THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

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

Spring 2014

20 YEARS MAKING A DIFFERENCE

Recognizing
20
YEARS
OF SERVICE

THE TRANSVERSE MYELITIS
ASSOCIATION

INDEX

THE EDITOR'S COLUMN

Sandy Siegel, PhD

If you are a member of the TMA, and you haven't yet filled out our membership form powered by TraitWise technology, please take the time to complete the form. We need this information from you to help us better understand the diversity and variability in TM, NMO and ADEM. It doesn't matter whether you have been a member for 15 years or 15 minutes; if you haven't filled out this form, it is imperative that you get onto our website and complete the survey form. This is the link where you will find it on our web site http://myelitis.org/get-involved/become-a-member.

On Saturday, March 15, 2014, I spent the day with a room full of the most brilliant, creative and passionate supporters of The Transverse Myelitis Association. We engaged in a strategic planning process that was led by Dr. Peter Johnson, a reconstructive surgeon by training and a successful entrepreneur who volunteered his time to help facilitate our strategy retreat. Participants included clinicians and researchers focused on rare neuro-immune disorders, people with these disorders and family members, and the TMA board of directors and officers. Through this process, we were able to articulate the TMA's five-year mission and goals and develop a strategic plan to achieve these goals over the next five years. I left this meeting feeling incredibly hopeful and inspired by our directions, and also somewhat overwhelmed by the complexity of our tasks and the challenges we have in front of us to accomplish all of these critical objectives. These goals range from social, emotional and psychological support to growing the medical specialization to the expansion of our outreach and education programs to the establishment of a rapid response medical network for caring for acute cases to research focused on better defining and characterizing these disorders to research on restoration of function and biological repair.

The most positive and hopeful aspect of the process was that we are focused on programs and goals that address the needs of everyone in our community. Our members will benefit regardless of whether they have ADEM, NMO, ON or TM; whether they were diagnosed yesterday afternoon or twenty years ago, no matter their age, gender or what country is their home, and regardless of their recovery or their lack of any recovery. There is no one left out of our future. We will share the goals and the process in the next newsletter.

One might surmise that I came out of this process wondering how we were going to raise all of the money that we are going to need to operationalize and then effectuate all of these goals. And that wonderment would be correct. This plan will require accelerating and intensifying our fundraising efforts. And that should be no surprise. There are very few things that come for free – besides me. So, all of this is going to cost and we are going to be coming to you, and your family and your friends to make all of these great things happen. And we're coming to you, because no one else cares.

When I think about how our members are going to make these goals into a reality, it will require for everyone to get involved in fundraising; making donations, getting family and friends involved in fundraising and getting involved in our awareness and fundraising campaigns, such as the walks and the golf outing. We are going to need resources and those resources will involve more staff and more money to launch new education, outreach and research programs.

And honestly, I'm not allowed to get tired of asking, and you aren't allowed to get worn out from hearing about it. I'm in a great place in all of this to be doing the asking, because I have never benefited in a monetary way from the work I do for the TMA. In fact, this organization has been a huge financial commitment for Pauline and me going back 20 years. For the first 5 or so years of the TMA's existence, we ran the organization out of our personal bank account. We cover as many expenses as we can afford, and we donate what we can. So, please do what you can to help. And if you don't have friends or family, and you aren't in a position to make donations, then please consider getting involved by volunteering your time. There are lots of things people can do to help us. Please get in touch with me and we can explore all of the opportunities.

While my focus will be on raising money, that's not my primary concern at the moment. One of the most important issues we discussed at our strategic planning meeting was about developing a better understanding of these disorders. It is amazing that after 20 years of our work, we still don't understand very much about ADEM, NMO or TM. We are going to do our part to try to make a difference by encouraging and funding research. But we also need for you to do your part. Let me focus on transverse myelitis, just to simplify my case; the same issues apply to ADEM and NMO.

Physicians and researchers are not going to figure out transverse myelitis by reading medical literature. There aren't very many good studies being done with large enough numbers of people to arrive at any great insights. They are going to learn about the disorders as you describe your experiences and as you come forward to donate biological samples, i.e., blood, DNA, spinal fluid, and imaging studies. YOU hold the key to these understandings and insights.

The most direct, easiest and cheapest way for us to systematically collect this information is to share your information. This information can be collected and analyzed very quickly and without very much or any cost, since so many people are donating their time to these efforts.

We rolled out our new membership form and survey powered by TraitWise technology in the Fall 2012 and we started promoting to our members the need to get onto the survey on our web site to fill out your information. New members are also filling out this information to become members of the TMA. Over the past two years, we've had more than 2,000 people fill out the survey and most of them have been new members. We have more than 10,000 members. That means that most of our members haven't filled out this survey; more than 80% of the people in our community haven't done their part to help us better understand your disorder. That is just such an incredible bummer. How are we going to get to the place where we understand these disorders, if we can't get the people who have them to take fifteen minutes to fill out a form on our web site?

And allow me to connect some numerical dots. We estimate that there are about 33,000 people in the US who have TM, thus about .01% of the US population.

That probably means that the numbers outside of the US track approximately this percentage. And these are really rough approximations. Our membership in the US is about 5,500 people and some of those people are medical professionals and family members. Thus, our membership represents less than 20% of the people in the US who have transverse myelitis. The numbers for NMO and for ADEM are smaller, both in terms of the numbers of people who have these disorders and also the numbers who are among our membership. The short story is that we don't have the luxury for people not to get involved. We have the double whammy of being a rare disorder population and also having a relatively small representation of people who have these disorders among our membership. If we are going to better understand these disorders, we need EVERYONE involved in sharing their information with us. Our membership survey provides you feedback on how you compare to others who answered the same question, so you can see if you are among 50% of people with the symptom, for example, or 10% with a unique manifestation. We also will periodically analyze this data and share with you. Recently, we sent out a survey asking for your opinion on research priorities; 643 members responded from the 10,000 members, and we have shared your responses in the newsletter.

These diagnoses are incredibly difficult and incredibly complicated. It is likely that transverse myelitis is more than one disease. We don't know enough about it, really, to say this definitively, but it sure looks to be that way. And until we figure out what it is, no pharmaceutical company is going to be interested in it. Think about that. Our hope for the future depends on researchers from academia, from pharmaceutical companies, from everywhere in the medical world, knowing enough about the disease to find targets for treatment and procedures for repair. We can't attract interest or effort or money without this basic understanding.

I am not at all confused as to the difficulties we experience in making our case to people to donate as much as possible. Dealing with people and money has been an amazing tour on the cultural funk machine. I wasn't home yesterday because I was taking care of my 88-year-old mother and also going to a doctor appointment for myself. Someone called the international headquarters of the TMA, i.e., my kitchen phone. They left messages on my telephone system. Remember, I do all of this work as a volunteer. The person leaving the messages was really peeved that they had to leave a message and they called three times. Each subsequent message employed ever more colorful vocabulary. Finally in total exasperation the person left the message that if they were calling to make a donation that someone would probably pick up the phone immediately. This was an elderly woman who, from my cursory linguistic analysis, is likely a retired lumberjack or longshoreman; no offense intended to lumberjacks and longshoremen. My life in the funk machine. But, hey, I signed up for this gig. And as a cultural anthropologist, I am in full understanding of our cultural meanings surrounding money and what we do with it.

Here's where the bafflement becomes pretty overwhelming for me. I listen to the suffering people experience all day long. And I also hear about the suffering that people experienced, even from those who have improved tremendously. And those who have gotten past their worst of this experience are compassionate enough to realize that there are others who are far less fortunate than themselves. If you knew you were in a position to help someone, starting with yourself, why wouldn't you take fifteen minutes on our web site to do that?

Please don't make me come looking for you. And when we periodically ask you to do this survey work, please participate. Please help us understand what happened to you so that we can make the case to researchers that ADEM, NMO, ON and TM are worthy of their commitment of efforts and dollars.

Please take good care of yourselves and each other.

Sandy

CEREBROSPINAL FLUID INTERLEUKIN-6 IN CENTRAL NERVOUS SYSTEM INFLAMMATORY DISEASES

Wullschleger et al. published a paper in 2013 about the role of interleukin-6 (IL-6) as a potential biomarker (http://en.wikipedia.org/wiki/Biomarker) of central nervous system (CNS) diseases. Being able to differentiate between diseases like multiple sclerosis (MS) and other inflammatory neurological diseases, like Transverse Myelitis (TM), is extremely important for a clinician to be able to do, as the treatments and disease course are different for these diseases. It is also important because it is unlikely that there will ever be a single biomarker that can be used to diagnose MS, but there may be several biomarkers, like IL-6, that can differentiate MS from other diseases.

Cerebrospinal fluid (CSF) is thought to be one place where biomarkers related to chronic CNS diseases such as MS might be found. Wullschleger et al. compared IL-6 levels in CSF samples of 374 individuals in several disease categories. They tested 117 CSF samples of those with demyelinating diseases, including 76 with MS, and 30 with optic neuritis (ON). They also tested the CSF of 10 people with idiopathic transverse myelitis (TM), 35 CSF samples from people with other inflammatory neurological diseases (e.g., neurolupus), and 212 samples with non-inflammatory neurological diseases (e.g., normal pressure hydrocephalus).

IL-6 is a pleiotropic glycoprotein cytokine (a mouthful!), which generally means that it is a protein that tells cells what to do, and in particular, IL-6 mediates the communication between immune cells. It can have differing effects on the immune system, and can cause inflammatory responses or responses that protect the nervous system. IL-6 has been found in the CSF of people with diseases such as TM, acute disseminated encephalomyelitis (ADEM) and neuromyelitis optica (NMO), which is why it was chosen as the biomarker for this study. A cut-off value of IL-6 was set at 10 pg/ml, meaning any concentration above this level was considered positive for IL-6. They found CSF to be IL-6 positive in 40% of patients with TM and 51% of patients with other inflammatory neurological diseases, but only 3.9% of MS patient samples had CSF that was IL-6 positive, and none of the patients with non-inflammatory diseases or other demyelinating diseases like optic neuritis had CSF that was positive. Although some people with MS had CSF that was positive for IL-6, levels were lower for these individuals than for those with TM or other inflammatory neurological diseases. As a result of their findings, the authors believe that measuring IL-6 levels in CSF should be a screening tool used to rule out MS in individuals who present with MS-like symptoms who don't actually have the disease.

Dr. Benjamin Greenberg, Director of the TM and NMO Centers at University of Texas Southwestern Medical Center in Dallas, commented on the lack of data in this study around treatment of MS relapses in the samples that were obtained within a month of an MS relapse, and whether treatments such as steroids could influence results. Furthermore, there was incomplete information on the 10 patients that were categorized as having idiopathic TM, which if probed further could skew data. Further studies will be needed to confirm whether or not measuring IL-6 levels is a useful diagnostic tool for differentiating MS from other inflammatory neurological diseases.

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

Original research: Wullschleger A, Kapina V, Molnarfi N, Courvoisier DS, Seebach JD, et al. (2013) Cerebrospinal Fluid Interleukin-6 in Central Nervous System Inflammatory Diseases. PLoS ONE 8(8): e72399. doi:10.1371/journal.pone.0072399

REPORTED CASES OF POLIO-LIKE ILLNESS & ITS RELATIONSHIP TO TRANSVERSE MYELITIS

News reports from California have recently come out identifying a series of patients, mostly children, affected by a polio-like illness with symptoms that can mimic transverse myelitis (TM). Naturally, these reports have raised questions within our community so we thought it would be important to address some of the concerns. First, it's important to have some background.

The spinal cord is comprised of several different pathways and cell types. Connections from the brain descend in the spinal cord and 'attach' to neurons in the spinal cord that then project out to muscle groups. When a person wants to move their hand, their brain sends a signal down a pathway to a set of cells within their cervical spinal cord and form a connection (a synapse). The signal from the brain activates the neurons in the spinal cord, which in turn, propagates the signal to the muscles of the hands, leading to the intended movement. This pathway can be interrupted in many ways.

Polio is caused by a virus that specifically infects the cells within the spinal cord responsible for projecting out to muscle groups (the so called lower motor neurons). When these cells die the muscles they connect to cannot be activated. Classically, transverse myelitis causes damage to the wires that are responsible for connecting the brain to these lower motor neurons, leaving the connection from spinal cord to muscle intact, but interrupting the signal that was originally meant to activate the pathway. In clinic, we tend to describe this as "wire number 1 and wire number 2". Wire number one goes from brain to spinal cord and wire number two goes from cord to muscle. Polio damages wire number 2 and traditionally, TM damages wire number 1.

The second issue that must be addressed is the mechanism of injury. In traditional transverse myelitis a "confused" immune system inappropriately causes damage to the spinal cord. When the immune system invades the cord there is no virus there to be fought off. In the cases of patients reported from California, a virus directly infects and kills the cells. Any inflammation in the spinal cord is responding to the virus. TM is often a missed diagnosis. Sometimes this occurs because of a lack of vigilance from medical personnel, but sometimes it is because the diagnosis is unclear. In addition, the problem with diagnosing TM is that there is no single blood or spinal fluid test that definitively identifies TM. In addition, the spinal fluid markers of inflammatory responses cannot differentiate between an autoimmune response and a response to an infection.

Sometimes people will read that a virus has been associated with TM, but these reports are difficult to interpret. The infection could have been the inciting event but the spinal cord injury was caused by a secondary autoimmune process after the infection, or the association could have been incidental in that the patient had previously had the infection but now has an unrelated process. Also there could actually be two processes causing the spinal cord injury – both an infection-related component and a separate inflammatory component. Finally, the patient could have tested positive for the infection even though they did not have the infection at all (a false positive). Keeping these in mind, it makes it difficult to interpret many of the case reports regarding infection and TM. In addition, we must always keep in mind that the viruses and pathogens we do actually know about (and can test for) are a fraction of those that exist in nature, there are likely hundreds and hundreds of viruses or virus subtypes (meaning we know several but not all in a certain virus "family") that we are not aware of.

Although we do not know the intricate details of the cases in California, the clustering of extremely similar cases in a short time frame is more suggestive of a common infectious cause, likely a virus, that has a tendency to target the same and/or closely similar areas in the spinal cord and, thus, causing similar symptoms.

In a series of upcoming papers, our team at UT Southwestern and Children's Medical Center has described differences among patients classically diagnosed as having TM. Some of these patients have evidence of damage to BOTH wire number 1 and wire number 2. We are using these features and others to differentiate patients relative to treatment options and outcomes. In California, the public health system has identified a series of polio-like illnesses, where only wire number 2 has been affected. Some of these patients may have originally been diagnosed with TM, but in retrospect this may have been an inaccurate diagnosis. While we do not have specific case details, this is not an unexpected event given the rate of misdiagnosis of TM.

There is a virus that has been identified in some patients – a previously recognized cousin of the poliovirus – that may be the causative agent. It is also worth noting that this syndrome (viral damage to wire number 2) has been described with multiple viruses, including west nile virus. In the end, this is a reminder of the importance for improved diagnostic algorithms for patients and increased research into the world of acute paralyzing illnesses. The TMA and the UT Southwestern/Children's Medical Center TM program will continue to monitor events and update our community.

By Benjamin Greenberg, MD, MHS and Allen DeSena, MD – University of Texas Southwestern, Dallas.

SUBSCRIBE TO THE TMA BLOG!

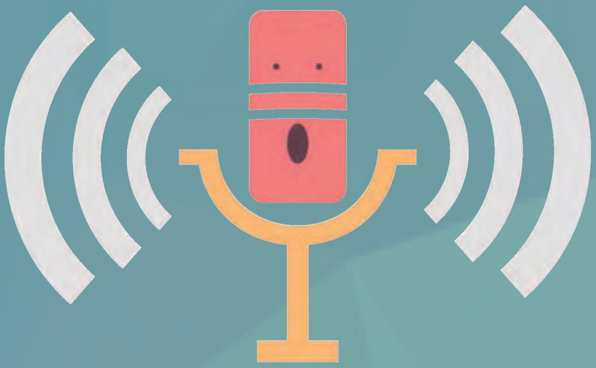
Have you read the TMA BLOG (https://myelitis.org/category/resources/tma-blog) lately? We publish weekly stories and articles written by individuals living with rare neuro-immune diseases, caregivers and families, as well as leading researchers and clinicians. The blog covers a wide variety of relevant 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.

AUSTRALIA AWARENESS DAY PROGRAM

Spinal Injuries Australia will host Transverse Myelitis Day on 26 May 2014 at their Brisbane office located at 109 Logan Road, Woolloongabba, starting at 10:00 am local time. The day will be opened by the CEO of the Spinal Injuries Australia, Bruce Milligan. Speaking live from the USA, guest speakers will include Chitra Krishnan, Executive Director, TMA and Rebecca Whitney, Program Manager, TMA, and Dr. Benjamin Greenberg, MD, MHS Director of the Transverse Myelitis and Neuromyelitis Optica Center at University of Texas Southwestern in Dallas. Professor Graham Martin, OAM, MD, FRANZCP, DPM, Psychiatrist will join us at the Brisbane Office along with Belinda Kropp, Manager Spinal Allied Health Service, Spinal Injuries Australia and Louise Remiliton, Facilitator, Transverse Myelitis Network. Lunch will be provided and the day will be closed by the President of the Spinal Injuries Association, David Riley at 2.30pm.

TMA ASK THE EXPERT PODCAST SERIES



Thank you to those who joined the podcast on “Understanding Autoimmunity & Rare Neuro-Immune Disorders” as part of TMA’s Ask the Expert podcast series on March 24, 2013. The physician-experts on the panel were Dr. Benjamin Greenberg from University of Texas Southwestern in Dallas and Dr. Carlos Pardo from Johns Hopkins Medical Center.

The podcast recording has been made available at our website https://myelitis.org/education/podcasts.

Stay tuned for more details on future podcasts also at our website - http://myelitis.org/education/podcasts.

TRANSVERSE MYELITIS **PLUS SYNDROME** & ACUTE DISSEMINATED ENCEPHALOMYELITIS **PLUS SYNDROME**

A CASE SERIES OF 5 CHILDREN

DeSena et al. published a paper in 2014 in JAMA Neurology describing a case series of five children (aged 29 months to 14 years) who had clinical characteristics that are not normally seen in transverse myelitis (TM) or acute disseminated encephalomyelitis (ADEM). All 5 children presented with flaccid paralysis to the University of Texas Southwestern Medical Center between 2009 and 2012 and were initially diagnosed with either TM, TM with brainstem involvement, or ADEM, but further magnetic resonance imaging (MRI) indicated that these children had inflammation in either the proximal ventral nerve root or the cauda equina. A spinal nerve root, like the ventral nerve root, is the beginning portion of a nerve as it leaves the spinal cord and goes towards the muscles. The cauda equina is a group of spinal nerves and spinal nerve roots that innervate the pelvic organs and lower extremities, including motor innervation of the hips, knees, ankles, feet, internal anal sphincter and external anal sphincter, and sensory innervation of the perineum and some parasympathetic innervation of the bladder (source: http://en.wikipedia.org/wiki/Cauda_equina).

Nerve root and spinal nerve involvement as seen in these five children is unusual because in most cases of TM or ADEM, only the wires in the brain and/or spinal cord are affected, and not the wires after they leave the cord and go towards the muscles (there is more information about this topic in a recent TMA blog post - https://myelitis.org/resources/tma-blog/reported-cases-polio-like-illness-relationship-transverse-myelitis). The nerve root or cauda equina involvement was discovered in imaging that was done after the initial diagnosis, so it is unclear if nerve root inflammation in patients with TM or ADEM represents a different disease mechanism than classic TM or ADEM, or if more people with classic TM or ADEM have nerve root involvement that was not caught in their initial imaging. Interestingly, the five cases described in this article all presented with TM/ADEM symptoms in the mid to late summer, and the authors note that this suggests that there may be a common viral or bacterial cause to these cases. Furthermore, nerve conduction studies were conducted on all five children as part of their diagnostic testing; nerve conduction studies measure nerve and muscle function in the body. Three of the patients' nerve conduction results showed "evidence of possible axonal loss," or damage to the nerves going into the muscles. Other studies have indicated that abnormal nerve conduction results are associated with a greater chance of incomplete motor return. The authors note that it is possible that some individuals who are diagnosed with TM and ADEM who do not recover may actually have nerve root involvement, so they suggest that all individuals who have nerve root inflammation and/or demyelination should have neuroimaging. They also argue that patients with TM who do not respond to treatment should have imaging redone to rule out nerve root involvement. The authors conclude that they believe that these patients are a separate category within the TM family of diseases, but that more studies are needed to better understand people with these clinical characteristics.

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: DeSena A, Graves D, Morriss MC, Greenberg BM. Transverse myelitis plus syndrome and acute disseminated encephalomyelitis plus syndrome: A case series of 5 children. JAMA Neurol. 2014; E1-E6. doi: 10.1001/jamaneurol.2013.5323

AWARD FROM PATIENT-CENTERED OUTCOMES RESEARCH **TO STUDY** PEDIATRIC TRANSVERSE MYELITIS

The first multi-center, innovative, pediatric transverse myelitis study led by University of Texas Southwestern in Dallas, along with the Transverse Myelitis Association, Johns Hopkins Transverse Myelitis Center, Children's Hospital of Philadelphia, Kennedy Krieger Institute, and Hospital for Sick Kids in Toronto, has recently received a research award from the Patient-Centered Outcomes Research Institute (PCORI). The study is part of a portfolio of projects that will advance the field of patient-centered comparative effectiveness research and provide patients with information that will help them make better-informed decisions about their care.

Dr. Benjamin Greenberg, MD, MHS, Director of the TM and NMO Center will lead the research project at UTSW in Dallas. The proposed study, entitled the 'Collaborative Assessment of Pediatric Transverse myelitis: Understand, Reveal, Educate' or CAPTURE, will be the first to combine assessments from health care providers and patients relative to pediatric TM outcomes. The collaboration will involve multiple health care centers across North America, the Transverse Myelitis Association and most importantly, patients. It will assess the current state of Pediatric TM in terms of diagnosis, treatment and outcomes. Ultimately, it will lead to an improved understanding of the current status of care for individuals afflicted with TM and reveal what are the current best practices. Patients will educate clinicians and the study will educate the broader health care system about what outcomes are important and achievable. It will develop a multi-metric outcome measure based on combined patient generated and provider generated data that can be used in future controlled trials

"Pediatric transverse myelitis is a rare potentially devastating condition that affects children of all ages. To date, there has never been a coordinated effort to understand the patient experience or clinical outcomes," said Dr. Greenberg. "This PCORI grant is the first opportunity for an international effort to collect data about pediatric TM with an intense emphasis on patient and family reported outcomes. Working with outstanding institutions and the TMA, we plan to enroll families from around North America and gain a better understanding of this condition. Partnering with our patients and families is an exciting and welcome opportunity to make meaningful advances!"

Dr. Sanford Siegel, President of the TMA added, "The parents in our community are incredibly well educated about transverse myelitis and they are informed and effective advocates for their children's medical care. They are well positioned and highly motivated to make a significant contribution to the pediatric study of this rare and challenging neuro-immunologic disorder. To date there has not been a single study or clinical trial to guide any treatment of transverse myelitis or to guide the treatment of any of the symptoms from this disorder. The CAPTURE project represents the first study to systematically analyze the most effective acute treatments and symptom management practices in transverse myelitis. The results of this work will have critical and far-reaching benefits for everyone who receives the transverse myelitis diagnosis."

"This project was selected for PCORI funding not only for its scientific merit but also for its potential to fill an important gap in our health knowledge and ultimately help patients and those who care for them make more fully informed decisions about their care," said PCORI Executive Director Joe Selby, MD, MPH. "The project reflects PCORI's commitment to support patient-centered comparative effectiveness research, a new approach to health research that emphasizes the inclusion of patients and caregivers at all stages of the study process. We look forward to following the study's progress and working with UTSW and the collaborating organizations to share the results."

The study is one of 71 projects totaling more than $114 million approved for funding by PCORI's Board of Governors on Tuesday, Sept. 10. The awards were a mix of projects that included studies specifically targeting improvement of research methods. All were selected through a highly competitive review process in which scientists, patients, caregivers, and other stakeholders helped to evaluate more than 570 proposals that responded to five PCORI funding announcements.

Proposals were evaluated on the basis of scientific merit, how well they engage patients and other stakeholders, their methodological rigor, and how well they fit within PCORI's national research priorities. The awards are part of PCORI's latest round of primary research funding. Through previous funding cycles, including a round of pilot projects, and other initiatives, PCORI has committed a total of $304 million since 2012 to support patient-centered comparative effectiveness research.

For more information about PCORI funding, visit http://pcori.org/funding-opportunities.

ABOUT THE TMA

The Transverse Myelitis Association (TMA) is a not-for-profit international foundation dedicated to the support of children, adolescents, and adults with a spectrum of rare neuro-immune disorders – Transverse Myelitis, Neuromyelitis Optica and Acute Disseminated Encephalomyelitis. Membership of the TMA includes individuals with these rare disorders, their family members and caregivers, and the medical professionals who treat individuals with these disorders. The TMA currently has over 10,500 members from more than 80 different countries and has a large number of support groups across the United States and around the world. More information is available at http://myelitis.org.

ABOUT PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed health care decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.

FIRST ANNUAL GOLF OUTING

THE TRANSVERSE MYELITIS ASSOCIATION

RECOGNIZING 20 YEARS OF SERVICE

Chippin' in against Transverse Myelitis

WHAT

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

WHEN

Monday, September 29, 2014
9 – 11 a.m. Registration
11 a.m. Shotgun Start
5:00 Dinner, Awards Ceremony, Guest Speaker: Dr. Benjamin Greenberg

WHERE

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

GUEST SPEAKER

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

WHY

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

REGISTER

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

HOW TO VOLUNTEER

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

THE SUCCESS OF OUR FIRST TMA ANNUAL GOLF OUTING IS YOUR SUCCESS!

HERE IS HOW YOU CAN HELP US!

BE A SPONSOR OR ASK YOUR COMPANY TO SPONSOR YOUR CAUSE
Information is available on our web site at https://myelitis.org/golf-outing

BE A PLANNING COMMITTEE MEMBER OR VOLUNTEER ON THE DAY OF THE EVENT
Please contact Sandy Siegel by phone (855) 380-3330 or email ssiegel@myelitis.org

PLAY A ROUND OF GOLF AS AN INDIVIDUAL OR A TEAM WITH YOUR FRIENDS AND FAMILY
You can register at https://myelitis.org/golf-outing

JOIN US FOR THE DINNER RECEPTION, MEET OTHER MEMBERS, AND LEARN ABOUT THE LATEST RESEARCH FROM DR. BENJAMIN GREENBERG OF UTSW!
You can register for dinner only at https://myelitis.org/golf-outing

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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.

GIVE US A HAND

TO GET US BACK ON OUR FEET

WWW.MYELITIS.ORG/WALK

Our ambitious nationwide 2014 Walk-Run-N-Roll campaign to raise awareness, celebrate the resilience, perseverance and indomitable spirit of individuals living with rare neuro-immune diseases and the care and commitment of friends and family was kicked off again this year with the 3rd Annual South Jersey Walk led by Colleen Spaeth and her daughter Amanda Edwards, who sparked the genesis of the campaign last year!

Volunteer leaders are planning upcoming walks in Maryland, Texas, Florida, Illinois, and Michigan. More states are joining the campaign to raise awareness about these rare neuro-immune diseases. To join one of the walks in these States or to start your own, please visit http://www.myelitis.org/walk!

If you would like to create awareness in your community about these diseases, email us at info@myelitis.org.

We are so grateful to the volunteers and leaders who are working hard to spread the word about these rare neuro-immune diseases and are raising funds to support the research and education programs that we offer! Our heartfelt THANK YOU!

OUR NEXT WALK-RUN-N-ROLL IS IN MARYLAND ON JUNE 22, 2014! FOR THOSE ABLE TO JOIN US, PLEASE VISIT BIT.LY/TMA-MD-WALK FOR MORE INFORMATION!

More about the 3rd Annual South Jersey Walk for Transverse Myelitis...

I had the privilege of attending the 3rd Annual South Jersey Walk For Transverse Myelitis on April 5th, 2014. Balloons and banners greeted participants at Cooper River Park on a sunny, but windy day. As in the past two years, the event was hosted by Colleen Spaeth, her daughter, Amanda Edwards, and many other friends and family members. Many TMA members joined to show their support. Colleen's warmth and vitality made everyone feel welcome.

About 15 people living with TM, NMO, or ADEM joined the walk with family and friends. There were several new faces that were eager to connect with people who were experiencing many of the same disease related issues. There were the usual conversations – "How were you diagnosed (or misdiagnosed)", "What doctor are you seeing", "Are you doing physical therapy", etc. There was also a lot of discussion about how the long, cold winter in the northeast had an adverse effect on almost everyone with these diseases. There was a wonderful sense of community even at an event that was grounded in adversity.

There were approximately 100 people who completed the 4-mile walking course. Some TMA members were able to participate and some were not, although their families and friends represented them well on the walk. Many cheers were heard at the finish line for all the participants.

I believe that when the event was over, there was a huge sense of accomplishment, rejuvenation, and belonging for the affected members and their families. So far, over $13,000 has been raised to support the TMA mission and goals! Many thanks to Colleen and Amanda for a truly successful event and to all of the attendees and donors for their support.

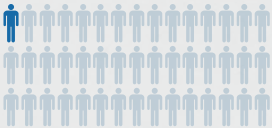
-Linda Malecky, Board Member of the Transverse Myelitis Association

THE POWER OF GIVING

In 1994 The Transverse Myelitis Association was founded.
Our membership has grown...

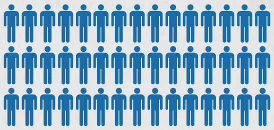
1997

187 MEMBERS



2014

> 10,700 MEMBERS



In 2013...

1874 MEMBERS
PARTICIPATED IN SURVEYS

2358 MEMBERS
JOINED OUR CLINICAL REGISTRY

10,333 MEMBERS
RECEIVED NEWSLETTERS

36 FAMILIES
ATTENDED TMA FAMILY CAMP

4458 INDIVIDUALS
VIEWED 2013 SYMPOSIUM VIDEOS

525 INDIVIDUALS
ATTENDED PODCASTS

You might wonder....

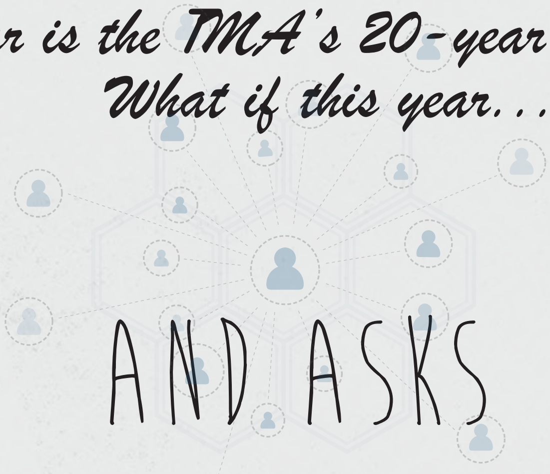
WHO GIVES BACK?

OF OUR ACTIVE MEMBERS

ONLY **4.5 %** OF TMA MEMBERS DONATED IN 2013

This year is the TMA's 20-year anniversary.
What if this year...

EACH OF US **GIVES $20**



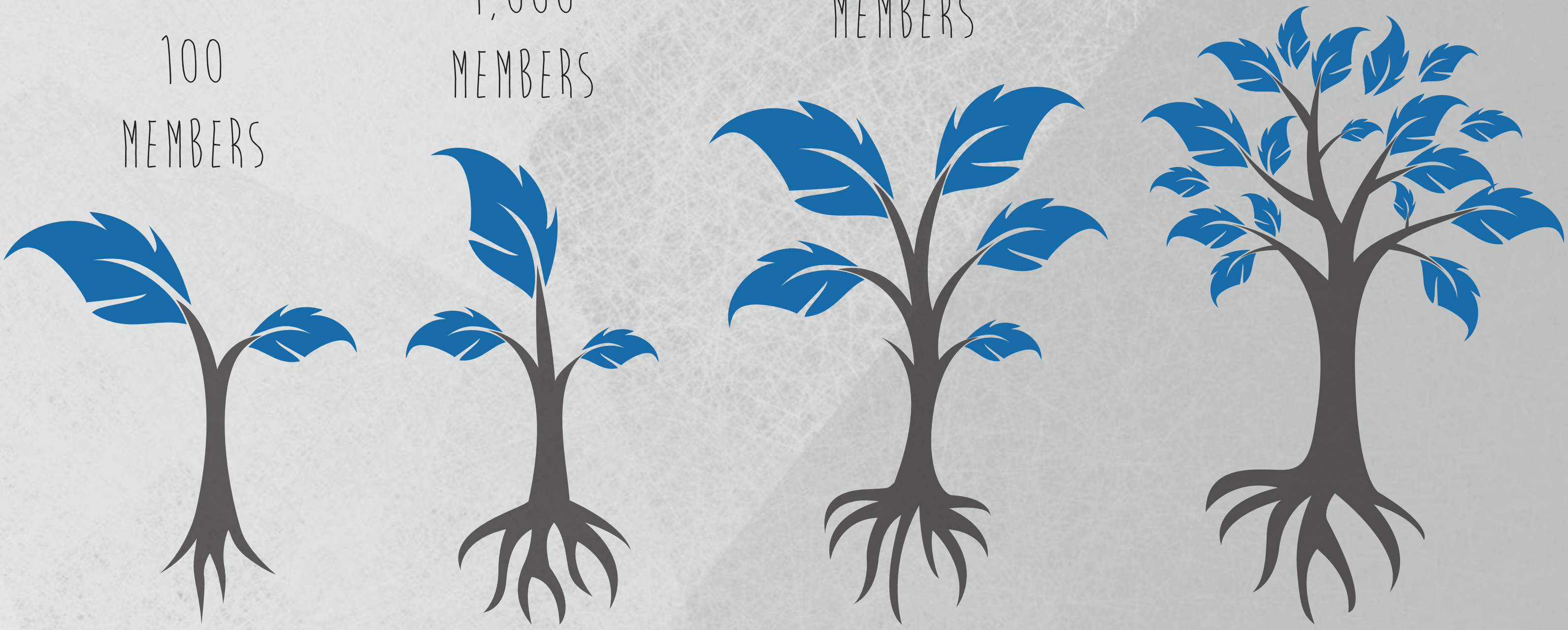
AND ASKS

20 FRIENDS & FAMILY TO GIVE $20

Then. . .

1 MEMBER CAN
RAISE $420

& . . .



100 MEMBERS

$42,000

1,000 MEMBERS

$420,000

5,000 MEMBERS

$2,100,000

10,700 MEMBERS

$4,494,000

Think of the **IMPACT** *you could make!*

WITH **YOUR** SUPPORT WE CAN...

CREATE
NEW CLINICAL
CENTERS OF EXCELLENCE

FUND
EDUCATION
& RESEARCH

LAUNCH
NEW COMMUNITY
SUPPORT PROGRAMS

ADVOCATE
FOR YOU & YOUR FAMILY

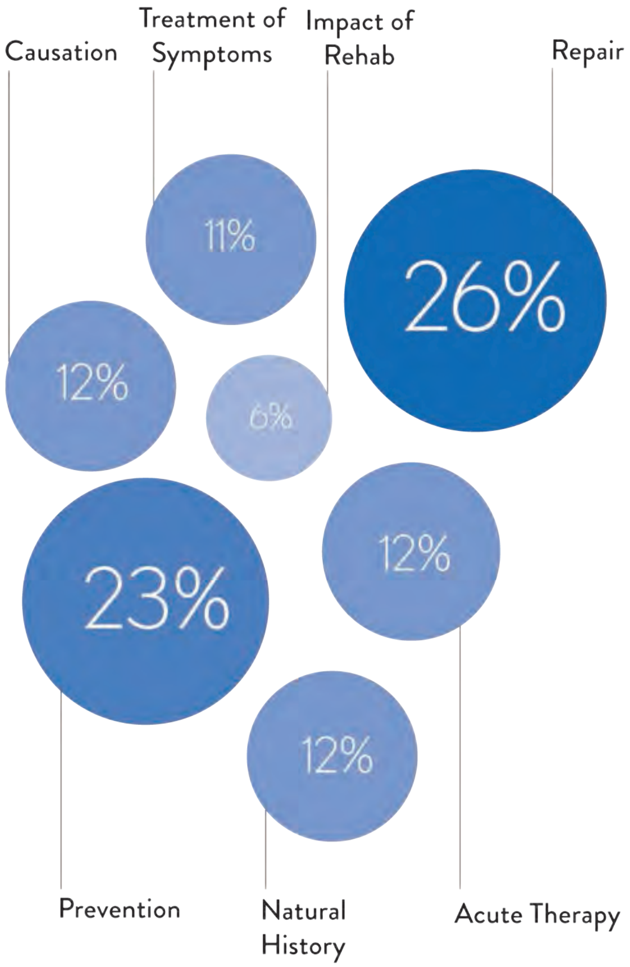
Help us help you...

WWW.MYELITIS.ORG/DONATE

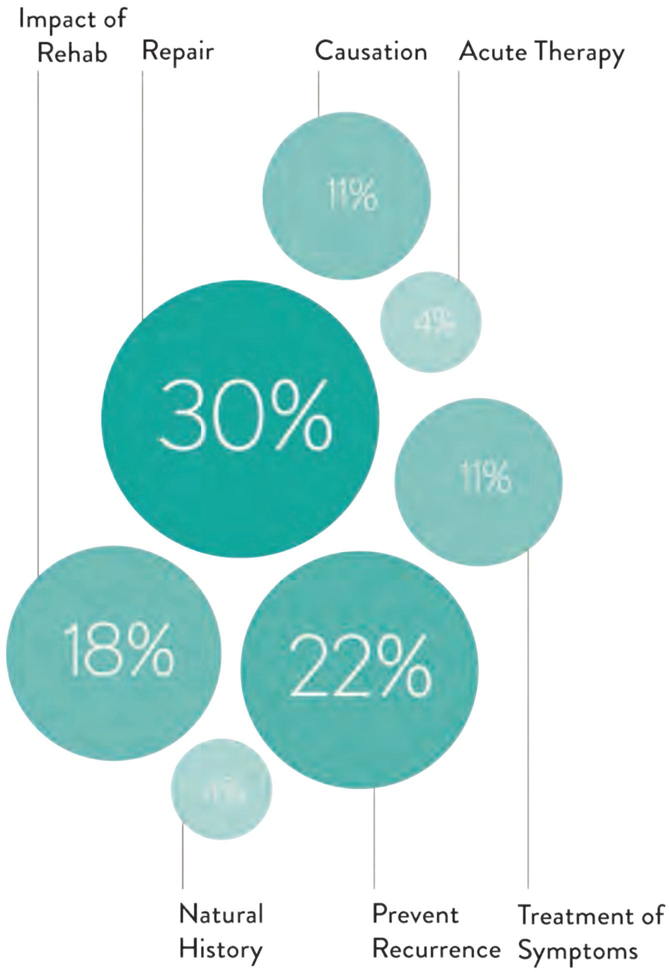
TMA COMMUNITY
RESEARCH PRIORITY SURVEY RESULTS

In January of 2014, we launched a survey to gather community feedback on research priorities and what issues were most critical from a patient, caregiver and medical professional's perspective. Of the 643 people who took the survey, 81% were individuals diagnosed with these rare neuro-immune diseases, and 14% were caregivers. The leading diagnosis was Transverse Myelitis (82%) followed by NMO spectrum disorder (10%). Below are the results from the survey.

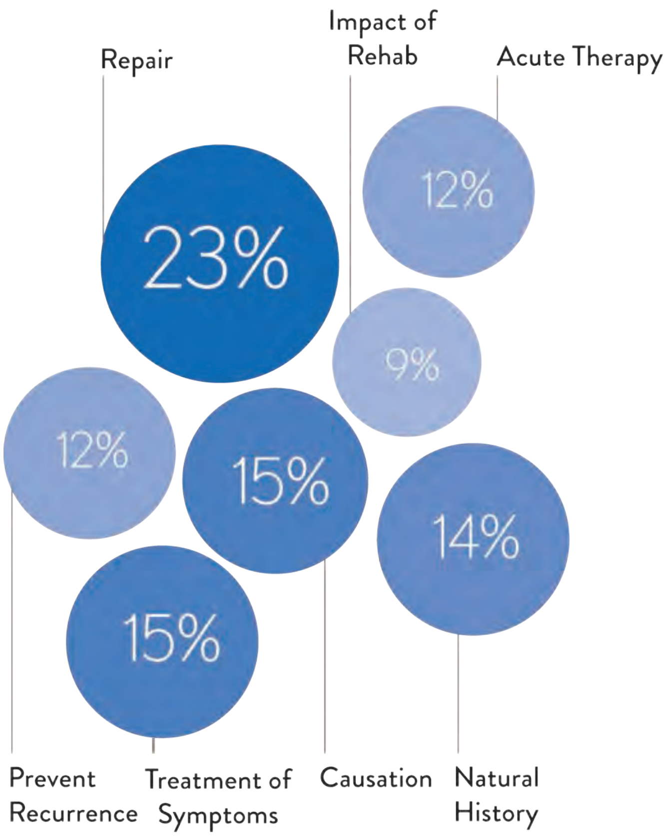
NMO PATIENT RESEARCH PRIORITIES (N=45)



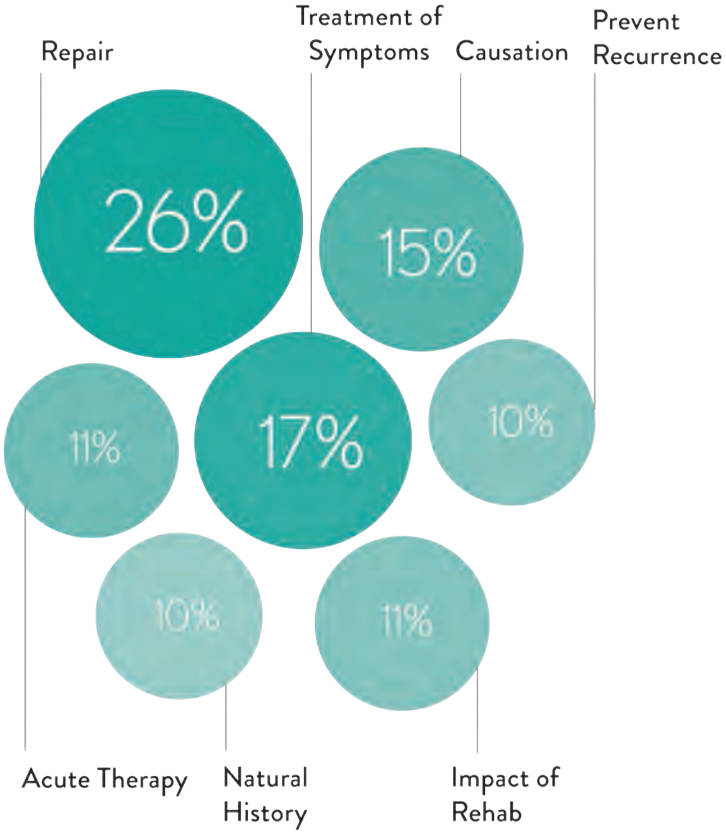
NMO CAREGIVER RESEARCH PRIORITIES (N=11)

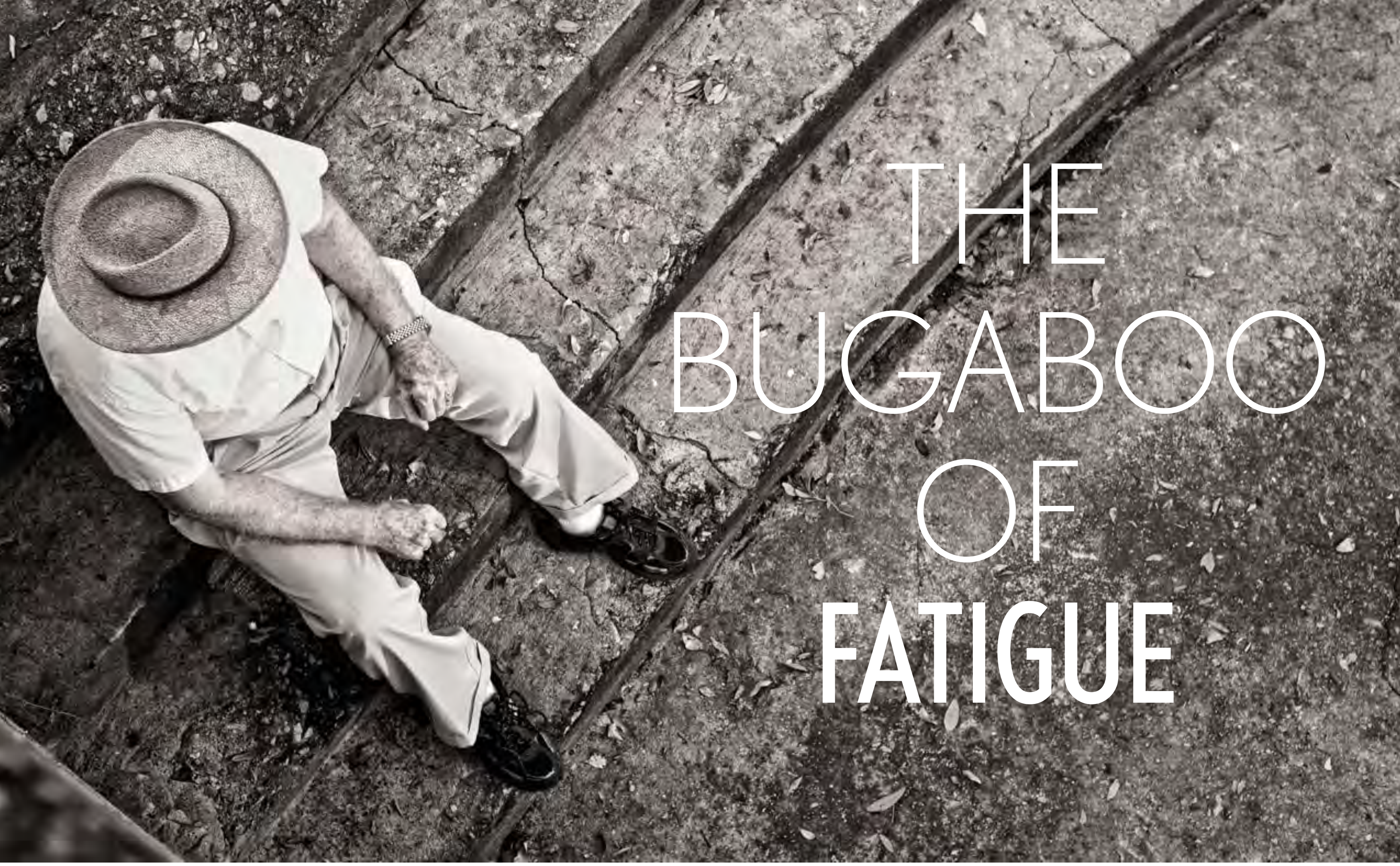


TM PATIENT RESEARCH PRIORITIES (N=410)



TM CAREGIVER RESEARCH PRIORITIES (N=68)





THE BUGABOO OF FATIGUE

Why am I so tired all the time? I know, it goes with the paralytic territory, but like Charlie Brown and the football gag where he lands on his backside every time, I'm always shocked when all of sudden I feel like I just hit the wall at the Boston Marathon. It is infuriating that I have to stop my day, every day, to take a nap and recharge what batteries I have. A late friend of mine, actor/'writer Jim Troesh, a high quad, once told me that he was asleep more during the day than he was awake. Despite what I do, it seems like I'm getting there.

What's really bothersome about fatigue, as opposed to, say, an infection or a wound that won't heal, is its psychological impact. It is, in a word, demoralizing. We are taught from an early age in this go-get-'em society that if you are tired when you shouldn't be, you are a) lazy, a serious moral infraction, b) staying up too late watching TV, or c) in some way responsible for being so "weak." This is hardwired into the brain, at least my brain. Napping is for retirees who have run out of juice. For the rest of us, it is an indulgence or luxury-or both, and from the workaholic Calvinist perspective, you are wasting your life away.

But why is this fatigue happening? And what can you do about it?

Let's ask the experts.

Benjamin Greenberg, MD, MHS, Associate Professor, University of Texas Southwestern in Dallas, does research and provides care in the areas of mobility disorders and specifically, neuroimmunological disorders like transverse myelitis, neuromyelitis optica, encephalitis, multiple sclerosis and infections of the nervous system. Since I have transverse myelitis, he could explain at least my situation, if not that of a wide swath of the paralysis community.

Here's why you are most likely to be abnormally tired, says Dr. Greenberg. By far the number one cause of chronic fatigue is sleep disturbances. You are most likely tired because you haven't gotten enough sleep. You may think you are sleeping, but often you are only semi-conscious, wiggling around, waking up for brief interludes. Sleep has to be undisturbed for long periods of time to be restorative. Three trips to the bathroom in the night will throw you off. I myself have trouble sleeping because of general discomfort, specific muscle aches, and the fact that I wear a C-PAC mask every night. Just fiddling with that thing wakes me up two or three times a night. Spasms, neuropathic pain, anxiety, depression, and stress may also be factors.

The number two reason, especially for those with mobility disorders, is excessive energy output. You are burning a lot of fuel to move around while all or half of your body is immobile. According to Dr. Greenberg, for every common activity, from using the facilities to turning over in bed, you are using up to ten times as much energy as a non-disabled person. Ten times! It makes me tired just thinking about it. Take, for instance, a simple activity like transferring into a car. If you are non-disabled, getting in a car is merely plopping down on the seat. But the act of transferring involves the actual transfer itself, breaking down and putting the wheelchair someplace, and doing the reverse when you get out again. Do that eight to ten times a day – going to the doctor's office involves at least four transfers – and it adds up.

Thirdly, many common medications can engender fatigue. I forgot to ask Dr. Greenberg for a list. Next time. And the right or wrong diet can have a blatant effect. And if you have a neuroimmunologic disorder, there may very well be an additional factor: residual immune-disorder effects on the brain leading to fatigue and depression. This is not a scientific certainty but a well-shared thought among medical researchers. Future research is needed.

Fixing the problem, or at least mitigating it, is essentially the reverse of those factors. Get 8-9 hours of pure sleep every night, and if not, there are a million experts out there to help you do it. Get serious about it. Don't think you will "catch up" down the line. And be very careful with anything you ingest that can disturb your sleep: alcohol, recreational drugs, too much liquid after six, even light pepper-uppers like Focalin.

Though it may seem counterintuitive and you are probably sick of hearing this mantra, you pretty much have to exercise. Get into a vigorous exercise regimen like your life depended on it, because it probably does. Dr. Greenberg says to look at the energy you store in exercise as income and all of your daily activities as expenses. Build up those energy savings. You are sure to need them.

In my own case, exercise is the best antidote to sleep deprivation that I know of. Besides making me stronger and marginally less tired during the day, it helps relieve tight muscles, stress, depression, and feelings of self-inadequacy. I slack off like everyone else, but have no illusion that I can avoid it for very long. If you want to live well and sleep well and at least, in part, mitigate the bugaboo of fatigue, exercise is not a bad place to start.

Now it's time to take a nap.

~ Allen Rucker

IN THEIR OWN WORDS ARTICLES

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

FACEBOOK

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

It is a fearful thing to love
what death can touch.
A fearful thing to love,
hope, dream: to be -
to be, and oh! to lose.
A thing for fools this, and
a holy thing,
a holy thing to love.
For your life has lived in me, your laugh once lifted me,
your word was gift to me.
To remember this brings a painful joy.
'Tis a human thing, love,
a holy thing,
to love
what death has touched.

- Rabbi Chaim Stern

An angel has left the earth and she left us way too soon. The phone rang on Sunday night at 6:00. It was Mladen from Croatia. Pauline heard me say Mladen's name and she saw my face and grabbed a telephone. She heard Mladen tell us that our beautiful and sweet Jasna had died on Saturday night. And because he is so kind and caring, he made sure that Pauline understood that her passing away had nothing to do with transverse myelitis. Jasna died at home, in the arms of her beloved Mladen, from cancer.

I knew that there was something wrong because there had been a drastic change in our communications. But Jasna and Mladen were private people … especially in their sadness, and I didn't want to push or interfere. So, I gave them the space they obviously wanted. I would check in periodically, but the responses were short and didn't include very much information. If we lived closer than an ocean away, we would have gone to their house to check in on them. That was not possible. And now we understand. A very painful understanding.

We know just how much Mladen loved his dear Jasna, and we are just aching for his pain. They had a lifelong love affair; they were everything to each other. And Mladen took such good care of his Jasna in every way and with such devotion and love. This will be so very difficult for him. And the pain is that much more acute for us, because we can't be there for him to comfort and console him … just by being there with him. Not saying a word … just by being there for him. All we can do is hope that he feels our presence.

Jasna got transverse myelitis 17 years ago. Mladen found me on the internet, and they joined the TMA. Jasna did not know English very well; Mladen could speak it and write it fairly well. Jasna asked if she could write to me to practice her English. That email began a correspondence that I had with Jasna that went on for many years, every single weekend. We never missed a weekend. Jasna would write me on Saturday evening or Sunday morning, and then when I would wake up on Sunday, I would find Jasna's message and would respond. We were so observant of our

correspondence, that in the event one of us was traveling or knew that we would not be sending a message that weekend, we wrote and warned each other …or we called, because we didn't want the other to worry. And we would have worried. Over those many years, we celebrated birthdays, we toasted New Years, we wished each other the best of health and happiness on so many occasions, and we shared the grief and sadness of losses. We didn't write about politics or current events; we wrote about life. We shared each other's lives … the joys and the sorrows and everything in between. We shared what mattered to us. We became family. One year on my birthday, Jasna called and left a message singing "Happy Birthday" in English. It was priceless. I must have listened to that message twenty times. And I'm cherishing the thought that in all of those many years that Jasna and I wrote to each other, I never deleted a message and I saved every photograph that she ever sent to me. We will have our memories.

Jasna was born and lived as a child on the Island Rab. Over the years, I had seen many photographs of her beautiful homeland in the Adriatic and had heard many stories. She still had her home on the Island, but because of her physical issues found it too difficult to travel home. She and Mladen lived in Rijeka. Jasna was born in 1951 … like me. We shared many of the same interests, including all of the rock and roll bands that we had grown up with. Jasna was an artist; a wonderful and incredibly talented artist. And she had an artist's soul. I haven't known many people who were as pure goodness as Jasna. One of the most difficult and painful aspects of getting transverse myelitis was that she lost the use of her hands. Jasna was no longer able to create her art and it was a terrible loss. My sister is an occupational therapist and I spoke to her about Jasna's situation. My sister came up with some possible solutions for her, and sent Jasna a number of different devices that she could use with her hands to try to manipulate her brushes. She was just not able to find the right solution.

Jasna suffered some significant challenges from her transverse myelitis. While she worked so hard on her rehabilitation, she lost significant motor function. It was hard for me to understand until I watched a similar thing happen to Pauline. All of it is just so difficult to comprehend. Jasna and Mladen sent me videos of her walking and doing leg exercises, and then she's in a wheelchair and can barely move. Was there something recurrent going on with Jasna? We were never able to figure it out, and Jasna was seeing some very good physicians. I was always troubled by the descriptions I was hearing from Jasna and Mladen about the things that were going on with her. When we were discussing her health, more precision in our communications was needed, and often times I would write or speak with Mladen on the telephone. And even those communications were not the best. It is a helpless feeling not to be able to help someone you love.

Pauline and I were at the symposium in Baltimore in 2006. We sat down at a table for lunch on Friday and started a conversation with the couple that was sitting next to us. It was the beginning of a very sweet relationship for us with Frank and Florence. Frank had transverse myelitis. During the course of the conversation, we discovered that Frank was Croatian and still had family in Croatia; and Frank spoke fluent Croatian. And because the world is what it is, we later found out that Frank's sister and Jasna were good friends. And of course I received a photograph from Jasna sitting at her kitchen table with Frank's sister. When Frank would go to Croatia, he would make a visit to Jasna and Mladen. Frank and Florence helped us a lot in our important medical communications with Jasna and Mladen, and it was wonderful to share that relationship.

When Cody had the symposium in Albuquerque, there was a fellow on the program agenda who was doing her training in neuroimmunology. When I saw her name, I asked about her nationality, and was told that she was Croatian. At the end of her presentation, I tackled her in the hallway. Of course, I spoke to her about Jasna. And because the world is what it is, this wonderful physician's mother still lived in Rijeka, and she would stop by to see Jasna and Mladen when she went to visit her mother. And we have photographs of Jasna with this incredible doctor at their kitchen table.

Jasna loved her garden and all of her beautiful flowers. She had a wonderful dog, Monica, who she loved dearly. There was a bird that was hurt near her home, and Mladen built a cage for it, and she and Mladen nursed the bird back to health. She had many cats. From what I could make of her descriptions, it sure sounded to me like she was feeding every cat that lived within a five-mile radius of her home in Rijeka. And she named all of them. Jasna was just a beautiful person with the most amazingly kind and caring heart. She had a wonderful sense of humor; she and Mladen both; a very dry and witty sense of humor that translated perfectly into broken English. I sometimes found myself writing back to her in broken English. Jasna was just a trip … the most exceptional and magnificent trip.

Croatia remained a long distance away from us, even in our very small world. We would have loved nothing more than to spend time with Jasna and Mladen sitting at the kitchen table and sharing a bottle of wine. We aren't going to get that opportunity, and feel crushing sadness for our loss. We can't begin to imagine Mladen's feelings today and where his mind and his heart are. And we are so sad that we can't be there to help him.

Mladen wrote to us last night after our call. He wanted to be sure that Paulina (this is how Jasna and Mladen referred to Pauline) clearly understood that Jasna did not die from anything that had to do with TM. He wanted to thank us for all that we had done for them over the years. And he wanted for us to know that Jasna had asked him to call us to be sure to give us her final good bye.

Good-bye our sweet Jasna. You will be so missed … but you will always be in our thoughts and in our hearts. Thank you for all that you did for us over these many years. You filled our lives with such joy and love.

Her memory should be a blessing.

We love you, Mladen, and we wish you peace. And so we need to find ourselves at the kitchen table where we can share that bottle of wine and raise a toast to our beloved Jasna.

Paulina and Sandy

THE 2014 TMA FAMILY CAMP AT THE CENTER FOR COURAGEOUS KIDS!

The TMA Family Camp will be held at The Center for Courageous Kids in Scottsville, KY from July 23 – 27, 2014! Applications are now open. Please apply by going to http://www.thecenterforcourageouskids.org/camperapp.html and select **Family Retreat Application**. We have limited space, so we encourage you to apply early! The camp will accept the first forty completed applications from our members for review. The application **must be completed** – both the electronic, online portion **and** the medical portion in order for camp to consider it a completed application. The subsequently submitted applications will be placed on a waiting list. We cannot wait to experience the magic of camp at CCK with you in 2014!

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

2012-2013 DONOR INDIVIDUAL LISTING (ADDENDUM)

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Plucky Knitter
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The Transverse Myelitis Association
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ANNOUNCEMENTS

2014 TMA Family Camp: July 23–27, 2014. Details inside.

DONATE

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