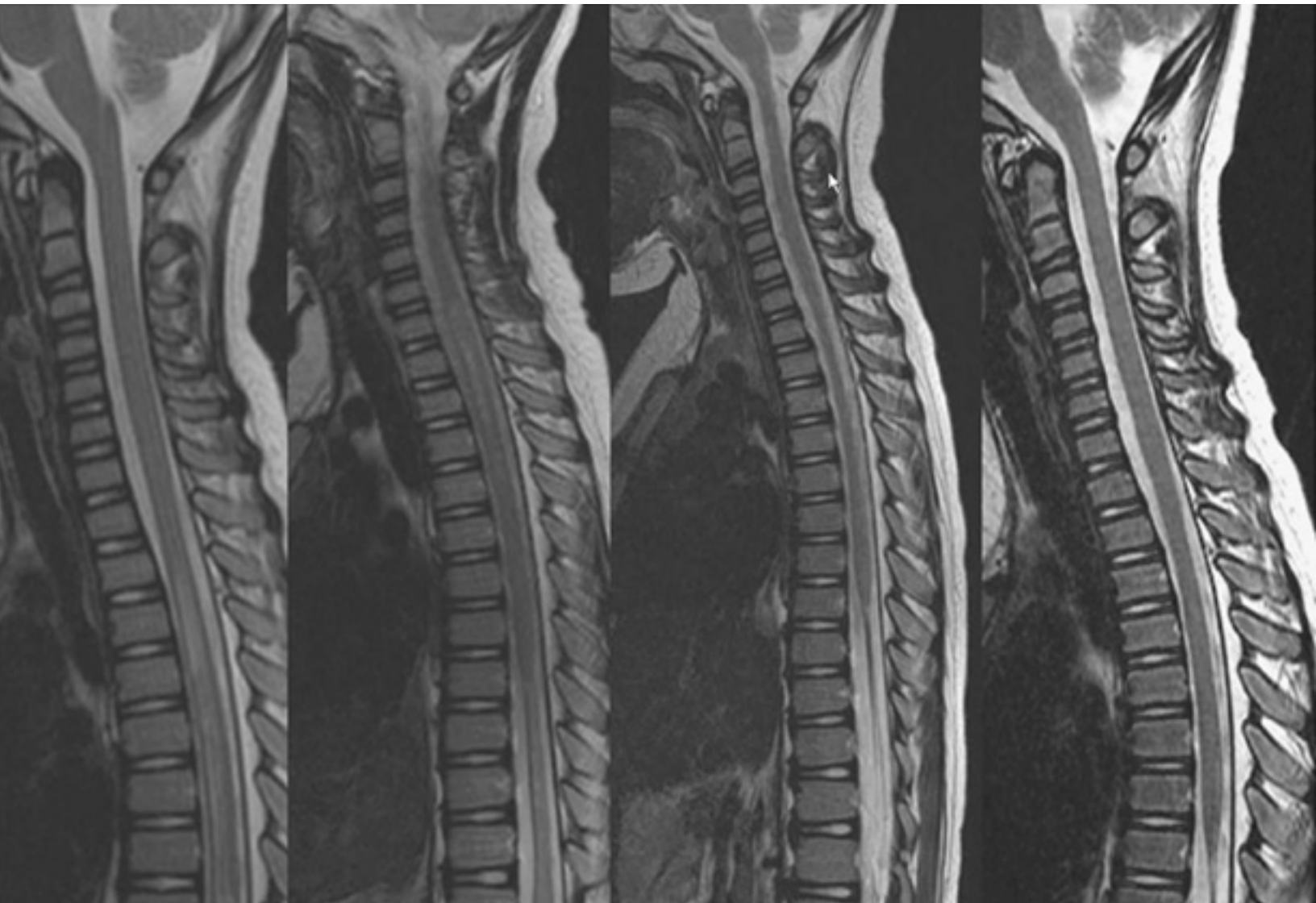
INDEX

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

The most important study ever done on transverse myelitis was initiated on May 31st of this year. The study is focused on pediatric transverse myelitis, but the results will have critical implications for adults who have transverse myelitis as well. This study represents the first attempt to systematically collect information about diagnosis, the effectiveness of treatments in the acute phase of transverse myelitis and their outcomes. It is a multi-centered study that will ultimately improve treatments for people who will be diagnosed with TM in the future and those who have had TM for weeks or decades as it will allow for further collaborative, randomized and controlled intervention trials. This is the first large-scale study of TM that has received significant outside funding. All previous studies were either carried out by TM Centers at their own expense, or funded by the TMA.



This innovative study is called CAPTURE

COLLABORATIVE
ASSESSMENT OF
PEDIATRIC
TRANSVERSE MYELITIS
UNDERSTAND
REVEAL
EDUCATE

You may have read about it in our previous publications, and Dr. Benjamin Greenberg has an excellent article about the study in this newsletter. Dr. Greenberg is the Principal Investigator and the study is being funded by the Patient Centered Outcomes Research Institute (PCORI). The three-year study represents a collaboration with The Transverse Myelitis Association and The University of Texas Southwestern (UTSW) in Dallas, TX, Hospital for SickKids in Toronto, Johns Hopkins Hospital, Children's Hospital of Philadelphia and Kennedy Krieger Institute. The TMA and the Medical Centers are committed to capturing the data from 180 TM families. The inclusion criteria for the study are as follows:

1. Diagnosis of transverse myelitis
2. Under 18 years old at time of symptom onset
3. Within 90 days of symptom onset

Some of the children will be enrolled in the study through each of the centers. The majority of the children will be enrolled in what is being referred to as a virtual cohort. Their information will be collected in a virtual manner and the children will not have to travel to one of these centers. These children represent those around the country that are not being diagnosed by a TM specialist and in this way, we can achieve much broader participation.

It would be impossible for me to exaggerate the importance of this study for our children, for our community, for the Medical Centers who specialize in TM and for the TMA. In order for this study to go on from year to year, and to continue to receive funding from PCORI, the centers and the TMA have to meet their milestones. We must be able to enroll the numbers of children and families into the study that are required. Given the rarity of TM, and the geographic spread of its occurrence, that is a tall order. But we have to make this recruiting happen, and we have to succeed.

What is at stake for us? The results of this study will certainly have a critical impact. The approach being used is truly innovative; the doctors are seeking information from the families about what therapies are the most effective in the acute treatment of TM based on quality of life questionnaires answered by the child and their family. At present, there's never been a systematic attempt to measure the most effective treatments that are focused solely on TM.

The other critical reason this study must succeed, and what might be the most compelling reason, is that we need to be able to demonstrate that we are a highly motivated community ready and willing to participate in research. There isn't a government agency or a pharmaceutical company that will be interested in funding research on TM if we can't recruit significant numbers of people who have

TM into a study. If we want research done to figure out what transverse myelitis is about; what causes this horrible disorder and what are the disease mechanisms, people have to be willing to participate.
This is a rare disorder; no one can sit on the sidelines and think that someone else will take care of this for us. It has to be all of us.

The people who are eligible to enroll are children under the age of 18 whose symptoms started within three months from the time they are recruited into the study. That's not much time for us to find these families. We're doing all that we can. We are carefully screening new members, we are reaching out to neurologists, medical centers, rehabilitation centers, and specialists. We are networking through social media and through our support group networks. We're doing everything we can possibly think of to first find these families, and then to make the most compelling case for why they should get involved in this study. And to be clear, there isn't a single downside to this study. If children are seen at the centers, they will benefit from being evaluated by the world's most experienced clinicians on these disorders. If they are part of the virtual group, they will have their records reviewed by an expert and will be able to participate in providing all of this valuable information from their experiences. There are no complex issues involved in any way in the design of this study.

We need your help. If your child meets the criteria and you are not yet enrolled in the study, please get in touch with us immediately. If you hear of a child that meets the criteria, please get in touch with us immediately. Through social media, through our social circles, from our experiences traveling to rehabilitation centers and medical centers, our community is meeting new people all the time. It is truly amazing how much networking goes on regularly. It is possible that you are going to meet a family with a child who is eligible to enroll. If and when it happens, we are urging you to remember our request, and for you to get in touch with us, and then ask the families to get in touch with us.

You can contact Rebecca Whitney of The Transverse Myelitis Association at 1-855-380-3330 ext. 5 or at rwhitney@myelitis.org for more information about this research opportunity.

Please do what you can to help us make this study a success. We believe that the future of research on TM depends on the success of this one critical study.

Please take care of yourselves and each other.

Sandy Siegel, President of The Transverse Myelitis Association

IN THEIR OWN WORDS ARTICLES

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

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.

UNITING SCIENTIFIC AND PATIENT COMMUNITIES TO CREATE KNOWLEDGE ABOUT TRANSVERSE MYELITIS

Rare diseases require novel approaches to facilitate scientific study. The Transverse Myelitis Association (TMA) has partnered with Consano, a non-profit crowdfunding platform for medical research, to unite scientific and patient communities to advance our knowledge of transverse myelitis (TM). Consano utilizes a "crowdfunding" platform, a novel and exciting mechanism to enable individuals to donate directly to specific medical research projects and engaging and empowering the patient community served by the research efforts. There are many needs in the TM community and the TMA reviewed several proposals for this endeavor, ultimately selecting the research proposal led by Dr. Lana Harder of Children's Medical Center Dallas (CMCD) and the University of Texas Southwestern Medical Center (UTSW) entitled, "Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis." Dr. Harder's previous work with her team at CMCD and UTSW has uncovered cognitive problems (i.e., deficits in memory and attention) in patients affected by TM, suggesting brain involvement, a finding that has been surprising given that the focus of TM research, assessment, and treatment has been on the spinal cord. Findings from the cognition study have led researchers to seek a deeper understanding of the potential impact of TM on the brain and challenged our current knowledge of the central nervous system injury associated with TM.

Utilizing brain-imaging techniques, not routinely performed as part of standard clinical care, Dr. Harder's study will determine if there is damage to the brain, previously not identified, in patients with TM. This study has the potential to change our understanding of the biology involved in TM, identify new areas of immune-mediated damage, and broaden the scope of current assessment and treatment methods. Through research, we are able to create knowledge that will inform our interventions to improve the quality of life for the patients and families we serve.

There is much to be discovered, but the discoveries will not come solely from physicians and scientists. Studies like these are not possible without the partnership and support of our patient community. We are privileged to have the opportunity to join forces with our patients to advance our understanding of this rare disease.

~ Benjamin Greenberg, MD, MHS & Lana Harder, PhD, ABPP

We have just 80 days to raise the funds to support Dr. Harder's critically important study. Please help us to make this project a success by going to the Consano website (https://www.consano.org/projects/51-utilizing-brain-imaging-to-understand-cognitive-dysfunction-in-transverse-myelitis) and donating to this groundbreaking work. You are all acutely aware of the need for research on TM. This study and the Consano approach offers all of us this very unique opportunity to make a significant difference for ourselves. If you have family and friends that would be interested in supporting this work, be sure to share this information with them, as well.

IDIOPATHIC ACUTE TRANSVERSE MYELITIS: OUTCOME AND CONVERSION TO MULTIPLE SCLEROSIS IN A LARGE SERIES

Calvo et al. published an article in 2013, describing patients who were initially diagnosed with idiopathic acute transverse myelitis (IATM) who then converted to multiple sclerosis. They reviewed the medical records from 87 patients who were diagnosed with IATM and who had never presented with neurological symptoms prior to their first attack of transverse myelitis. The authors excluded two patients who were positive for the NMO antibody, bringing the total number of patients they studied down to 85. They then split these 85 patients into a group that remained with a diagnosis of IATM and a group that converted to MS. Eleven (13%) of the patients converted to MS, and 74 (87%) kept the diagnosis of IATM. Those patients who converted to MS converted at a median of 1.2 years after the first neurological event.

Lesions were found via MRI in the cervical spine (36.5%), thoracic spine (38.8%), and lumbar spine (12.9%), and there was no statistically significant difference between the groups in terms of where lesions were located in the spine. The patients also had their cerebrospinal fluid tested for oligoclonal bands, which are bands of proteins that are used by the immune system to attack things like viruses and bacteria. Calvo et al. found that those with oligoclonal bands were more likely to convert to MS than those who did not have them. Five out of the 15 patients with oligoclonal bands converted to MS, while one out of 44 patients without oligoclonal bands converted to MS. They also found that those who were younger at the onset of symptoms were more likely to convert to MS than those who were older. Calvo et al. also analyzed patients' CSF for pleocytosis, which is an increased white blood cell count. They found pleocytosis in only 23.4% of the patients; this finding is in contrast to other studies, where 42%-62% of patients had pleocytosis.

Twenty-six patients (30.6%) had longitudinally extensive transverse myelitis (LETM), which is a descriptive term for myelitis that extends more than three vertebral sections. Those with LETM had greater long-term disability scores than those with short myelitis. Two of the patients with LETM converted to MS, and converted one month and seven months after the initial attack. Urinary sphincter dysfunction was also associated with a higher disability score. Calvo et al. conclude that at least 13% of patients who meet the diagnostic criteria for IATM will convert to MS.

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: Calvin AC et al. Idiopathic acute transverse myelitis: outcome and conversion to multiple sclerosis in a large series. BMC Neurol. 2013;13(135):1-8.

AQUAPORIN-4 ANTIBODY–POSITIVE CASES BEYOND CURRENT DIAGNOSTIC CRITERIA FOR NMO SPECTRUM DISORDERS

Sato et al. published an article in 2013 describing patients who were positive for aquaporin-4 (AQP4) antibody but who did not otherwise fit the criteria for neuromyelitis optica or neuromyelitis optica spectrum disorders. Being AQP4 antibody-positive is a strong indicator that one has NMO or NMOSD, but NMO is also associated with "single or recurrent events of longitudinally extensive myelitis (3 vertebral segment spinal cord lesion seen on MRI) and recurrent or simultaneous bilateral optic neuritis." They looked at the medical results of 298 consecutive patients who presented to Tohoku University Hospital in Japan with inflammatory central nervous system disorders. They then compared those who were positive for AQP4 antibody who did not fit the criteria for NMO or NMOSD, with those who were also AQP4 antibody-positive but who did fit the criteria for NMO or NMOSD. 72 of the 298 patients were AQP4 antibody-positive, and of these patients, 45.8% fit the criteria for NMO, 36.1% had some characteristics associated with NMOSD, while 18.1% of the patients did not fall into the NMO or NMOSD diagnostic category. More than half (53.8%) of the patients who were AQP4 antibody-positive did not fit the diagnostic criteria for NMO or NMOSD and had monophasic optic neuritis, while 30.8% of them had lesions less than three vertebral lengths, and 15.4% had attacks solely in the brain stem. These patients had fewer attacks, lower levels of AQP4 antibody, and a lower disability score than patients who had NMO or NMOSD. Yet, there was a significant overlap in clinical and demographic features, which suggested that the presence of anti-AQP4 antibodies could be used to define a disease with variable presentations. As a result of this study, Sato et al. suggest that patients with AQP4 antibody positivity who have one or more attacks of optic neuritis, myelitis (whether short or longitudinally extensive), and/or brainstem involvement should be diagnosed with NMOSD and receive immunosuppressants.

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: Sato DK et al. Aquaporin-4 antibody–positive cases beyond current diagnostic criteria for NMO spectrum disorders. Neurology. 2013;80:2210-2216.

NEW SUPPORT GROUP IN WA

As a mom of a super active 10-year-old boy new to the transverse myelitis world, connecting with others is critical. We are very aware of the isolation that many feel as they fumble through the day to day tasks of living, and the frustration of dealing with the ins and outs of this rare neurological disorder. We want to offer an opportunity for others living in the transverse myelitis world to come together to share successes, struggles, encouragement and most of all HOPE. My son said it best during an interview, "There is always hope!" We want to invite anyone in Spokane, WA and surrounding areas (Oregon, Idaho, Montana) to join us.

For times and other information, please contact:

Danielle Kemp
509-389-4573
TMwithhope@gmail.com

2014 ANNUAL

We received a new member form from a Mom on July 1st. Her 10-year-old son suffered an inflammatory attack in the high thoracic region of the cord and received a TM diagnosis. The attack started on May 12th. They live on the west coast. When we receive new member forms from people who are very recently diagnosed, we contact them as quickly as possible to make sure they are receiving good medical care, help them develop expectations about acute treatment and rehabilitation by directing them to information on our web site, and offer them support. When they are told that a loved one has TM or ADEM or NMO or ON, we know that it is very likely that they are hearing those terms for the first time, and they have absolutely no context for thinking about what happened or what their future is going to look like. We know that our contacts can make a difference for them.

And so it was with this family. I spoke to the Mom and we talked about his acute therapy. I assured her that her child received exceptional care and that he was provided the most aggressive acute therapies possible for his attack. He received high dose intravenous steroids, PLEX and Cytoxan. He didn't respond dramatically to any of these therapies. We spoke for a long time, and I made sure that Mom understood how to find information on the website and connect with other families who would be able to provide this family with support and information.

And then I said the following to Mom, "My wife got TM 20 years ago. If someone had told me what I am about to tell you, my head would have blown up. But I'm going to say what I have to say, and then I'm not going to make it easy for you to say no. We have our TMA Family Camp coming

TMA FAMILY CAMP

up on July 23rd, and your son and your family need to be at this camp. It is at the Center for Courageous Kids located in Southern Kentucky. You would need to fly into Nashville airport, and Debbie and Michael Capen will pick you up from the airport and bring you to camp. I know that your son just had this attack, and I understand what I am saying to you about putting your lives on hold three weeks from now, and flying with a paralyzed child across the country to get there, but you have to do this. There will be no one at this camp who will benefit more from this experience than your son and your family."

Mom told me that she was a stay at home Mom with two children. She said that her husband was in school, so they had very limited funds. And they were also in the process of moving into a new home. Her son was going to be discharged from the hospital the next week and then the move was going to happen at about the same time. I heard what she was saying, I confirmed that her life was way more than totally insane, and then I reiterated that none of this mattered and that she had to find a way to get to camp. I told her that I would help her brainstorm about how to raise the funds to get there, because their flights would likely cost them almost $3,000.

I told Mom that by virtue of their coming to camp, everything about her son getting TM would change. We organize a three day education program for the parents, and we cover every major aspect of these disorders, from what happens acutely, the importance of rehabilitation, all of the symptom management issues, as well as psychological, emotional, educational and social issues. Drs. Kerr, Greenberg and DeSena will be at camp. There aren't any more knowledgeable or experienced physicians

anywhere who understand these neuroimmune disorders better than they do. And these physicians don't just have the knowledge and experience, they also genuinely care for their patients and for the members of our community. This is the case with all of the medical professionals we invite to camp. They take a week away from their busy schedules and away from their families to spend this time with us at camp. In addition to the education program, they also make themselves available to the families all day long. There are informal discussions that go on between the physicians and the families at the archery range, at the fishing dock, at the horse stables, in the swimming pool, at arts and crafts, and in the dining hall, during meals and between dancing. Dr. Becker who has a specialization in neuro-rehabilitation will join us and provides parents with critical information about expectations in regard to an aggressive rehabilitation program for their children. Audrey Ayers is a nurse from UTSW and Janet Dean is a nurse practitioner from Kennedy Krieger Institute. Both have extensive knowledge and expertise with all of the rare neuroimmune disorders, and will offer important information about the management of symptoms. Drs. Lana Harder and Joy Neumann are clinical psychologists. They will be talking to the parents about issues involving cognition, mood and emotional issues that can be associated with these disorders. Also, during camp, these clinical psychologists, along with Sam Hughes, a researcher from UTSW, will be conducting an important follow up study on cognitive dysfunction in pediatric TM. Finally, Dr. Anjali Forber-Pratt will be attending camp. Anjali got TM before she was one year old. She is currently an Assistant Research Professor at the University of Kansas' Beach Center on Disability and is also a Paralympic gold medalist in wheelchair racing.

Her presence is inspirational for the children and for the parents. She is a wealth of information about living with these disorders, and in maximizing quality of life.

Your child will meet other children who have TM and who understand what he has gone through better than anyone … even his own parents. That connection will be incredibly powerful for him, and he will make friends at camp that he will have throughout the year, and for the rest of his life. And being at camp is not at all about being sick. It is about having fun. The camp is entirely accessible and they offer an accessible recreation program. The kids and the families have an awesome time. The kids have incredible activities all day long, beginning at 7:30 in the morning and going until dinnertime at night. There is awesome dancing after breakfast and dinner. And then every evening there is a wonderful program for the families that includes everything from the infamous messy games to movie night to Carnivals that culminates with fireworks and a beautiful closing ceremony. The siblings have every bit as much fun as the kids who come with these rare disorders.

And the children receive so much nurturing and support. There is an excellent camp staff and the program and camp counselors are so attentive with the children and offer them so much care during the week. These counselors really bond with the children. Dr. Lana Harder also meets with the children who have the disorders, and they are given the opportunity to have a discussion between themselves. The same discussion session is led by Dr. Harder for the siblings. This is a great opportunity for the children to have an open, honest and safe conversation without anyone else in the room.

It will be a fabulous week for your child and for your entire family. You have to find a way to do this. And you and your husband will meet other parents who have been through all of what you have been through, and more importantly, have been through everything you will be going through in the future. You won't have to hack your way through the jungle; these parents are going to be able to show you the paths, and this is going to make your journey with this disorder so much easier to negotiate. I often believe that you will learn more and gather more important information from other parents than you will from the physicians. And they will offer you understanding and support in ways that you just cannot get anywhere else. Their empathy is the most immediate and the most intense and the most sincere. They understand you in the most intimate way. My experience has been that the friendships that are formed at camp, as with the children, will go on all year long and for the rest of your lives.

And so, I took Mom through the application process and then followed up with some phone calls to help her

Camp was fantastic! We were only two months into our journey with TM and it was only because of Sandy that we even managed to get the paperwork in. He told me over and over again how important it would be for our family to be there and to meet the TM community and learn from the best of the best. Boy was he right! We found all the families to be so amazing, warm and incredibly helpful. We watched Aiden play hard with the others on wheels, and saw the look of hope in his eyes that he just might walk again like many of the kids. I don't think our kids have EVER experienced so much crazy fun. They have talked non-stop about next year.

As for the parents, I can tell you there are not words enough to tell you how grateful we are for the information we received from the parent sessions. We learned a few critical things that will help us to guide our therapists on how to meet Aiden's needs. This could not have come at a better time as we had just been discharged from the hospital and had just transitioned over to outpatient therapies. Because of this amazing opportunity, we are now actively pursuing the best possible care for our son. Thank you TMA for giving our family such a valuable experience.

~ Danielle Kemp, Mother of Aiden, 10 years old

brainstorm about ideas for how she might raise the funds to pay for flights. I also told Mom that since they were flying from across the country that they might consider coming to camp on Tuesday so that they had a day to decompress and relax before camp started late Wednesday afternoon. And that is precisely what they did. They came to camp and they arrived late on Tuesday night. When Pauline, Kazu and I arrived around noon on Wednesday, one of the first families I saw was this family, and I introduced myself to Mom and to Dad and the two children. And of course, I hugged Mom. What a journey.

It was an awesome camp. It was just as I described. We had 36 families attend from across the United States, from Canada, and from Norway, Australia and China! At the end of camp, the Mom from China asked me if I went to Ohio State, and I told her that I did. She said that she went to Ohio State for a year as an exchange student from Shanghai. We both laughed, and then we said good-bye, and we both sobbed. O-H-I-O.

During the entire camp, I was totally transfixed by the experience this family was having who had come from across the country just two months from the time their beautiful son got TM. I kept thinking about what Pauline's and my experience was like, as compared to what this family and this child were experiencing. There were no specialists when Pauline got TM; it wasn't until 1999 that Dr. Kerr announced his specialization in TM and the establishment of the first TM Center at Johns Hopkins. This family, just two months from the attack was attending an education program with specialists who directed TM Centers and who had acquired experience and expertise through more cases of TM, NMO and ADEM than anyone else in the world (along with Dr. Pardo at Johns Hopkins). It took three years before Pauline and I met another person who had TM. In just two short months, this family was surrounded by people who would offer this child and this family a critical part of their support network going forward. There was absolutely no information available for us about TM or about symptom management or about rehabilitation. This family was immersed in an education program that offered them the information they needed to advocate with their physicians at home for the best possible rehabilitation program for their son and also the most effective symptom management strategies. This family was connecting with the medical professionals and arranging to travel to see these physicians so that they could evaluate their child and offer him direct medical care. As a result of their coming to camp, the experts on pediatric TM would be taking on the care of this child.

What a blessing. Thinking about how this all happened and the experience of this family just totally blows my mind. Seeing the family covered in every kind of goop known to human kind during the messy games and then taking their place under the water coming out of the fire truck, put this entire event into the proper perspective. Camp

Don't miss the Messy Games video! Watch it by going to: http://youtu.be/93qGef2LCp0

is not about being sick or being a family with a child with TM or NMO or ADEM. Camp is about bringing a family together to celebrate life – to celebrate their lives. It was a blessing for this family and it is a blessing for every family who attends. It is a blessing for the doctors and medical professionals who come to camp, and it is a blessing for everyone who comes to volunteer. This camp is such a very special place. We remain so grateful to The Center for Courageous Kids for this incredible opportunity.

And now we will just think about and look forward to next year. 2015 Annual TMA Family Camp at Center for Courageous Kids in Scottsville, Kentucky, July 21 – 25, 2015.

~ Sandy Siegel, President of The TMA

When I first learned that I was going to the TMA camp I was nervous, because I didn't know what it would be like. Once we got to the camp we went to the dining hall and we met a girl named Lindsey. Her TM was a lot like mine but in her left arm. After we met Lindsey we went back to the blue lodge and started unpacking. When we were just going to make our second luggage trip Mary Ann stopped and introduced my family to her daughter Bridget. Bridget was affected in her legs and hands. Bridget was very nice to me the rest of the camp week. On movie night she sat next to my family and we watched Monsters University.

During the week I had so much fun meeting Allen, our blue lodge counselor, and doing the activities, such as archery, open gym, horseback riding, woodshop, and weird science! But my favorite thing to do at camp was swimming! I can't wait till I come back next year!

~ Manny Green, 13 years old

2015 TMA FAMILY CAMP ANNOUNCEMENT

The Transverse Myelitis Association is thrilled to announce our annual **TMA Family Camp at The Center for Courageous Kids (CCK) in Scottsville, KY from Tuesday July 21 to Saturday July 25, 2015.** We are incredibly grateful to CCK for hosting us for the past three years and are just as excited to return in 2015! **Children with ADEM, NMO, ON and TM who are 5-17 years old and their immediate family members are eligible to apply to the TMA Family Camp.** If you have a child younger than 5 or older than 17, you may still apply. Acceptances will be considered on a case-by-case basis. Space at camp is limited and we encourage you to submit your **complete** (i.e. Step 1 and Step 2) application as quickly as possible once they become available. Please visit our website at www.myelitis.org/education/camp after November 1, 2014, for the announcement when applications open and for further information. If you haven't done so already, please be sure to check out our camp webpage for photos and video of the great time we had in 2014 and read the stories of families on our blog. TMA Family Camp is an incredibly fun and life-changing experience for so many in our community! If you have any questions concerning TMA Family Camp, please contact Rebecca Whitney via email at rwhitney@myelitis.org or +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

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

CAPTURE

The Collaborative Assessment of Pediatric Transverse Myelitis: Understand, Reveal, Educate – CAPTURE - study is the first large-scale international study of pediatric transverse myelitis. Funded by the Patient Centered Outcomes Research Institute (PCORI), this study is the first of its kind to track the outcomes of pediatric TM patients. Identifying how patients respond to various acute therapies is critically important for several reasons. First, determining the responses to different treatment regimens may identify which treatments work best for which patients. Secondly, determining the outcomes among patients is vitally important for understanding the needs of our patients relative to restoration of function. A number of companies have developed therapeutic options for repairing damage to spinal cords, but are targeting conditions such as traumatic injury and multiple sclerosis. With the right outcomes data, biotech companies could invest in studying TM for novel therapeutic targets. This would create tremendous opportunities for our patient community.

We need the help of our community of patients, caregivers and medical professionals to succeed. While some patients will be evaluated at one of the five participating centers (UT Southwestern, Johns Hopkins, Kennedy Krieger Institute, Children's Hospital of Philadelphia and Toronto Hospital for Sick Children), we are seeking over 100 patients to be followed via electronic surveys. We are asking for patients and families to log in to a website and answer questions about their condition. The first data collection has to occur within 3 months of the onset of symptoms. Thus, we are asking for your help! As you are introduced to families who are in the midst of a new TM diagnosis, please refer them to the TMA website (www.myelitis.org) and Rebecca Whitney (rwhitney@myelitis.org // 1-855-380-3330 ext 5). We are looking for your assistance to help families understand the importance of this study and to help us meet our recruitment goals.

~ Benjamin Greenberg, MD, MHS

Director, Transverse Myelitis, Neuromyelitis Optica and Pediatric Demyelinating Disease Programs, University of Texas Southwestern, Dallas, TX
Member of TMA Board of Directors
Chair of the TMA Medical and Scientific Council

SAFETY AND EFFICACY OF SUSTAINED RELEASE DALFAMPRIDINE IN TRANSVERSE MYELITIS

INVESTIGATOR

Michael Levy, MD, PhD

STUDY SITE

Johns Hopkins University
Baltimore, MD

CONTACT INFORMATION

Maureen Mealy, RN
hopkinstmcenter@jhmi.edu

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.

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).

A DOUBLE BLIND TRIAL TO EVALUATE THE SAFETY AND EFFICACY OF ECULIZUMAB IN RELAPSING NMO PATIENTS

SPONSORED BY ALEXION PHARMACEUTICALS

STUDY DETAILS

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.

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.

CONTACT INFORMATION

If you are interested in participating, please contact the sponsor by email at clinicaltrials@alxn.com or call 203-272-ALXN

You may also contact:

Warren W. Wasiewski MD | VP Clinical Development Neurology
Alexion Pharmaceuticals Inc. | 203-699-7701

Idil Cavus, MD | Medical Director, Neurology
Alexion Pharmaceuticals Inc. | 203-699-7859

http://clinicaltrials.gov/ct2/show/study/NCT01892345?term=ALexion&rank=5

ELIGIBLE PARTICIPANTS

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.

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.

As with all medications there are potential side effects, which will be discussed prior to enrollment and detailed in the informed consent.

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

Thank you to those who joined the podcasts on "Understanding Pediatric ADEM, NMO and TM" in July 2014 and "Understanding Clinical Trials in NMO and TM" in August 2014 as part of TMA's Ask the Expert podcast series. The podcast sessions provide an avenue for individuals diagnosed with these disorders and their family members to ask questions of experts who specialize in these disorders. The physician-experts on the podcast panels in July and August were Dr. Teri Schreiner from the University of Colorado School of Medicine and Children's Hospital Colorado, Dr. Benjamin Greenberg from University of Texas Southwestern in Dallas, Dr. Michael Levy from Johns Hopkins Hospital in Baltimore, and Dr. Dean Wingerchuk from the Mayo Clinic in Scottsdale.

The podcast recordings have not only been made available on our website at https://myelitis.org/education/podcasts, but you can also find all recordings on iTunes by going to:

https://itunes.apple.com/us/podcast/tma-ask-experts-podcast-series/id893008309?mt=2

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

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.

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.

CONTACT INFORMATION

If you are interested in participating, please contact:

Clinical trials information clinical-trials@chugai-pharm.co.jp

SA237 Clinical trial 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

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 PATIENT'S PERSPECTIVE

Chugai Pharmaceuticals is currently conducting a study 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).

On May 19 and 20, 2014, the Pharmaceutical Company hosted an Investigator and Study Coordinator Training Meeting in Miami, FL. One of our members and Support Group Leaders in the state of Texas, Barbara Nichols, had the opportunity to attend the meeting as a representative of the TMA. Barbara was able to catch a rare glimpse of how these meetings are conducted and received further insight into how the drug and the study participants are prepared for the trial. You can read more about her experience below.

I had the honor of attending the Investigators Meeting hosted by Chugai Pharmaceutical and Parexel in Miami this past May. It was a fascinating experience and opportunity to get a glimpse of the scope of work, research and time that goes into preparing a drug for trial. While hosting a table for the TMA, I met many caring doctors and clinicians all gathering for the common goal of pursuing better treatments for NMO. As a NMO patient, that in and of itself was an exciting thing to see. To come from losing my vision in one eye twelve years ago and no one having a clue what was wrong with me, to a spinal cord attack seven years ago with still no answers other than I "must have MS, but something about that doesn't look right", I sometimes felt I must pinch myself to know that I am in a room full of experts on my disorder! Definitely a nice shift from having so many experiences with medical folks giving me a blank stare when I tell them my diagnosis, as I know you have all been there, right? I am very appreciative and humbled that I was allowed to attend such a meeting and be given the opportunity to address this group and present a patient perspective. I had the opportunity to encourage them to not lose sight of the great personal decision this is for each participant in a clinical trial. It is one that must be thoroughly researched from a patient perspective as well, with careful consultation and expert medical advice from not only a doctor who is well trained and versed in this disorder, but one that we trust. We as patients have much to consider and weigh as this affects our lives and future, as well as the future of our families. Hopefully, we will continue to see more progress in the path to better treatments for our community.

~ Barbara Nichols

For more information about this study and other clinical studies and trials, please visit https://myelitis.org/research/clinical-studies-trials

MY COMMONWEALTH GAMES EXPERIENCE

My time as a 'Clydesider' has come to an end and in one word my entire experience was BRILLIANT.

Yes, the Games are all about the athletes, but without the 15,000 volunteers, it would not have run so smoothly. The Games included seventeen sports over 11 days in 14 venues.

I was privileged to be given a post in the Transport Team based at the SECC Precinct. The SECC was the only venue open 24/7, as not only were 7 sports taking place there, but it was also the venue for all worldwide and local media reporting and Committee Meetings.

My post was to ensure that VIP's, athletes and their families arrived and departed safely at the venue and got to their specific areas and other places on time in any one of the 1700 Fleet vehicles. My challenge was to do all 17 shifts and although fatigued and exhausted at the end of some, I did manage to complete every one of them. Getting the medical "all clear" to do so only the day before my first shift was a huge relief. Despite spasms and pain, I gave a smile and welcome to all I came in contact with. Another tick on the 'Bucket List'!

There were 40,000 people that attended the Commonwealth Games Official Opening Ceremony and a photograph taken of Ryan and I took up the entire front page of our National Newspaper the following day. What odds are that?

We had a fantastic time and the entire show was brilliant to be part of.

Although I had previously paid for tickets to some events, I was lucky to attend some others between shifts.

These events included the Opening Ceremony, Athletics and Medals, Discus, Long Jump, Sprinting, Badminton Finals, Boxing Finals x 2 gold's, Hockey, Lawn Bowls Finals, Netball Finals (Australia vs. New Zealand) and Swimming Medals. The best moment was when Libby Clegg won her Gold and took 45 minutes to go round the track thanking everyone. Singing 'Flower of Scotland' with 40,000 others at her Medal Presentation was some experience.

During my shifts, I met so many friendly and chatty people, including the Games Chair Lord Smith of Kelvin, the Games President, HRH Prince Imran of Malaysia, International Provosts, Princes and Premiers, Tom Tate Mayor of City of Gold Coast (where 2018 Games are being held), Jann Stuckey, Queensland Minister for the Commonwealth Games whom I arranged for her to get makeup chosen and picked up for Closing Ceremony. I have been asked to attend their 2018 Games also so will wait and see what the future brings as it is too far away to plan for at present.
Others I recall are Sir Chris Hoy, Clare Baldwin, Kathy Grainger, Laura Trott and so many athletes, too numerous to mention. I received two pins from Frankie Jones when she got her silver then gold medal in rhythmic gymnastics.

She is now retiring at 23 years of age, being such a great influence to young people to take up the sport.

Others gifted pins to me representing all six continents so I have a great collection now. I was chosen by Workforce to be presented to the Duke and Duchess of Cambridge (Kate and Will) and Prince Harry.

I chatted with Will and Kate about volunteering at Games and daily meeting VIP's, athletes and families, but how they were my highest VIP's I had that day! With Will, I discussed medal count as he was impressed with top totals, but I reminded him per head of population, Scotland was doing very well in comparison to England and Australia.

I told them I wished they had brought wee George with them and Kate went into a conversation about how chubby his cheeks were and he is always on the go so he wouldn't have settled at the Boxing they had just seen! I thanked her for coming to Glasgow and she said she was delighted to come along to the Games and see some of the events. Meanwhile, Prince Harry was busy chatting with some army personnel but he did shake hands and told me the volunteers were great and he had better go as the cars were waiting for him! I found that accessibility was very good within venues, in time for events, and accessible transport excellent from park and ride areas and as near to venues as

possible, such as gate entrances. I used this free service for every event and can only praise all the friendly experienced staff I came into contact with. Accessible seating was excellent, all seats I had pre-paid, as well as those arranged day-of, were in premium viewing areas and couldn't have been any nearer to sporting areas. Staff couldn't do enough to assist me and the atmosphere was so positive and friendly. Food (lunches and dinners) received on shift and at venues was good and variable, including vegetarian options. Our Workforce Team was brilliant and our Team Managers were very supportive. The Games Legacy is that all of Scotland benefits and when one checks out on the Legacy map what has already happened or will in their area, I believe it has been a success and still in process.

Glasgow City will never be the same and its friendly people are now known and acknowledged worldwide.

UNICEF was chosen as the Charity for the Games and during the 11 days over 5 million pounds was raised for it. WOW!

I had a PURE DEAD BRILLIANT experience and if you get the chance to do likewise, go for it and pass it forward; it's amazing and I am proud to have been part of it all.

~ Margaret's Shearer, TMA Support Group Leader, Scotland


The Herald

Shining example

15 years

I have Transverse Myelitis. Many years ago the doctors thought I could have recurrent TM, but it turned out to be regular 'ole TM. I flare up with the usual heat, illness, and high stress/fatigue. Sandy Siegel's article on flares being a normal part of TM got me going on a path of acceptance and less anxiety with symptom flare up. I have to say that my TM is still mild compared to some folks. I use a cane with flare-ups only, so maybe two-three weeks out of a year. I am a Clinical Assistant Professor and Social Worker at University of Texas at Austin I still get several calls a year from folks who have TM in TX and are wondering what to expect. Besides directing them to the TMA in general and their neurologists (of course), I always send them the link to that article. I've found it comforting to know what you're experiencing is to be expected. This is a poem I wrote.

~ Cossy Hough, TX

It starts with a hug
Not of affection
A hug of control, a girdle with inconsistent pressure.
Then pins and needles, maybe some itching.
Different every time
Mix it up, keep me guessing.
Then I am trying to figure out how I've been caught this time.
Heat outside, heat internal, heat in my mind?
Worn down heat maybe or heated up?
Whatever the reason, I am felled.
The message from my brain
Stopped at a yield sign I can feel about halfway down.
Can I try the muscles to the left or right?
What can get the message through?
How can I change the message? What translation does it need?
Top and bottom speaking German and Spanish, with an occasional commonality of vowel or tone.

The tingling moves up from my toes, it may stop at my ankles or my knees,
Or even at the thighs which starts to make me nervous.
Higher means there will likely be worrying and poking and testing. Others wondering if the meaning has changed.

At this point I am definitely stuck.
Maybe not for long but long enough to stop me.
I'm never consulted first. Is now a good time? Do you have plans you can cancel, an event you can miss? Someone you meant to connect with?
Never a guarantee of attendance. Just a stop.

Deep breaths and resignation, occasional acceptance, occasional tears.
Getting through the stop, the goal. Staying in the stop without guilt or sorrow or anxiety, the process.

Staying still
Staying calm
Staying
Staying in it.

Until the hug gives its slight release,
The skin calms,
The muscles start to talk, not without difficulty,
And not without the spasm of a waking, unsure limb.
The spasm, the pain, signaling
I'm almost through.

Given the gift of relief and fatigue on the other side,
I am released.
Always with caution,
A strange mix of caution and thankfulness.

And if it's a long time before the next,
The thankfulness grows into a soft but never quite hopeful, amnesia.

Until again there is heat and tingles and a promised embrace reaching out to me.

5K FOR TRANSVERSE MYELITIS

On April 20th, 2014, my life changed. That evening, I was diagnosed with Transverse Myelitis, a vicious neurological condition that paralyzed me from the waist down. The next few months presented a truly unforeseen challenge in my life, both mentally and physically, but today I leave my fellow peers with this: I beat it, and so can you.

Now, instead of talking about all of the hardships I faced -- the hardships that myself and all of those fighting transverse myelitis are all too familiar with, I wish to write about what helped me overcome perhaps the greatest obstacle of my life. These five factors contributed greatly towards my recovery, and it is my hope they can benefit all of those who are currently fighting transverse myelitis as well.

1. KEEPING THE FAITH

Knowing that God has never steered me wrong in the past helped me cope with the reality of my disease. During the initial, most heart wrenching stages of my diagnosis (and the days following), simply trusting God and believing that "everything happens for a reason" induced an unbelievable state of calm in me. Today, I have a closer relationship and reinforced belief in my God.

2. HAVING A POSITIVE ATTITUDE

The quickest way to give the disease the upper hand is wiping the smile off of your face. I cannot stress the importance of staying positive when fighting transverse myelitis. Naturally, there will be times of sadness, but when these moments occur; it is of the utmost importance to pick yourself up again.

3. WORKING HARD

When your body is faced with new limitations, it's easy to become lazy. Unfortunately, if you plan on coasting through rehabilitation, it's unlikely you will make any progress. Dedicate a solid block of time each day to your recovery, and it's quite possible that you will see a huge difference in your function.

4. BEING IN A STRESS-FREE ENVIRONMENT

When you are focusing on your recovery, liberate yourself of any additional stress. Stress can certainly take a physical toll on your body, and now simply isn't the time. Strive to be in an environment in which you feel as comfortable as possible.

5. STAYING CLOSE TO LOVED ONES

Now is not the time to distance yourself from the ones you love. Instead, try to invite your family and friends into your life. Having the support of those that care about you can serve so many different functions, including boosting your confidence and attitude.

On October 18th, nearly six months after the date of my diagnosis, I plan to run a 5K in honor of all of those fighting transverse myelitis, and to prove that there is nothing the human spirit can't conquer. Read more about my story and donate to my campaign here: www.youcaring.com/tm

~ David Markovich

LETTER TO MY 16 YEAR OLD SELF

Hira,

You'll suffer. The next two months will prove to be the most difficult obstacle you have to overcome. At times you might feel depressed and scared, but this experience will shape you. It will be filled with bruised veins and MRI scans. But you'll come to the realization that "everything happens for a reason" is not just a common saying. It's a concrete thought that will guide you for the rest of your life.

Today is Sunday, June 16th of 2012. You had a good outing yesterday with your family but it has drained every inch of your being and you're going to convince yourself that all the walking you've done in the past 24 hours is to blame for your extreme weakness. Today is going to be a good day, a day well documented by ImprovEverywhere (http://improveverywhere.com). However, you have a light fever and when you stand your eyes overcome with a bright light that leaves you dizzy. Nonetheless, you'll manage to pull it together and go shower, soaking your quick deteriorating health in lukewarm water. You won't feel any noticeable symptoms for the next ten hours while you take part in MP310, a flash mob that you and your sister have awaited for months. Once home, your symptoms will kick in almost instantly and you'll fall asleep, skipping dinner. Little do you know you are skipping your last chance to eat a real meal without the help of an NG tube.

It's Monday, June 17th, and you have work at Phebeana Preschool. Your body is radiating heat but you eagerly get up to shower and with every step you feel your brain being pushed against your skull. And like a snow globe, you feel it being violently shaken even with the slightest movement. You're going to decide to call out of work today. You will soon find out that you won't be able to work this summer. You won't be able to work for the next year. However, don't be too upset by this. You didn't like Phebeana Preschool anyways. You'll crawl your fragile self back into bed and snuggle against your sheets to prevent the horrid trembling. By the time you awake, you're burning. You'll feel like you've been through hell and back. You get out of bed and manage to stumble yourself into your mother's room. You know her well. You know that she doesn't need a thermometer to tell you how sick you are. She offers to take you to the hospital. You both can feel something terribly wrong, you have never been so ill. You'll agree and in the next ten minutes you're out of the house and waiting in the Emergency Room at Miamonades Medical Center. You'll be hooked up to fluids and given Tylenol. Stay calm because you will be discharged in the next few hours with a "possible bladder infection". For the rest of your life you'll wonder why they ran no other test except a urine culture. For the rest of your life you'll wonder why they told you to go home and tough a bladder infection out when your urine culture came out clean.

On June 18th, you'll return to the ER. You've spent all day sleeping with the blinds down and curtains closed preventing any ray of that beautiful hot summer sun from entering your room. You haven't eaten anything. You notice that you're using the bathroom more, almost every half hour, and figure it's because of all the Gatorade you're drinking to hydrate yourself. Mom will be worried and she'll pressure you to go to the ER again. You'll refuse each time, until you've finally had enough. You can't get up without falling over and you'll panic. You'll stand up and pass out. You'll be rushed to the ER once again and a battery of tests will be run. You won't remember any of this except your first spinal tap. You'll vaguely remember your mom signing a consent form. You'll vaguely remember waking up to a sore back and having your mom tell you you're being admitted and transferred into the isolation room in the Pediatric ward. But what you'll remember most is panicking, fearful that your hallucinations will hurt your mother. Don't worry, your fever and the medications are just getting to you. You won't remember much of the next month and a half, but the stories your family members and visitors tell you will remain in your mind forever.

What you do remember will change you. You'll remember the horrid nightmares from which you never wake up. You'll remember pleading with the doctors to send you home. You'll remember all the bruises on your arm from the blown veins. You'll remember the bruises on your stomach from blood thinners. You'll remember the failed attempts to get an IV in and the blood that rushed out when it was removed staining your hospital gown and sheets. You'll remember the high from the steroids and the hallucinations. You'll remember struggling to lift a glass of water because your fragile body will be too weak. You'll remember learning how to walk with your physical therapist. You'll remember learning how to pour milk into a cereal bowl with Chari, your occupational therapist. And this will change you. It'll make you bitter, and you'll be angry for a long time. But then you'll remember the deliciously moist blueberry muffins your sister brought for you every morning. You'll remember playing Scrabble with Chari and walking to the play room for the first time holding your sister's hand as the physical therapists carefully held your waist to prevent you from losing balance. You'll remember the conversation you had with your mother about the grandfather you so badly wish you knew. You'll remember the worry in the curvature of her lips as she tried to smile and her hopeful eyes. You'll remember the tight hugs she gave you. You'll remember how much she loves you. And this will change you.

Morning interrogations with Dr. Tran, lullabies sung by Tatyanna, crafts made with Madeha and conversations with Amy will inspire you. Amy will inspire you. You have been introduced to the medical field, and though you may not want to be a patient forever, you won't want to leave. This experience will shape you. It will give you your calling. You will no longer consider yourself a regular, materialistic teenager. Instead you will look in the mirror and see a girl who knows what she wants from life. You'll see a girl who wishes for more than just fancy clothes and nice things. You'll be exactly who you want to be, and this wouldn't have been possible if you weren't the unfortunately lucky individual to have been diagnosed with what your nurse practitioner, Emily, calls "Transverse Myelitis".

Sincerely,
Hira Tanvir

Hira is 18 years old and was diagnosed with TM at 16. Her TM was triggered by a brain infection. Hira was homeschooled and fell into a depression. The only people she communicated with were her parents and doctors. Fast-forwarding to now, she realized that her experience has taught her a lot. She is who she is today because of TM and wants to share her story with others. She wants to let others know that TM is not the end of the world. That's why Hira wrote a letter to her 16-year-old self -the age she was diagnosed with TM.

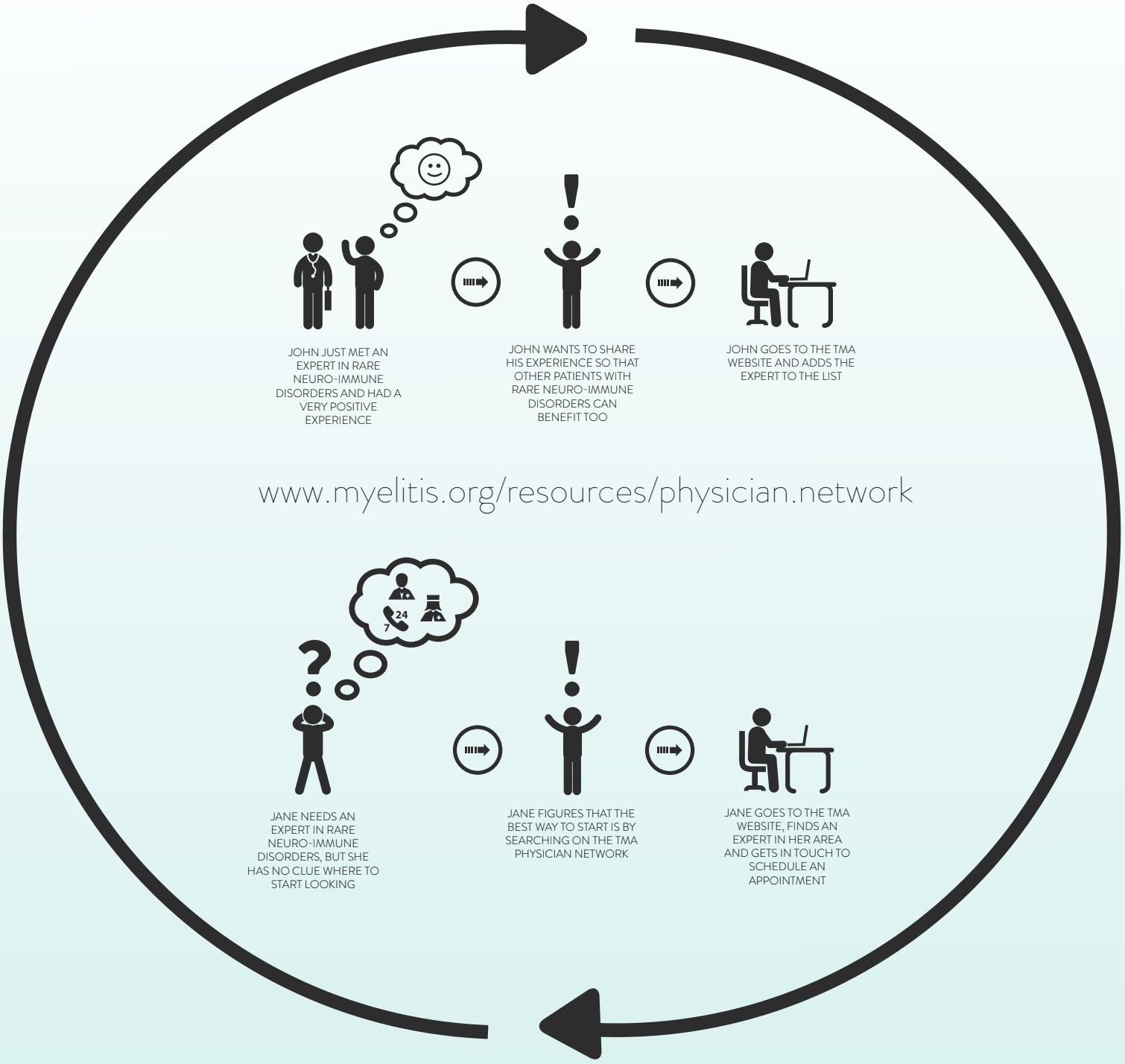
REFER YOUR MEDICAL PROFESSIONAL TO OUR **PHYSICIAN NETWORK!**

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 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!


JOHN JUST MET AN EXPERT IN RARE NEURO-IMMUNE DISORDERS AND HAD A VERY POSITIVE EXPERIENCE
JOHN WANTS TO SHARE HIS EXPERIENCE SO THAT OTHER PATIENTS WITH RARE NEURO-IMMUNE DISORDERS CAN BENEFIT TOO
JOHN GOES TO THE TMA WEBSITE AND ADDS THE EXPERT TO THE LIST
www.myelitis.org/resources/physician.network
JANE NEEDS AN EXPERT IN RARE NEURO-IMMUNE DISORDERS, BUT SHE HAS NO CLUE WHERE TO START LOOKING
JANE FIGURES THAT THE BEST WAY TO START IS BY SEARCHING ON THE TMA PHYSICIAN NETWORK
JANE GOES TO THE TMA WEBSITE, FINDS AN EXPERT IN HER AREA AND GETS IN TOUCH TO SCHEDULE AN APPOINTMENT

THANK YOU TO OUR 2014 WALK-RUN-N-ROLL TEAMS!

new jersey

COOPER RIVER PARK | PENNSAUKEN TOWNSHIP

april 22

maryland

GOUCHER COLLEGE | TOWSON

june 22

texas

COTTONWOOD CREEK PARK | IRVING

october 4

illinois

MCCOLLUM PARK | DOWNERS GROVE

october 5

wisconsin

FIREMAN'S PARK | DE FOREST

october 5

florida

ROTARY PARK | MERRITT ISLAND

december 13

For more information about the walks in Illinois, Wisconsin and Texas, please visit http://myelitis.org/walk

2nd Annual Central Florida Auction & Walk-Run-N-Roll

Auction & Dinner Fundraiser

Join us and Food Network Celebrity Chef Beau MacMillan to support our cause!

WHERE:

Doubletree Hotel Cocoa Beach Oceanfront

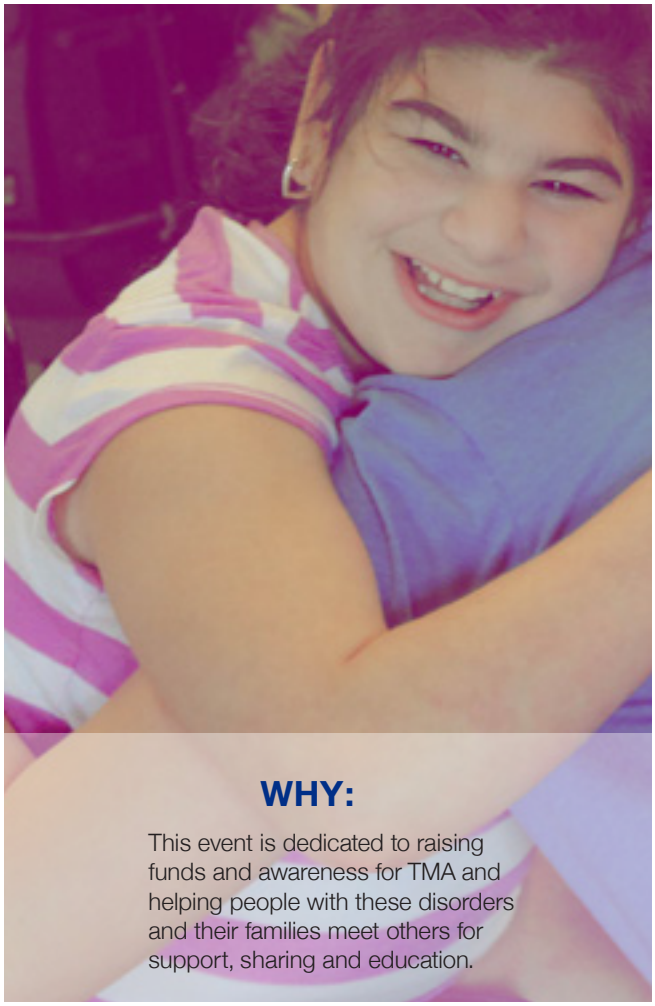
2080 North Atlantic Avenue
Cocoa Beach, FL, 32931

WHEN:

Friday
December 12, 2014
Start: 6p.m.

MORE INFO:

http://myelitis.org/2014-florida-fundraiser



WHY:

This event is dedicated to raising funds and awareness for TMA and helping people with these disorders and their families meet others for support, sharing and education.

2014 FLORIDA Walk-Run-N-Roll FOR THE TMA

Raising funds and awareness for rare neuro-immune disorders

TM (Transverse Myelitis) | NMO (Neuromyelitis Optica or Devic's Disease)
ADEM (Acute Disseminated Encephalomyelitis) | ON (Optic Neuritis)

WHERE:

Rotary Park

County Road 3
Merritt Island, FL 32952

WHEN:

Saturday
December 13, 2014
Registration: 8 a.m.
Start: 9a.m.

MORE INFO:

https://www.crowdrise.com/2014-Florida-Walk-Run-N-Roll

THE STORY

It was November 2011 - our 10-year old daughter, Sarah, walked into our bedroom in the morning after she awoke and within 30 minutes collapsed in front of our eyes. Our already mentally challenged daughter was now paralyzed by an attack of transverse myelitis (TM) and life had forever changed. We were told we were lucky that the acute onset was not in the cervical part of her spine or she may have needed permanent assistance to breathe. We were not feeling lucky. The world for our family changed that day and now we were faced with the everyday challenges of raising our paralyzed daughter. We tried to comprehend the doctor's explanation that currently there is no medicine or treatment plan available to heal this child or anyone else suffering from this disorder. We were told she could possibly walk with constant and consistent physical therapy, or she might not.

Now, our mission has begun. We are asking that you join us on this mission, a mission to raise enough funds to keep the TMA financially secure to continue to pay for the ongoing research, to provide families with information and support and to continue to raise awareness for these rare disorders. We cannot fight alone and need your help! It is a cause worthy of your donation and not only our family, but also every family that suffers with TM, ADEM, NMO will be grateful and humbled by your donation.

~ Jason and Tina Robbins

FIRST ANNUAL GOLF OUTING

THE TRANSVERSE MYELITIS ASSOCIATION

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Chippin' in against Transverse Myelitis

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K&K VETERINARY PATHOLOGY

Queen of the Transverse Myelitis Association: Pauline Siegel

McCloskey Family

Friends of Our 'Superhero Mark McCloskey'

The Gee Family - In Honor of Mark McCloskey

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20 YEARS OF SERVICE

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20 for 20 ANNIVERSARY CAMPAIGN

IF YOU GIVE $20 AND ASK 20 FRIENDS & FAMILY TO GIVE $20

Then... YOU CAN RAISE $420

&...

ONLY 90 DAYS LEFT TO GET TO $420,000

ALL IT TAKES TO GET STARTED IS $20

WWW.CROWDRISE.COM/THE-TMA-20-FOR-20-CAMPAIGN

HERE IS HOW OTHER MEMBERS HAVE DONE IT

When I was diagnosed with transverse myelitis almost five years ago, neither I nor anyone in my family had ever heard of transverse myelitis. While I was in the hospital receiving steroids and other treatments for transverse myelitis, my family searched the Internet and found The Transverse Myelitis Association's website. By looking at the TMA's website and speaking to a support group leader from the state I was in, my family and I learned more about transverse myelitis and felt less alone in dealing with my diagnosis. I was so relieved to see that there was an organization working on behalf of people with rare neuro-immune diseases.

I am thrilled to be a part of the 20 for 20 fundraising campaign to raise money for the TMA's research, education, and advocacy efforts. I created a Crowdrise account on the campaign's page and shared the link with my friends and family via social media, and asked others to share the link as well. I also sent an email to my family and close friends explaining the work that the TMA does and asked them to contribute and/or forward the link. Spreading the word about this campaign helps ensure that the TMA continues to grow for the next 20 years and beyond!

~ GG deFiebre

When I was diagnosed with TM in 2006, my first neurologist said to me, "You have transverse myelitis and there's nothing I can do for you except refer you to a psychologist so you can learn to live with it". I said, "I have WHAT and you WHAT?" I had never heard of TM! My GP had to get his books out! Needless to say, I don't know what I would have done without the TMA.

We have to keep this association active! We are orphans! We have few advocates but those we do have are champions and serve and share with the TMA, which in turn informs the rest of us. This is one of those "hang together or hang separately" things!

When I first learned of the fundraising campaign I thought, "What a great idea! Simple and easy and asking for only $20!" I emailed my family and friends and told our story. I encourage all who have not yet formed a team to do so. It is so easy and so essential. Let's get'er done!

~ Darlene Rogers

Much of what I have learned about my condition came from the TMA website. It is a resource I rely on. I was shocked to see that just 4% of members give to The TMA - members are probably the ones with TM or other similar conditions. These people should be the biggest advocates because they have the most at stake. When I raised money for Leukemia and Lymphoma Society, the patients and parents of children with blood cancer were the biggest fundraisers. TM is something that hit me. I have supported other people's fundraising activities for years, so now it is time to help myself.

~ Lynn Nelson

Suffering from a rare neuro-immune disease is very hard and frustrating every single day. Not a day goes by that I don't think about my future and the unknowns I am faced with. I joined in on the TMA 20-for-20 Anniversary Campaign to help spread awareness, and to help raise money for more research. My hope is that the money raised toward this campaign will help people like me have a brighter future and hope for tomorrow. Before getting this diagnosis I knew nothing about transverse myelitis, nor had I heard of it even through nursing school. By sharing my page with friends and family, as well as social media pages, I have been able to share my story and make people aware of The Transverse Myelitis Association. My family and friends have passed along my page to their family and friends and shared it on their social media pages in a huge effort to raise funds for this wonderful organization. I am hopeful with the money raised, we will have more local community support, and be able to have larger events in an effort to raise more money and awareness. Thank you for all you have done.

~ Julie Ostroski

I look at the TMA 20 for 20 campaign as something very personal to me. When I was diagnosed with TM, I felt so alone. No one had heard of TM, including many of the doctors and nurses I encountered. Through social media I found several Facebook groups full of people all around the world with TM, and that led me to the TMA. I am so appreciative that there is an organization like TMA to advocate

for us and support research efforts in finding a cause and treatment for TM. As a mother of two young girls, I feel blessed that I have had a good recovery from my initial attack, but I have so many friends with TM who haven't and who suffer daily from its effects. This is the letter I am sharing on social media to ask my friends and family to support this cause:

Dear friends,

Thank you to the 11 friends who have donated to my campaign to raise money for the Transverse Myelitis Association. Transverse Myelitis is a rare condition in which the immune system attacks the nervous system, often causing significant damage to the spinal cord.

You may or may not know, but the night that I initially became ill, the ER sent me home with a diagnosis of a pinched nerve, even though I was exhibiting neurological symptoms and repeatedly told them something was not right. By the time I went back the next morning, I had lost the use of the lower half of my body. I was fortunate to be in the 1/3 of TM victims who have a pretty good recovery, but many of my TM friends are paralyzed and have had NO recovery at all. This includes children as young as 6 months and up.

Had the hospital staff been more aware of the presenting symptoms of this disease, they might have ordered an MRI and treatment sooner and I might have avoided some of the irreversible damage to my spinal cord.

The TMA is working hard to advocate for those of us affected by the disease and to help educate and create awareness, especially in ER's where time is of the essence in diagnosing this disease.

Will you please consider donating just $20 to what I consider is a VERY worthy cause? You don't even have to get cold or wet to help me.

Facebook tells me I have hundreds of friends; just think, if each of them donated just 20 dollars. It could make a huge difference!

Thanks for considering,

Love,
Sara

~ Sara Casey

HERE IS HOW YOU CAN DO IT

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!

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

CHANGE SERVICE REQUESTED

CONTACT US

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ANNOUNCEMENTS

Second Annual Central Florida Auction & Walk-Run-N-Roll: December 12-13, 2014. Details inside.

2015 TMA Family Camp: July 22–26, 2015. Details inside.

DONATE

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