THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

ADVOCATING FOR THOSE WITH ADEM, NMO, ON & TM

WINTER 2015

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

THE EDITOR'S COLUMN | SANDY SIEGEL, PHD

The Transverse Myelitis Association held its first annual golf outing on Monday, September 29, 2014. It was a spectacular fall day in central Ohio and we had a wonderful turnout, including many people from our community from across the state of Ohio and from around the country. Most of the members of our board of directors were in attendance, and Roberta Pesce made the trip from Madrid, Spain, and Debbie Capen came from across the country. And both of them surprised me with their presence, which was pretty awesome. We had 92 golfers who played in a four-person scramble. There were more than 130 people who attended the dinner, and who came to hear Dr. Benjamin Greenberg deliver a great talk. We were so appreciative of Dr. Greenberg, and also Dr. Allen DeSena, for participating in our golf outing.

Barbara Ferguson and Mark McCloskey did a phenomenal job in organizing and putting on this event. The three of us formed the organizing committee. Barbara pretty much single handedly put on the silent auction. She was able to obtain many items from companies in central Ohio who generously donated for the silent auction, which raised about $5,000. We also need to recognize Mark and Michelle's efforts to make the silent auction and the entire event a great success.

The outing was made possible by some exceptional sponsors:
https://myelitis.org/get-involved/golf-outing/sponsors

The breakfast was provided by Tim Hortons; lunch was provided by Giant Eagle. Monks Copy shop donated most of our printing and Tansky Toyota donated a Prius for our hole in one contest. Dina O'Brien, a research technician from the neuroimmunology program at UT Southwestern Medical Center made the trip to Columbus to participate in the outing. Dina helped us raise money by having golfers try to better her shot into a green on a par 3 hole. Dina is a former member of the Baylor golf team.

The major sponsors for the outing were Aetna, the Narducci Family, Ohio Health, the Downey Family, The Roles Family Foundation, Boeing, Fifth Third Bank and Hanger Clinic. We are so grateful for the support we received from these families, organizations and companies.

JUNE 13
2015

PLEASE SAVE THE DATE

The second annual TMA Golf Outing will be held on Saturday, June 13, 2015. It will be an afternoon tee time with registration around noon. The outing will be held at Bent Tree Golf Course, a beautiful golf course just north of Columbus. The golf will be followed by a picnic style barbeque dinner. We will have a dinner only sign up for the event as well. We are hoping that by having the outing on a weekend during the summer, we can increase participation. Attendance at the event is a great way to spend some time with people from our community. If you are interested in playing and helping us recruit golfers, please get in touch. If you work for a company or an organization that might be interested in becoming a sponsor, please let me know. You can reach me through email at ssiegel@myelitis.org. We look forward to your involvement to make this event a great success!

2015 will be a very busy and productive year for the TMA. There will be many opportunities for education, advocacy, social support, research and awareness. The activities we have planned for this new year reflect the core of our mission and goals.

The TMA's monthly **ASK THE EXPERT EDUCATION PODCASTS** will continue in 2015. These podcasts are a way for our members to ask questions of experts in the field and to share their concerns about important issues. These podcasts cover the most pressing topics and they are made available for free to our community. All of the podcasts are recorded and can be found on our website and are also made available for download in iTunes. The first podcast was offered by Drs. Benjamin Greenberg and Teri Schreiner, and covered the issues surrounding vaccinations for people who have ADEM, NMO, ON and TM.

The TMA holds an education symposium for our community every other year. The **RARE NEURO-IMMUNE DISORDERS SYMPOSIUM** will return to Dallas at UTSW campus this year. We will be sharing details soon and look forward to meeting our members in Dallas. These programs are exceptional and provide critical information, which will help you become an informed advocate for your medical care. The symposia are also great ways for you to connect with others in our community, including all of the friends you've made on Facebook!

The TMA we will be at the **AMERICAN ACADEMY OF NEUROLOGY** meeting in April in Washington DC this year. We look forward to spreading the word about the TMA, increasing our physician network and helping spread the word about the CAPTURE study. Our presence at these meetings is an important way for the TMA to network with neurologists who care for people in our community and who are performing research on these rare neuro-immune disorders.

After years of writing grants to get funds to study transverse myelitis, we finally have our first-ever funded study in pediatric transverse myelitis focused on what acute treatments offer the best outcome. This is the **CAPTURE STUDY**; a virtual study that does not require travel. The only requirements for participation are to provide information from your experience online and to provide medical records for review to the research coordinator at the University of Texas Southwestern. During the first year of the study, only 8 children have enrolled in the virtual part of the study. We need your help to meet our recruitment goal of 150 patients within the next 2 years. We hear about newly diagnosed children every week and our goal as the TMA is to provide families with tools, knowledge and access to the best medical care so your child has the best possible chance for recovery. To date, there has been no systematic, large-scale collection and analysis of information to determine which are the most effective treatments for the acute inflammatory attack from transverse myelitis. Now is our chance to begin to answer the most critical question – what works? We need your participation and your help.

Are steroids an effective treatment, and if so, at what dose? Is IVIG effective? Is plasma exchange effective? We all have so many questions. Today, decisions are based on expert judgment because we lack the data. This study begins to provide that data. This information was not available when Pauline got TM. I sure wish it was. It wasn't available when your child got TM either. We have to change the world for children and for adults who get this horrible disorder. If we don't succeed with this study, we lose the funding. And this one, single study will either open or close the doors for future research of transverse myelitis. I believe we all want them to be opened.

Without your participation, we will not be able to get answers to our questions. If you are the parent of a child diagnosed with transverse myelitis or acute flaccid myelitis in the last 3 months, please contact Rebecca by email at rwhitney@myelitis.org or by phone at 1-855-380-3330 ext 5. If you know of other parents, please share our information with them and help us help you and the community.

Through the novel **CROWDFUNDING APPROACH OF CONSANO**, and the amazing efforts of our community, we will be funding a study using brain imaging to better understand cognitive dysfunction in transverse myelitis. The primary researchers in this study are Dr. Lana Harder and Dr. Benjamin Greenberg from the TM and NMO Centers at the University of Texas Southwestern in Dallas. In addition to the focus on cognitive dysfunction, this study has the potential to entirely change how we think about both the disease process and the definitions of transverse myelitis. If brain involvement is discovered through this important work, these researchers could change how the medical community considers what was thought to be an exclusively spinal cord disease. This was Consano's first patient-driven crowdfunding project, and the TMA is proud and delighted that we were successful in raising the funds required for the study.

The **ANNUAL TMA FAMILY CAMP** will be held at The Center for Courageous Kids in Scottsville, Kentucky from Tuesday, July 21 to Saturday, July 25. The camp will include an education program for older children and parents, and an incredible fun and exciting week of camp for the entire family. Applications are currently available on the CCK website. For more details on the application process and how to apply, please visit our website https://myelitis.org/education/camp/. We always anticipate a full house for camp, so if you are considering attending camp, please apply as quickly as possible. We will have families at camp from across the United States and from around the world. Some of these children have had ADEM, NMO or TM for years, and some of the children come to camp having been diagnosed within a few weeks to a year of coming to camp. It is a life-changing experience for all who come to camp, from the doctors to the volunteers to the families.

We are thrilled to announce the addition of **DR. PETER JOHNSON** to the TMA Board of Directors. There is an article in this newsletter introducing Dr. Johnson to our community. We are so grateful to have this wonderful physician, researcher, entrepreneur and visionary join our cause.

In 2008, The TMA established the James T. Lubin Clinician Scientist Fellowship Award to support the post-residency training of clinicians who are committed to careers in academic medicine with a specialization in rare autoimmune disorders of the CNS, including TM, ADEM, NMO, autoimmune encephalitis and ON. Dr. Allen DeSena was the first Lubin Fellow and has completed his training and is practicing at a new TM Center at the University of Cincinnati. A new request for applications was released by the TMA and we are in the process of reviewing applications for our second Fellow. When the Fellowship Review Committee and the TMA Board have completed their selection process, we will announce the new fellow to our membership.

In addition to all of these activities, we will be publishing our quarterly newsletters, we will be communicating with you through the TMA Blog, we will be regularly posting information on our website and our Facebook page and other social networking sites, and we will be participating in and promoting the many fundraising and awareness campaigns. Please get involved. We need for our community to get behind our efforts as volunteers to serve as support group leaders, help recruit for important studies, and getting involved in fundraising and awareness activities. We are a rare disease community; we do not have large numbers. We ALL need to get involved to make a difference for ourselves and for each other.

Pauline and I wish you a great new year, filled with **GOOD HEALTH**, happiness and peace.

SANDY

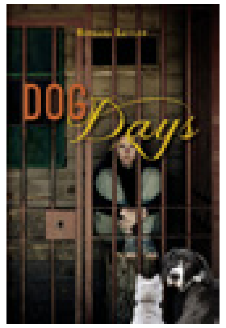
IN THEIR OWN WORDS ARTICLES

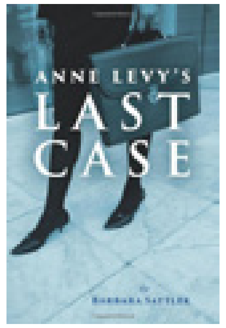
In each issue of the newsletters, we will bring you a column that presents the experiences of our members. The stories are presented In Their Own Words by way of letters we receive from members like you. We are most appreciative of your willingness to share very personal stories. It is our hope that 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.

Pauline and I just completed reading two really excellent novels by Barbara Sattler. Barbara's first novel is Dog Days and her second novel is Anne Levy's Last Case. Both of her novels can be found on Amazon. Barbara is an attorney. She served in the public defender's office and then served as a judge. She worked in both capacities for many years. After reading Barbara's books, Pauline and I have concluded that our dear friend Barbara has lived a very full and incredibly interesting life. Barbara has transverse myelitis, and she serves on the TMA Board of Directors. The main character in Barbara's second book has transverse myelitis. The highest praise I can offer is that I loaned the books to my mother and she told me that she thought that Barbara was really an excellent writer. My mom is an excellent writer herself and a great judge of talent. Pauline and I highly recommend these wonderful books. And all of the proceeds from the sale of these books are generously being donated by Barbara to The Transverse Myelitis Association. This donation along with the TMA web site appears on the back of the book, which is also great awareness for our organization. Thank you, Barbara!





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.

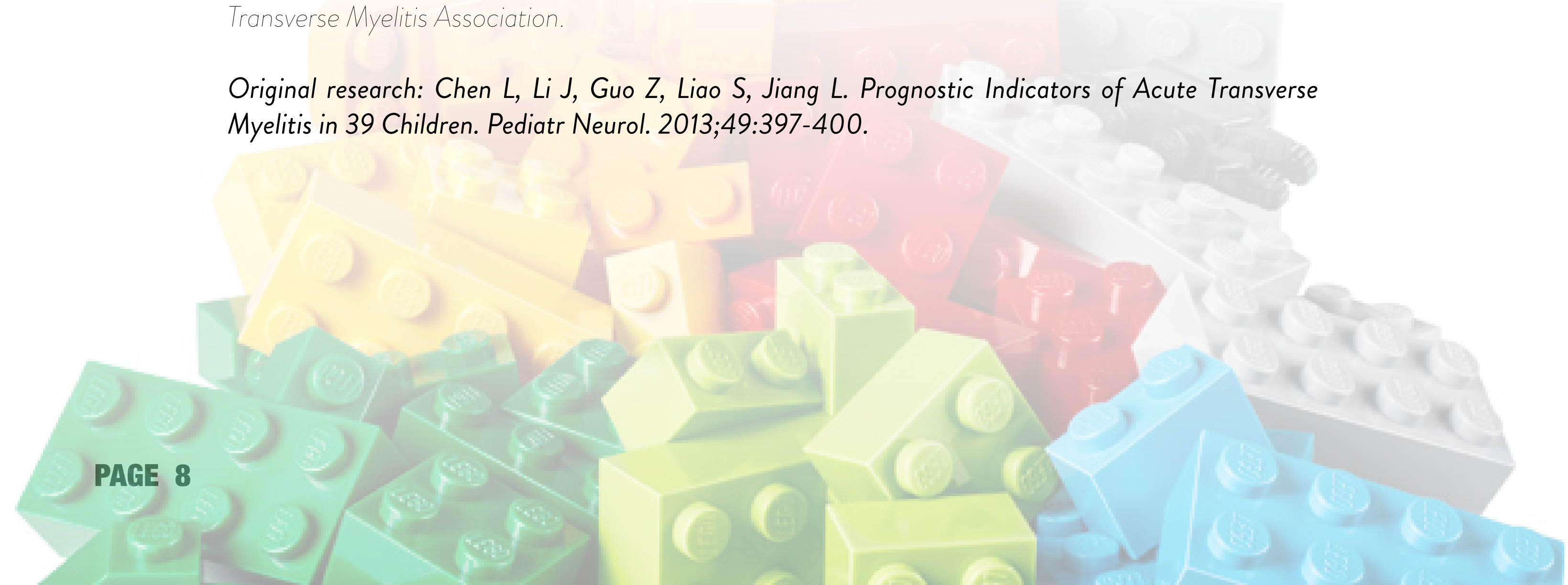
PROGNOSTIC INDICATORS OF ACUTE TRANSVERSE MYELITIS IN 39 CHILDREN

Chen et al. published an article in 2013 describing factors that contributed to the prognosis of 39 children (17 boys, 22 girls) who fit the diagnostic criteria for acute transverse myelitis (ATM). The diagnostic criteria were developed by The Transverse Myelitis Consortium Working Group in 2002. Children were admitted to the Children's Hospital of Chongqing Medical University between 1995 and 2008, and were followed for an average of 8.5 years. Chen et al. aimed to determine what contributed to a poor functional recovery versus a good functional recovery in this group of children. At follow-up, 22 (56%) of the children were completely functionally recovered, 9 (23%) had a good recovery with some residual effects, and 8 (21%) children were unable to walk unassisted and/or did not have complete control of urination. Of the latter group, 3 (38%) did not receive the correct treatment during their attack of ATM. Out of the total cohort, 24 (61%) of the children had an infection before experiencing ATM, and two children (5%) out of 39 eventually converted to multiple sclerosis.

Chen et al. found that there were several factors that predicted a poor prognosis in this population. These factors included: a) A short amount of time from initial symptoms to the most impairment, b) A long period of time elapsed during which the most impairment was being experienced, c) Increased levels of protein in the cerebrospinal fluid, and d) A secondary infection. Individuals that experienced any of the above-mentioned factors were more likely to have a poor prognosis. Similar to other studies, Chen et al. found that long waiting times before getting treatment were associated with poor prognosis. Some of their results are, however, in contrast to other studies. Therefore, the researchers caution that, because their study looked at medical records from the past, had a small sample size, and short observation time, the prognostic indicators they found may not be completely accurate.

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: Chen L, Li J, Guo Z, Liao S, Jiang L. Prognostic Indicators of Acute Transverse Myelitis in 39 Children. Pediatr Neurol. 2013;49:397-400.



UPDATE ON THE DIAGNOSIS AND TREATMENT OF NEUROMYELITIS OPTICA: RECOMMENDATIONS OF THE NEUROMYELITIS OPTICA STUDY GROUP (NEMOS)

Trebst et al. published an article in 2014 about the Neuromyelitis Optica Study Group's recommendation for diagnosing and treating neuromyelitis optica (NMO). NMO is characterized by optic neuritis (ON) and transverse myelitis (TM), typically with lesions extending over three or more vertebral segments. The prevalence of NMO is from less than 1 to 4.4 per 100,000 people, with more women than men having the disease. Most cases of NMO (80-90%) are relapsing, and the median age of onset is 39. A diagnosis of NMO is typically made when an individual has had at least one episode of ON, one episode of TM, and two of three of these criteria:

"(1) Contiguous spinal cord MRI lesion extending over three or more vertebral segments
(2) Brain MRI not meeting Paty's diagnostic criteria for MS at disease onset (Four or more white matter lesions, or more than three white matter lesions if one of these is located in the periventricular region)
(3) NMO-IgG seropositive status."

A patient with NMO may not always fit into these criteria, so Trebst et al. state that these criteria should be used to make NMO diagnoses but not exclude diagnoses of NMO. Trebst et al. also recommend a detailed medical history, including symptoms that are more likely to occur in NMO patients than MS patients, such as brainstem symptoms, neuropathic pain, and painful tonic spasms. They also recommend basic laboratory tests, and tests for the AQP4 antibody, as AQP4 is present in approximately 60-90% of patients who fit the diagnostic criteria for NMO. Even though AQP4 antibodies may still be detectable during treatment with immunosuppressants, Trebst et al. recommend adequately sensitive AQP4 antibody testing before patients are treated with immunosuppressants. They also recommend testing cerebrospinal fluid for oligoclonal bands (OCBs). Those with NMO may initially test positive for OCBs but then later test negative, and this is not usually the case for those with MS. Other biomarkers, such as IL-6 (https://myelitis.org/resources/tma-blog/research-studies/cerebrospinal-fluid-interleukin-6-central-nervous-system-inflammatory-diseases) may also be biomarkers for NMO. Magnetic resonance imaging (MRI) with and without contrast of the brain and the entire spinal cord is also recommended. MRI in those with NMO often show lesions extending more than three segments, and may show brain lesions in up to 60% of NMO cases.

Since there is currently no cure for NMO, treatment aims to improve symptoms and prevent relapse. During an acute attack, the authors recommend treatment with steroids, and potentially plasma exchange. After an acute attack and after a definitive diagnosis of NMO has been made, Trebst et al. recommend that immunosuppressants should be started. These include Azathioprine (first-line therapy), Rituximab (first-line therapy), high dose IVIg (can be first-line therapy), Mycophenolate mofetil (second-line therapy), methotrexate (second-line therapy), Mitoxantrone (second-line therapy), Tocilizumab (third-line therapy), combination therapy (third-line therapy), or Cyclophosphamide (if other treatment options no longer work). Trebst et al. do not recommend interferon-beta/glatiramer acetate, natalizumab or fingolimod as these have been shown to have negative effects on those with NMO.

The authors note that research in NMO has expanded greatly in recent years and will continue to grow, potentially leading to new discoveries and treatments.

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: Trebst C et al. Update on the diagnosis and treatment of neuromyelitis optica: Recommendations of the Neuromyelitis Optica Study Group (NEMOS). J Neurol. 2014;261:1-16.

2015 TMA FAMILY CAMP

TUESDAY, JULY 21 - SATURDAY, JULY 25

AT THE CENTER FOR COURAGEOUS KIDS (CCK) IN SCOTTSVILLE, KY

HOW TO APPLY?

Application is now open @

HTTP://WWW.THECENTERFORCOURAGEOUSKIDS.ORG/CAMPERAPP.HTML

STEP ONE: ONLINE APPLICATION

Please complete the form for Family Retreat @

HTTPS://INTERLAND3.DONORPERFECT.NET/WEBLINK/WEBLINK.ASPX?NAME=CCKIDS&ID=2

Select Transverse Myelitis Association Family Camp (July 21-25) in the drop down menu for Camp Session Requested. If you do not immediately receive an email, then your Step 1 has not been submitted. After you complete Step 1, continue to Step 2.

STEP TWO: PRINT APPLICATION

Download and print the Family Retreat application from

HTTP://WWW.THECENTERFORCOURAGEOUSKIDS.ORG/PDFS/FAMILYRETREATAPPLICATION0914.PDF

Please complete the form, have the doctor sign it and return to CCK by mail or fax at the address below:

THE CENTER FOR COURAGEOUS KIDS
ATTN: CAMPER ADMISSIONS
1501 BURNLEY ROAD
SCOTTSVILLE, KY 42164

FAX: (270) 618-2902

FOR MORE INFORMATION, PLEASE VISIT

HTTPS://MYELITIS.ORG/EDUCATION/CAMP/APPLY-2015-TMA-FAMILY-CAMP-CCK

AN UPDATE ON THE CAPTURE STUDY

In May 2014, we launched the first funded study in pediatric transverse myelitis. The potentially groundbreaking study entitled CAPTURE is led by Dr. Benjamin Greenberg of the University of Texas Southwestern in Dallas in conjunction with The Transverse Myelitis Association and four other pediatric centers, and funded by The Patient Centered Outcomes Research Institute, PCORI.

SUMMARY OF CHILDREN ENROLLED IN THIS STUDY AS OF JANUARY 2015

UT SOUTHWESTERN MEDICAL CENTER	3 CHILDREN ENROLLED	SickKids	1 CHILD ENROLLED
JOHNS HOPKINS	IRB APPROVED	International Center for Spinal Cord Injury at Kennedy Krieger Institute Research, Restoration, Recovery	2 CHILDREN ENROLLED
CHOP The Children's Hospital of Philadelphia®	7 CHILDREN ENROLLED		8 CHILDREN ENROLLED (VIRTUAL PARTICIPATION)

Since we began enrollment, four participating centers and the virtual cohort have been IRB approved and are actively enrolling. On the next page you can find a quick summary of children enrolled in this study as of January 2015.

We are tremendously thankful to the families that have signed up thus far to participate.

OUR TARGET RECRUITMENT GOAL IS 6 PATIENTS PER YEAR PER SITE AND 60 PATIENTS PER YEAR FOR THE VIRTUAL COHORT (OR 5/MONTH FOR TWO YEARS). WE HAVE QUITE A BIT MORE WORK TO DO IN ORDER TO ACHIEVE THE REQUIRED GOALS.

Our biggest challenge to enrollment into the virtual cohort is the time frame for eligibility. To study the effects of the different acute treatments on the outcomes, it is imperative to enroll children with a diagnosis of transverse myelitis or acute flaccid myelitis within three months of onset of symptoms or diagnosis. This time frame is critical to study the biology of the inflammatory attack and the effect of the therapies – IV steroids, plasma exchange or IVIG.

We need your help in spreading the word about The Transverse Myelitis Association and this critically important study. **We need to reach every small town physician, every local and regional hospital, we need to be in every nook and cranny of North America** so that when a child is diagnosed with Transverse Myelitis or Acute Flaccid Myelitis, they know immediately to contact the TMA and know of the opportunity to participate in CAPTURE and help advance our understanding of these rare diseases.

Share the news on your social media pages, reach out to support fellow TM/AFM patients and caregivers, provide handouts to your physician, your therapists, your hospital. If you would like materials to hand to your doctors, please email me at rwhitney@myelitis.org. There are ways that you can make a difference. Chances are you will hear of a new diagnosis in your area before they would find the TMA via Google search.

Many parents have contacted us willing to participate. Thank you! Unfortunately due to the eligibility criteria for the study, we are not able to enroll children who were diagnosed more than 3 months from when they contact us or who are outside North America. Families who are past the 3, 6, or 12-month mark understand how devastating the diagnosis is and in their conversations with clinicians and in their search for hope, they have found that very little information concerning treatment, recovery, and research exists. And families outside of North America are looking for opportunities in which to participate but at this time, the study is structured to only include those in the U.S. and Canada for logistical reasons. If we are successful with this study, we will have the opportunity to expand research globally and we are working hard to make that happen.

As a mom of a young son diagnosed with transverse myelitis, I remember the first three months were an insanely raw and sensitive time for me. I don't have to reach deep to sense the emotions, often indescribable, that I had when my son was diagnosed – it (still) constantly bubbles at the surface and if you have spoken with me on the phone and I have told you I know how you feel – I know how you feel. I live and breathe the complications of this diagnosis with my young son every single day. I know how I may have reacted when asked to participate in a study during those acute days. I likely would have been indifferent, still in shock, not fully comprehending what was ahead, just worrying about if I was going to be able to take my baby home. Please, if you are reading this and your child is newly diagnosed, learn from my hindsight and do not meet the opportunity with indifference. I promise that you won't regret the small amount of time it takes to participate in this study.

The TMA receives countless inquiries about where we are with research on TM and the demyelinating disorders. This is where we are at – merely the beginning – we are standing on the springboard for further funding and in-depth studies. A sturdy structure can't be built without a firm foundation. CAPTURE is the foundation of data and longitudinal study necessary that will allow us to continue to build the bricks of research by proving these rare disorders do matter and are worth funding so that future, broader studies can ultimately provide all individuals affected with answers. Please spread the word and help us make CAPTURE a success.

> **"We need your help in spreading the word about The Transverse Myelitis Association and this critically important study."**

REBECCA WHITNEY, TMA PROGRAM MANAGER & CAREGIVER AND MOM OF A YOUNG CHILD WITH TRANSVERSE MYELITIS.

UCF MEN'S LACROSSE
WALK-RUN-N-ROLL

It was December 27, 2006 when what was a "perfect" life turned into a nightmare. Sarah woke up with excruciating lower back pain, which then led her to collapsing on the floor, resulting in her brother carrying her into the doctor's office. As a 14 year old and partially paralyzed from the waist down, Sarah thought her life had come to an end. With the love and support of her nine siblings and two faithful parents, she remained positive as she was bed-ridden for three weeks. When the moment came to be released from the hospital, a tear fell from her Doctor's eyes when she was able to stand up for him right before his eyes. The doctor was in disbelief seeing the dire situation she was in and now she was the first of all his patients with transverse myelitis to regain the ability to walk.

At that moment she knew it was a miracle for her to have the blessing to live a normal life after having Transverse Myelitis. With inpatient rehab and six months of outpatient rehab, Sarah is now walking and puts her remaining disabilities aside as she lives life as a normal 21 year old.

Sarah is partnering up with the University of Central Florida Men's Lacrosse team to help raise money and awareness for transverse myelitis! The goal of the "UCF Knights Lacrosse Leads the Charge for Transverse Myelitis Awareness" is to increase awareness and raise funds for research and programs for individuals suffering from Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON), Transverse Myelitis (TM) and Recurrent Transverse Myelitis, and their caregivers.

Our target financial goal is to raise $10,000. We need YOUR help! **PLEASE JOIN US ON APRIL 18, 2015 ON THE UCF MEMORY MALL ON CAMPUS FOR THE WALK-RUN-N-ROLL.** Afterwards, we invite you to stay as UCF takes on Rollins College; face-off begins at 7:00 PM. We look forward to a great turnout to support The Transverse Myelitis Association.

VIEW EVENT DETAILS HERE

HTTPS://WWW.CROWDRISE.COM/UCF-LACROSSE-LEADS-THE-CHARGE

FOR MORE INFORMATION CONTACT

ANTONIO LIGUORI
Phone: 561-414-4849
Email: Antonio@AntonioLiguori.com

2014 TEXAS WALK RUN-N-ROLL

A time of "firsts" always seems to bring excitement in our lives. As a mom, I remember how exciting it was to see my sons' first smiles and steps; hear their first giggles and words. In 2014, local patients and caregivers began meeting monthly, which informally began our support group, to learn from each other and from some amazing speakers. On October 4, 2014, our DFW TM/NMO Support Group hosted the first TM/NMO Walk-Run-N-Roll held in Texas for the benefit of the Transverse Myelitis Association. Despite a few challenges as we planned the event, excitement abounded on the day of our Walk-Run-N-Roll. Our event was held at a beautiful, completely accessible park designed for children. We raised money (approx. $23,000) for this worthy cause and many new relationships and friendships were formed. There is no price tag to be placed on the feelings that come from meeting someone else fighting the same disease that you do on a daily basis. To see the comfort of people meeting someone else that truly understands your struggle and to know that you are not alone with this disease is priceless. Bonds of new friendships are forming as well as an army of advocates rising up to benefit the others that will unfortunately follow in our footsteps until a cure is found.

> **"To see the comfort of people meeting someone else that truly understands your struggle and to know that you are not alone with this disease is priceless."**

I hope you enjoy the video of our event - 2014 TX Walk-Run-N-Roll (http://youtu.be/kkr6zlpHHjM). My special thanks to my amazing co-chair, Chris Hill, for the endless tasks he took on, including this great memento of the event, and lending so many hours, support, and determination to see this event come to fruition. Many thanks to all the folks that came out to help on the day of the event - patients, family members, friends, and most of all, our amazing extended family of support from Dr. Ben Greenberg and his staff at UTSW. How encouraging it was to have Dr. Greenberg stand in front of what is called "Miracle Field" at the park and listen to him share news of progress in the areas of better treatments, understanding of these disorders, and hope for our future. I think we all felt like we had experienced a miracle that day!

I hope you are able to go to a support group meeting this year to bond with others, learn, and help educate others about our diseases, and treatments. Exciting things are in store, thanks to the TMA and the magnificent work they do.

If you don't have a support group near you and would like to see one come to your area, please communicate that with the TMA, and please consider starting one. We hope to see more groups coming together for our common cause.

Wishing you all a Happy & Healthy New Year!

BARBARA NICHOLS, TEXAS SUPPORT GROUP LEADER

clinical studies & trials

SAFETY AND EFFICACY OF SUSTAINED RELEASE DALFAMPRIDINE IN TRANSVERSE MYELITIS

STUDY DETAILS

The goal of this clinical trial is to test the efficacy of dalfampridine in patients diagnosed with transverse myelitis. Dalfampridine is a sustained-release potassium channel blocker that has been shown to be effective in improving gait and other neurologic functions in multiple sclerosis. Dalfampridine has the potential to improve gait and neurologic function in patients with transverse myelitis because of a similar pathogenic process with multiple sclerosis.

The clinical trial will focus on monophasic Transverse Myelitis (TM) and will evaluate the efficacy of dalfampridine in primary neurologic outcome – 25-foot timed walk, and several secondary outcomes including valid behavioral and neurophysiological measures. To better understand the mechanisms underlying the proposed behavioral gains, the investigators will use Transcranial Magnetic Stimulation as the neurophysiologic measure to identify changes in corticomotor excitability in the spinal cord.

INVESTIGATOR
Michael Levy, MD, PhD

STUDY SITE
Johns Hopkins University
Baltimore, MD

CONTACT INFO
Maureen Mealy
RNhopkinstmcenter@jhmi.edu

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.

ELIGIBLE 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 seizures | 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 may be 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 in 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.

EFFICACY & SAFETY STUDY OF SA237 AS MONOTHERAPY TO TREAT NMO AND NMOSD | SPONSORED BY CHUGAI PHARMACEUTICALS

STUDY DETAILS

This research is being conducted to evaluate the efficacy, safety, pharmacodynamic, pharmacokinetic and immunogenic profiles of a humanized anti-human IL-6R neutralizing monoclonal antibody (SA237) in patients with Neuromyelitis Optica (NMO) and Neuromyelitis Optica Spectrum Disorder (NMOSD). This study is being conducted in the US and Canada and will enroll seventy (70) patients to participate in this research.

Mechanism of Action: SA237 is a humanized anti-human IL-6R neutralizing monoclonal antibody that was designed by applying recycling antibody technology to the approved anti-IL6 receptor antibody, tocilizumab, which is currently marketed as a treatment for rheumatoid arthritis (RA), systemic juvenile idiopathic arthritis, polyarticular juvenile idiopathic arthritis and Castleman's disease. The recycling antibody technology enabled SA237 to bind to IL-6 receptor multiple times and be slowly cleared from plasma, which is expected to contribute to improvement and is convenient with once monthly dosing frequency. The longer plasma half-life of SA237 compared with tocilizumab was confirmed based on the results of a non-clinical study and a Phase 1 study in healthy volunteers.

CONTACT INFORMATION

If you are interested in participating, please contact:

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

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

ELIGIBLE PARTICIPANTS

INCLUSION CRITERIA

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

EXCLUSION CRITERIA

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

THANK YOU FOR FUNDING A STUDY

UTILIZING BRAIN IMAGING TO UNDERSTAND COGNITIVE DYSFUNCTION IN TRANSVERSE MYELITIS

> "We were overwhelmed with gratitude by the response to the crowdfunding efforts, which make it possible to continue to advance our understanding of transverse myelitis. We are so grateful for the support of our community and those who support our efforts to find answers and to better serve our patients and families."

We embarked on a novel approach to fund research when we partnered with Consano, a non-profit crowdfunding platform for medical research. Thank you to our members, The Roles Family Foundation, as well as a matching donation from The Madison Charitable Foundation who supported this study. Dr. Lana Harder's study is fully funded!

The goal of this study is to understand cognitive dysfunction utilizing brain imaging. This type of imaging is not currently performed during routine clinical visits. Previous research has shown cognitive problems in memory and attention in individuals diagnosed with transverse myelitis, a disease of the spinal cord. This study has the potential to change our understanding of the biology involved in TM and help us understand the impact on the brain from an immune mediated attack of the spinal cord.

"Amazing organizations like the TMA are giving patients a voice in setting the research agenda. As our first patient-driven crowdfunding project on the Consano platform, it was amazing to see the TM community rally their support and fully fund the project. I hope there are many more opportunities to collaborate!" - Molly Lindquist, Founder and CEO of Consano.

"We were overwhelmed with gratitude by the response to the crowdfunding efforts, which make it possible to continue to advance our understanding of transverse myelitis. We are so grateful for the support of our community and those who support our efforts to find answers and to better serve our patients and families. With this funding, we are eager to execute our study and share what we learn!" - Dr. Lana Harder, University of Texas Southwestern.

DR. PETER JOHNSON

JOINS THE TMA BOARD OF DIRECTORS

We are thrilled and excited to announce that Dr. Peter Johnson has accepted our invitation to join the Board of the TMA. Last Spring, Dr. Johnson joined us in Baltimore to lead a strategic priorities meeting where we discussed our strengths, our weaknesses, where we want to be in 5 years and how to get there.

Peter C. Johnson, MD is a University of Notre Dame and SUNY Upstate Medical University graduate. After General and Plastic Surgery training, Dr. Johnson practiced reconstructive surgery for ten years at the University of Pittsburgh where he founded and was the first President of the Pittsburgh Tissue Engineering Initiative. Subsequent roles were co-founder/CEO of Tissue Informatics, Executive Vice President of Life Sciences, CMO and CBO of Icoria, and EVP of Entegrion, Inc. He presently serves as the Vice President of Research and Development and Medical and Scientific Affairs of Vancive Medical Technologies, an Avery Dennison business. He Chaired the Plastic Surgery Research Council, was President of the Pennsylvania Biotechnology Association and the Tissue Engineering Society, International and is presently the Co-Editor-in-Chief of the three-part Journal, Tissue Engineering. He serves on the Industry Committee of Tissue Engineering and Regenerative Medicine International Society (TERMIS) and on the board of The Transverse Myelitis Association. He is an Adjunct Professor of Surgery, Bioengineering and Business at the University of North Carolina at Chapel Hill, of Bioengineering at NC State and of Regenerative Medicine at Wake Forest University School of Medicine. He is an avid cook, fly fisherman, artist and novelist.

> "I am looking forward to contributing to the activities of the organization as we pursue prevention and cure of this affliction"

"It is a pleasure to join the Board of The Transverse Myelitis Association. I am looking forward to contributing to the activities of the organization as we pursue prevention and cure of this affliction," shared Dr. Johnson.

On behalf of the community, we thank you for joining us in our efforts.

THE LATEST TMA
ASK THE EXPERT PODCASTS

JANUARY 2015 UNDERSTANDING VACCINATIONS AND AUTOIMMUNE DISEASES

dr. benjamin greenberg, university of texas southwestern, dallas, tx
dr. teri schreiner, university of colorado school of medicine and children's hospital colorado

DECEMBER 2014 UNDERSTANDING TRANSVERSE MYELITIS: TM 101 (SPONSORED IN PART BY KRONUS)

dr. allen desena, cincinnati children's hospital medical center, oh
dr. carlos a. pardo-villamizar, johns hopkins medicine, baltimore, md

NOVEMBER 2014 HOW TO COPE WHEN A LOVED ONE IS DIAGNOSED WITH NMO, ADEM OR TM

audrey ayres, rn, bsn, university of texas southwestern, dallas, tx
katherine treadaway lcsw, mscir, university of texas southwestern, dallas, tx
sanford siegel, phd, president of the transverse myelitis association

OCTOBER 2014 UPDATE ON OUTBREAK OF PARALYSIS IN US: ACUTE FLACCID MYELITIS

dr. benjamin greenberg, university of texas southwestern, dallas, tx
dr. teri schreiner, university of colorado school of medicine and children's hospital colorado

OCTOBER 2014 THE ROLE OF PHARMA COMPANIES IN DRUG DEVELOPMENT FOR RARE NEURO-IMMUNE DISEASES

dr. benjamin greenberg, university of texas southwestern, dallas, tx
dr. douglas kerr, biogen idec, boston, ma

SEPTEMBER 2014 ALTERNATIVE THERAPIES AND LIFESTYLE MANAGEMENT AFTER TM, NMO AND ADEM

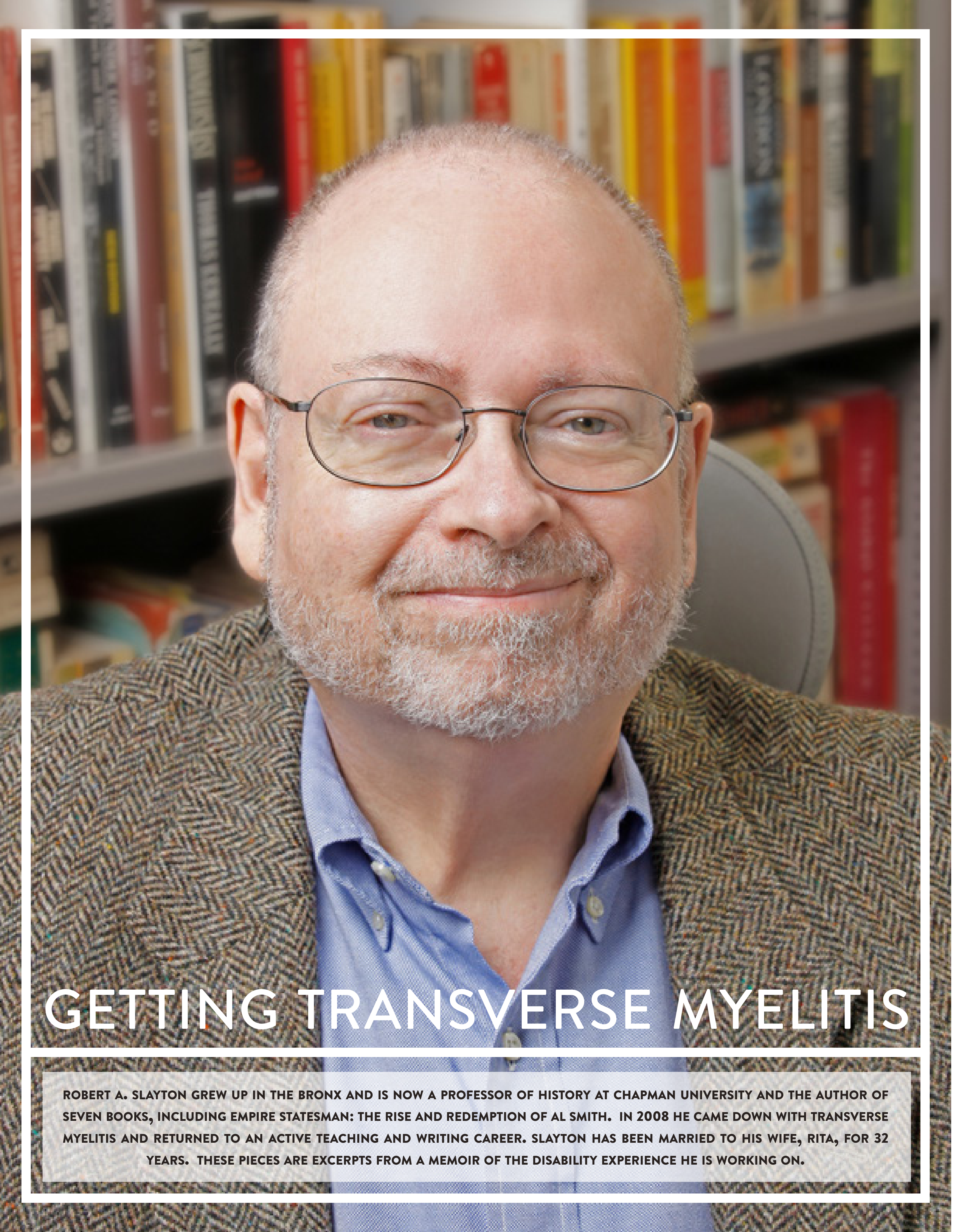
paula hardeman, mpas, pa-c, university of texas southwestern, dallas, tx
dr. scott newsome, johns hopkins transverse myelitis center, baltimore, md
katherine treadaway lcsw, mscir, university of texas southwestern, dallas, tx

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

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

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

HTTP://MYELITIS.ORG/EDUCATION/PODCASTS



GETTING TRANSVERSE MYELITIS

ROBERT A. SLAYTON GREW UP IN THE BRONX AND IS NOW A PROFESSOR OF HISTORY AT CHAPMAN UNIVERSITY AND THE AUTHOR OF SEVEN BOOKS, INCLUDING EMPIRE STATESMAN: THE RISE AND REDEMPTION OF AL SMITH. IN 2008 HE CAME DOWN WITH TRANSVERSE MYELITIS AND RETURNED TO AN ACTIVE TEACHING AND WRITING CAREER. SLAYTON HAS BEEN MARRIED TO HIS WIFE, RITA, FOR 32 YEARS. THESE PIECES ARE EXCERPTS FROM A MEMOIR OF THE DISABILITY EXPERIENCE HE IS WORKING ON.

BECOMING DISABLED WAS EASY. FOR SOME PEOPLE IT IS SLOW AND PAINFUL; FOR ME IT WAS FAST, SOFT, AND TOTAL.

On August 18, 2008 I was going up to school to do some work. I threw my bag in the back of the car and drove up to campus. But when I got there a funny thing happened. And not ha-ha funny either. When I went to the back of the car to get my bag, I found I could barely stand. As I walked to my office, it was like I was drunk. I couldn't put one foot after the other in a straight line. This was early in the day and I was cold sober, so something was very wrong.

I work hard, and I don't like distractions from my day's agenda, but I recognized that this was something I needed to look into-after I had finished. So I filed some papers and Xeroxed for twenty minutes, standing up, and holding the machine to steady myself. Then I drove home by myself. This was what sane people refer to as “sheer madness”.

I called the help line for my health care provider. They told me to get to the hospital right away. And not to drive, either. I got a cab and was on my way, to the emergency ward, and to a new life, although I didn't know that last part yet. August 18 is now my anniversary date; as anyone who has undergone a life-changing incident can tell you, for the rest of your days you are always aware of the date your life changed. And the celebrations aren't joyous, either.

Once I got to the hospital, they checked me in right away. Given my past history, they figured I had had another stroke, a much worse one this time.

They weren't the only ones. My wife Rita's first reaction was anger and fear. She later explained, “I was furious at you when we thought it was a stroke.” How strong were her emotions? Rita put it best when I asked her almost three years later: “Let me tell you, if it was a stroke, we wouldn't be sitting here today.” Her emotion was blunt, “I felt that you did it to yourself,” because of my bad habits.

But Rita loves me; twenty six years of marriage does that to you. After I called her at work, she “went flying down the stairs,” then briskly informed her boss, “'Bob called. He had another stroke. See you.'” Her strongest memory of that day concerned her drive to the hospital from work. That long journey—she only drives surface streets—normally takes fifty-five minutes. That afternoon she did it in thirty-five, with luck and the grace of God keeping her out of an accident, and the cops from spotting her.

Meanwhile, however, although she didn't show any of this to me, her mood remained angry. She figured this was payback for my mounting health problems, that I had done this to myself. She loved me too much to complain out loud when I had just gone into the hospital for a bad stroke, but she was really mad. I didn't hear a hint of any of this.

Three days later reality finally struck. The nurse had just written on my bulletin board that I should contact them at the first onset of paralysis. Good timing. Right after she left, I remember holding up my hand, looking at it as it stiffened, thinking, “that's interesting”… Immediately, I rang for the nurse.

Worse, much worse, was yet to come. The next day I lost control of my bowels. That destroyed me. Here I was, nearing sixty, a named professor at the university with multiple books from top presses, at the peak of my life and career. And now, I couldn't keep from soiling my bed. That was something infants did, not people at my age and station.

By then they were taking blood tests galore, and even more important, plenty of MRI's. I was wheeled out to the first one at 3am on the night that paralysis struck. The stiffness had grown, as well, and now my entire left side was paralyzed.

Some days later, with a lot more tests and scans, while the doctors beat their brains out trying to figure what was wrong with me, the verdict was in. I had transverse myelitis.

I had no idea of what this was, but one shouldn't feel bad. Neither does anyone else in this world, even if you're a neurologist. It is that rare. I always figured I was a pretty unique kind of guy; now I was proving it with a vengeance, and not in a way I had ever intended or desired.

The night I found out about TM, alone and in the dark, I sobbed. It would not be the last time.

This is the first post of the series “Bronx Accent” written by Bob Slayton

Robert A. Slayton grew up in the Bronx and is now a professor of history at Chapman University and the author of seven books, including Empire Statesman: The Rise and Redemption of Al Smith. In 2008 he came down with transverse myelitis and returned to an active teaching and writing career. Slayton has been married to his wife, Rita, for 32 years. These pieces are excerpts from a memoir of the disability experience he is working on.

BOB SLAYTON

2014 ANNUAL CENTRAL FLORIDA AUCTION AND WALK-RUN-N-ROLL

A Huge Success!

Thank you to the Robbins Family for a spectacular 2-day event to help raise awareness and funds to support the mission of The TMA. Please visit http://myelitis.org/get-involved/walk-run-n-roll-campaign/2014-florida-walk-run-n-roll-campaign *to view videos and photos.*

WITH MUCH GRATITUDE...

Pauline and I thoroughly enjoyed the Florida dinner and auction that took place on Friday evening, December 12th and the Florida walk on Saturday morning, December 13th. There was a wonderful representation by the TMA board, and it was great that Dr. Benjamin Greenberg was able to attend the dinner and speak to the audience about these rare neuro-immune disorders. The extended Robbins family did an awesome job of organizing the events. The dinner that was prepared by celebrity chef Beau MacMillan was just spectacular. The weather for the walk was great; and it was appreciated even more so coming from central Ohio in the middle of December.

It was great to meet Sarah's wonderful family and support network. Sarah is a special child with a beautiful smile and hugs for all those around her, and she has the love of a truly special family. Pauline and I really enjoyed meeting and spending time with people who attended both the dinner and the walk from our community. We so appreciate the effort the Robbins family put into raising awareness and resources for our organization. The people who attended had a great time, and supported a tremendous cause.

SANDY SIEGEL, PRESIDENT

I was lucky enough to be able to attend the 2nd Annual Central Florida Walk for TM in Honor of Sarah Robbins. The walk was only one small part of an event that started on Friday night with a dinner and auction.

From the moment I got off the plane in Orlando, this event was magical. Jason and Tina Robbins, helped by their families and friends, planned everything meticulously. The result was a fun event that raised over $50,000 in donations and gained supporters for the TMA.

After a quick change of clothes, I registered for the dinner and was welcomed by warm, delightful people who answered questions and handed me a beautiful corsage. (There are some kudos when you have a neurological disease.) The ballroom was tastefully decorated. My favorite touch was every table had delicious cookies in the shape of the TMA logo. I should know, as I ate more than my share.

I was expecting a special dinner but our celebrity chef knocked my socks off. I'm not great at describing gourmet

food but each course was better than the previous. We began with mushroom/ truffle soup. The main course was surf and turf but this wasn't your average piece of steak and fish. Both the filet and grouper were perfectly prepared and sauced and delicious. My favorite was the dessert. I have no words to describe except to say it was sweet, creamy and looked and tasted great. Even better than the food were my table companions: Sandy and Pauline Siegel, Dr. Ben Greenberg, and Anjali Forber-Pratt all of whom are awesome.

One of the most exciting moments of the night was the beginning of the live auction. In the door waltzed the most adorable Chihuahua followed by three kittens from the Florida humane society. These adorable animals were followed by the live auction of trip packages and sports memorabilia that Jason had put together. Both before, during and after the dinner there was also a silent auction of books, sports items, food, wine and a variety of other terrific items.

Saturday morning was the walk. I was honored to push Pauline Siegel's wheelchair and walk next to new and old TM friends on a beautiful, sunny morning. Of course, Jason and crew made sure that all the walkers got food, drinks and t-shirts. The star of the walk was Sarah Robbins, the 13 year old daughter of Jason and Tina, a beautiful girl who gives the most heartfelt hugs I've ever experienced in my life.

Special thanks go to: Angel who chauffeured me around, entertained me and is a terrific TMA supporter and I hope will continue to be a friend.

To Dr. Ben Greenberg for everything he does and for leading the bidding.

As always to Pauline and Sandy for their wonderful leadership, spirit and company particularly on Saturday afternoon as we walked on the beach.

To the Robbins family who have such busy personal and professional lives and yet took the time to plan and carry out this flawless event. No one who was there can doubt how much time and effort it took to pull off this dinner, auction and walk. Congratulations. You are the best.

And to Sarah, the inspiration for all of this.

BARBARA SATTLER, TMA BOARD MEMBER

I had the great pleasure of attending the second annual FL TMA Walk and Auction to honor Sarah Robbins organized by her outstanding family, including fellow Board member, Jason Robbins. The event was a tremendous success, in my opinion. We had the opportunity to interact and meet with many NFL celebrities as well as celebrity Chef Beau MacMillan. We bonded over our Boston pride, as I grew up in Massachusetts just outside of Boston, MA. The food was fantastic!

To me, one of the highlights of the evening was being able to educate attendees about transverse myelitis and to feel genuine love and support from everybody in the room. While there are some definite challenges and frustrations living with transverse myelitis, it is through awareness events such as these that we are able to come together and find allies in others to begin to better understand this disability and inform research and medical advances. Thank you so much to the Robbins family for their unwavering dedication to the TMA.

ANJALI FORBER-PRATT, TMA BOARD MEMBER

> "it is through awareness events such as these that we are able to come together and find allies in others to begin to better understand this disability and inform research and medical advances."

SMART PATIENTS & THE TMA

“I'm just so confused on what is going on. I have read the articles explaining what it is but what the heck am I suppose to do with this? I guess I'm looking for any and all advice, direction and any information that I should know or ask the Dr. Thank you and I'm so happy I have come across this group.”

“Sometimes I feel like I just don't know what questions I should be asking. Hearing what others ask can help me prepare for my next doctor's appointment.”

“I spent 20 years in healthcare, so I can't imagine what going through this without any background is like. Just saying hi, checking in, and thankful there is a forum for those of us with rare disorders to share our experiences.”

“We all struggle to understand and accept what has happened to our health! Be gentle with yourself and I hope you find something that helps.”

“Transverse Myelitis is an awful disease, but I have met so many wonderful people and it's made me realize that life is short and I have to do my best to enjoy it.”

JOIN US VIA THIS LINK: HTTPS://WWW.SMARTPATIENTS.COM/COMMUNITIES/TRANSVERSE-MYELITIS

Last summer, the TMA launched a partnership with Smart Patients, an online community designed specifically for patients and caregivers to gather, share their experiences and their stories and to learn from one another. It has replaced our previous online forum space for communication amongst members and has become a go-to site for many to connect with others encountering a new diagnosis or simply looking to share their experience of life with one of the demyelinating disorders. The site offers the ability to participate in focused, moderated conversation allowing the ability to cross disease boundaries. We know we share so many symptoms, treatments, resources and other similarities with other disease groups; it only makes sense to learn from each other across these boundaries. We are grateful to Smart Patients for this opportunity. If you haven't joined already, we encourage you to do so by going to https://www.smartpatients.com/partners/transverse-myelitis-association!

The Smart Patients team is passionate and committed to the patient and caregiver community. They acknowledge that we, the patients and caregivers, are experts in our own right and through this forum offer resources, which include stories, support, easier access to clinical trial details and more, allowing us to be truly participatory in our health care and the best advocates. It's an exciting and innovative approach to online communication amongst patient and caregivers and The TMA is privileged to be one of the early groups to partner with this highly motivated team.

To date, Smart Patients has welcomed 226 new members through the Transverse Myelitis Association, 49 of them within the last 30 days. We've also started 17 new conversations with 176 different posts this past month. Key words from some of these conversations include “Rituxan”, “walker”, “gait”, “flaccid”, “paralyzed”, “rehab”, “plex”, “spasticity”, “Amitriptyline”, and the list goes on.

We hope you'll take a few moments to join the TMA's Smart Patients forum. As a patient or caregiver, whether you are new to the diagnosis or have been living with TM, ADEM, AFM, ON, or NMO for years now, you are welcome and your experience, your story, your questions, are invaluable here.

If you have any questions about the forums, please feel free to call or send an email – info@myelitis.org. We look forward to seeing you on Smart Patients!

REBECCA WHITNEY, TMA PROGRAM MANAGER & CAREGIVER AND MOM OF A YOUNG CHILD WITH TRANSVERSE MYELITIS

“... your experience, your story, your questions, are invaluable here.”

July 1994 was an extraordinarily difficult and lonely time for our President, **Sandy Siegel** and his wife, Pauline, when Pauline was diagnosed with Transverse Myelitis. There were no specialists, no research, no customized rehabilitation programs and almost no understanding of a disease that was first described in 1882 by HC Bastian. Dr. HC Bastian was largely responsible for establishing transverse myelitis and separating it from non-inflammatory transverse myelopathies*.

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*For more about Dr. Bastian - http://timbates.wdfiles.com/local--files/language/Pearce2009_onBastian.pdf

HERE IS HOW **YOU** CAN DO IT

1 START A TEAM ON CROWDRISE WWW.CROWDRISE.COM/THE-TMA-20-FOR-20-CAMPAIGN AND SHARE YOUR STORY

2 DONATE $20

3 SEND AN EMAIL TO 20 FRIENDS AND FAMILY MEMBERS AND REQUEST THEM TO DONATE $20!

EACH OF US **GIVES $20** AND ASKS **20 FRIENDS & FAMILY TO GIVE $20**

Sandy took on a challenge and helped establish the TMA as we know it today, so no one would feel like he and Pauline did, so people would have research to reference, doctors to reach out to, places to network and a quality of life that matters!

To honor Sandy, Debbie, Jim and others who selflessly continue to give their time, commitment, passion and energy to help others and show your support, please join TMA's 20 for 20 Anniversary Challenge. The Challenge will remain open until July 2015!

Joining the challenge is easy, and takes only 3 steps!

Your friends and family can also start a team to support your cause and spread the word to their friends and family and join the challenge. Please spread the word.

Our goal is to have 1000 people join the challenge where each person raises $420. So far, we have raised over $85,000; funds that will be used to support camp, education, research and awareness efforts that are a mission of the TMA. Our goal is to help every individual, either newly diagnosed or diagnosed months or years ago, with knowledge and resources to improve outcomes after an attack of transverse myelitis, neuromyelitis optica, acute flaccid myelitis and acute disseminated encephalomyelitis. We need your help to achieve our goal!

Several members have started unique fundraisers to help support our cause. On the nex page you can find one example from our member Lynn Nelson who joined the 20 for 20 Challenge and now is spreading the word through her Bravelets Campaign. Thank you Lynn and thank you to all our members who have supported our goals!

FROM LYNN NELSON
IN HER OWN WORDS

I have done fundraising for two other charities and have found that over time, people get tired of being asked to donate to a cause. My initial fundraising efforts involved writing a letter discussing what the cause meant to me personally, why the organization was an important one to support, and asking for a donation. When the disease is one that resonates with people (e.g., breast cancer or leukemia/lymphoma), they are more likely to donate. But when the disease is one that they don't understand or have a personal connection to, I have found that it is harder to get donations.

I decided to set up the Bravelets fundraising page https://www.bravelets.com/bravepage/the-tma-20-for-20-anniversary-challenge because it is not just a plea for a donation; they are getting something too. By buying a bracelet, TMA will get $10 of every purchase. The bracelet has a phrase that can appeal to many people "Be Brave". We all have times when we need to be brave. A Bravelet would make a wonderful gift to someone who is struggling and needs encouragement. When I wear my bracelet, I remember how frightened I was when I first displayed symptoms. I had to be brave to face the MRI machine for hours on end. And my bracelet is an attractive piece of jewelry that I love to wear.

PLEASE JOIN THE 20 FOR 20 CHALLENGE WITH YOUR OWN FUNDRAISING IDEAS. HERE ARE A FEW:

1
GARAGE SALES

generate funds from unwanted items in your basement/attic or from donated items

2
BAKE SALES

set up outside a grocery store on a busy weekend, and don't forget to include gluten free items too!

3
POKER NIGHTS AND POKER RIDES

4
RAFFLES AND AUCTIONS

5
GOLF TOURNAMENTS

6
DON'T FORGET ABOUT YOUR COMPANY MATCHING PROGRAMS FOR THE DONATIONS YOU MAKE!

7
WORKING WITH A LOCAL RESTAURANT

another successful fundraising idea is working with a local restaurant or bar to get a portion of the proceeds from one night's sales in exchange for promoting the restaurant and getting people to come in. restaurants appreciate the help in getting more people in on nights when they otherwise would not have much business, such as tuesdays or wednesdays.

TOP TEN THE TRANSVERSE MYELITIS ASSOCIATION ACHIEVEMENTS IN 2014

... where your dollars and participation made it possible to fulfill our mission to support and advocate for individuals and their families diagnosed with rare neuro-immune disorders by promoting awareness through education; fostering clinician scientists dedicated to these rare diseases and supporting basic science and clinical research.

1 JAMES T. LUBIN FELLOWSHIP

DR. ALLEN DESENA, THE FIRST TMA FUNDED FELLOW, JOINS THE FACULTY AT CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER IN OHIO TO LAUNCH A RARE NEURO-IMMUNE DISEASES PROGRAM

2 TMA ANNUAL FAMILY CAMP

36 FAMILIES FROM THE US, NORWAY, CHINA, AUSTRALIA JOINED A DISTINGUISHED PANEL OF MEDICAL EXPERTS FOR A LIFE CHANGING, UNIQUE EXPERIENCE

3 NEWS & EDUCATION UPDATES

BLOGS AND PUBLICATIONS ARE EDUCATION AND ADVOCACY TOOLS THAT HAVE A READERSHIP OF OVER 10,700 MEMBERS WORLDWIDE

4 CAPTURE RESEARCH STUDY

WE LAUNCHED THE FIRST MULTI-CENTER, PEDIATRIC TRANSVERSE MYELITIS OUTCOMES STUDY LED BY UNIVERSITY OF TEXAS SOUTHWESTERN IN DALLAS AND FUNDED BY PCORI

5 ASK THE EXPERT PODCAST

PROVIDES UNIQUE ACCESS TO PHYSICIAN EXPERTS WHO ANSWER QUESTIONS FROM THE COMMUNITY AND DISCUSS TIMELY ISSUES AND TOPICS

6 ONLINE HEALTH FORUM

LAUNCHED PARTNERSHIP WITH SMART PATIENTS, AN ONLINE HEALTH COMMUNITY PLATFORM TO CREATE MORE EFFECTIVE ACCESS TO RESOURCES FOR PEOPLE IN OUR COMMUNITY AND TO EXTEND THESE RESOURCES TO AN EVEN BROADER GROUP OF PATIENTS

7 CHIPPIN' IN AGAINST TM

THE FIRST TMA GOLF OUTING WAS HELD IN COLUMBUS, OHIO TO RAISE AWARENESS AND TO SUPPORT TMA'S RESEARCH MISSION

8 TMA WALK-RUN-N-ROLL

AWARENESS EVENTS WERE ORGANIZED BY VOLUNTEER COMMUNITY LEADERS IN SIX CITIES IN NEW JERSEY, MARYLAND, WISCONSIN, TEXAS, ILLINOIS AND FLORIDA!

9 INNOVATIVE PARTNERSHIP

WITH CONSANO. "UTILIZING BRAIN IMAGING TO UNDERSTAND COGNITIVE DYSFUNCTION IN TRANSVERSE MYELITIS" WAS SELECTED AS THE FIRST RESEARCH PROJECT TO BRING TO "THE CROWD" FOR FUNDING

10 SUPPORT AND ADVOCACY

WE PERSONALLY CONNECT WITH OVER 1,200 INDIVIDUALS EVERY YEAR TO HELP THEM UNDERSTAND THEIR DIAGNOSIS, REFER THEM TO PHYSICIAN EXPERTS AND OTHER MEMBERS AND ANSWER THEIR QUESTIONS ABOUT THESE RARE NEURO-IMMUNE DISEASES. OUR GOAL IS TO OFFER A BETTER CHANCE AT RECOVERY AND AN ENHANCED QUALITY OF LIFE!

...&

FULL TIME PEDIATRIC PROGRAM MANAGER JOINS THE TMA STAFF

LIKE WHAT YOU SEE OR HAVE AN IDEA FOR 2015? LET US KNOW AT INFO@MYELITIS.ORG!

2014 TMA GOLF OUTING

FIRST ANNUAL GOLF OUTING

THE TRANSVERSE MYELITIS ASSOCIATION

RECOGNIZING 20 YEARS OF SERVICE

Chippin' in against Transverse Myelitis

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Queen of the Transverse Myelitis Association: Pauline Siegel

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ANNOUNCEMENTS

UCF Men's Lacrosse Walk-Run-N-Roll: April 18, 2015. Details inside.

2015 TMA Family Camp: July 21–25, 2015. Details inside.

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