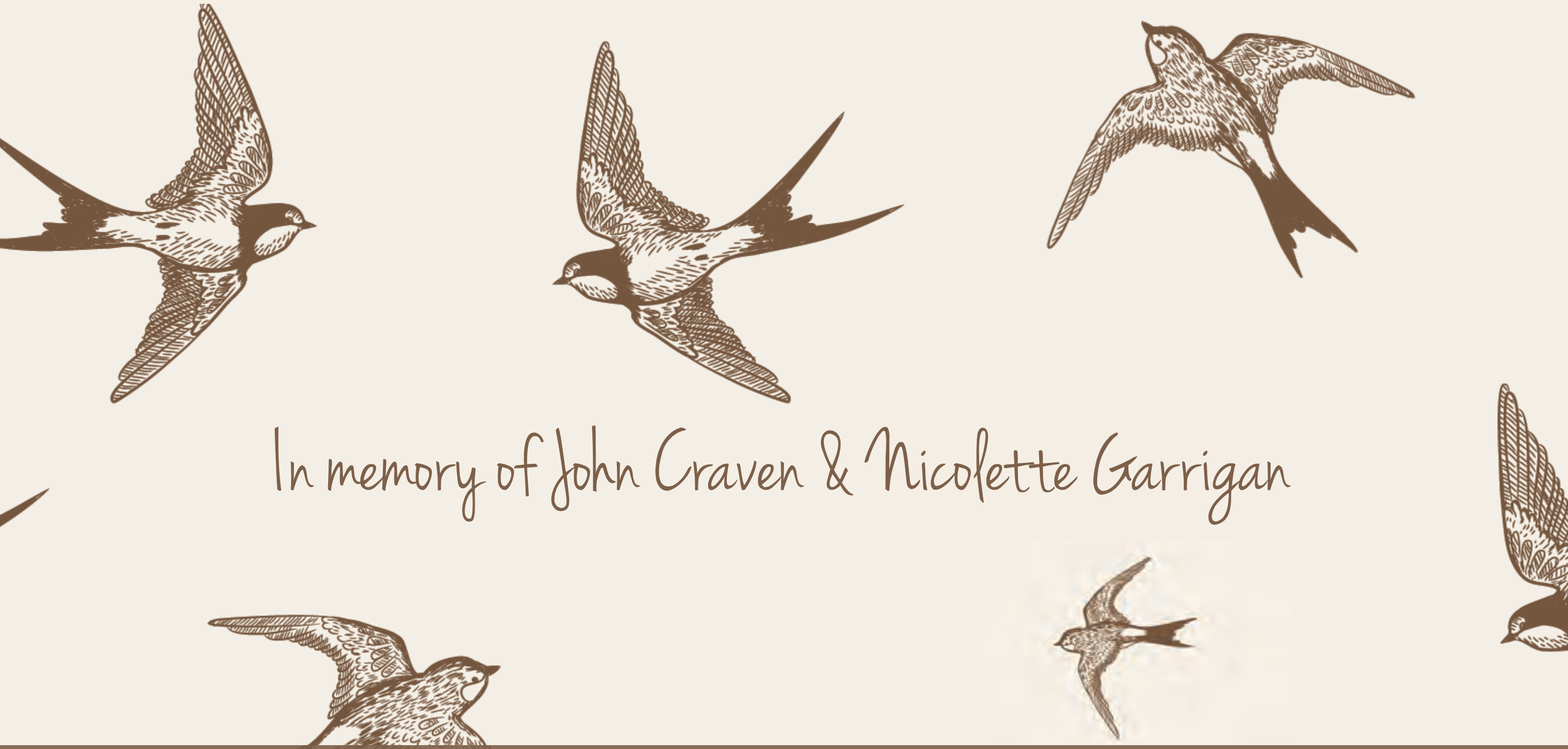
THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

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

Fall 2013



In memory of John Craven & Nicolette Garrigan

IN THIS ISSUE

2 THE EDITOR'S COLUMN
4 BACK-TO-SCHOOL
6 2013 RARE NEURO-IMMUNOLOGIC DISORDERS SYMPOSIUM
7 IN A GALAXY FAR FAR AWAY...
10 TMA'S 20TH YEAR GOLF BENEFIT
11 2ND ANNUAL FLORIDA AUCTION AND WALK
SUPPORT R US 12
A COLLABORATIVE PROJECT WITH CONSANO 14
CROWDSOURCING MEDICAL SPECIALISTS 16
ANNOUNCING 2014 TMA FAMILY CAMP 17
5K, BALLET, AND A SPINAL CORD INJURY 18
ASK THE EXPERT PODCAST 19

THE EDITOR'S COLUMN

Sandy Siegel, PhD

The TMA community has lost two great friends and the world has lost two really wonderful human beings.

I met John Craven in Seattle in 2003 at a support group leader meeting of the TMA. We had support group leaders attend from all over the country. John was our support group leader in Idaho. It was a great meeting and it was wonderful meeting John and his wife, Mary. John left an indelible impression and over the years, I was able to count on John's help and his support of our community. John had transverse myelitis (TM).

John passed away this summer, on July 5th, 2013. He was only 65 years old. John grew up in Sonoma, California. Before he got TM, he enjoyed soccer, triathlons, snow and water skiing and paragliding. He earned his Master of Science in mechanical engineering from University of California, Berkeley and a Master of Science in computer engineering from California State University, Chico. John worked at HP in Boise, Idaho for 24 years and held a number of patents for his work. His keen intellect and curiosity remained intact until the very end. John was a brilliant, loving and kind person. He was delighted with a good discussion on any topic. He lived a life that demonstrated love, encouragement of others, and a courageous daily battle to be as self-sufficient as possible. He was loved for his joyous laughter, keen intelligence and courtesy. John displayed a gentleness with the "wounded" be it human or animal. He was most happy to be with his family or eating desserts. He was a role model and an inspiration to everyone around him.

John suffered with significant neuropathic pain. As he possessed the mind of an engineer, he attacked his pain treatment full force with a very systematic approach. He went through all of the options using a thoughtful and incredibly well organized process, until he found the options that worked for him. Including, I might add, falling in love with and marrying one of the nurses from his pain clinic! Over the years, John became my 'go to guy' when it came to helping people deal with their pain. I am contacted by people all the time for all of the possible reasons people are seeking guidance and help. I am always very careful not to offer medical advice, because I am not a medical professional, and I am equally careful about referring people to someone in our community who is not a doctor, because I am cautious about people offering medical advice when they may not be qualified to do so. I referred to John because I knew he was always informative, helpful, understood what was appropriate and inappropriate to say to people, and he was loaded with compassion and a wonderful attitude. There was no one better than John to help people. John was able to share his experiences, and I knew that they would learn and find guidance from John, because he tried everything and the way it was tried and the way he was able to describe and explain what worked and what did not work was going to be rational, logical and helpful for people to consider.

I met Nickie and her mom, Fran, at the Children's Workshop that was held in Columbus in 2002. That first meeting of children and families from our community was about as intense of an emotional experience as one can imagine. Families who met each other at the workshop have remained close friends. I remained close to Nickie and Fran as well. They regularly attended our symposia and Nickie and I had telephone conversations.

Nickie Garrigan passed away on Thursday, September 9, 2013. She was just 35 years old; the same age as my oldest son, Aaron. It is impossible to really understand the suffering this young lady experienced in her lifetime, but it is important to try to comprehend the magnitude of the issues she was dealing with as a child. The fact that Nickie was not in the least defined by her physical challenges or this suffering was the most remarkable testament to her character, her determination and her personality. And it is equally the case that her positive attitude and positive perspective on life was a testament to her wonderful family, and particularly to her incredible mother, Fran.

Nickie was diagnosed with Recurrent Transverse Myelitis at the age of two and Lupus at ten years of age. She had so many complications through her difficult journey with both disorders. At one point, Nickie had surgery to implant rods because of scoliosis, a very common occurrence for children who are paralyzed at a very young age. She developed an infection and the rods had to be removed. Then during a therapy session, Nickie fell, and one of her vertebrae punctured her spinal cord. Then the rods needed to be implanted again. With each of these calls, my head would explode just thinking about what this kid was experiencing. Nickie didn't ever call me seeking pity. She called to talk and to have someone listen to her who had some understanding of her predicament. Nickie knew she was going to get empathy and compassion from me. There were always lots of tears during our phone calls; mine, not Nickie's.

Nickie was a fighter. She never allowed either TM or Lupus to define her or to limit her. At the age of five, she won the Scout Halloween Costume party dressed as a ballerina with her long metal braces attached to hard white shoes. She wanted to become an Olympic gymnast; her family encouraged her to pursue her dreams as a swimmer. The day camp award for achievement and effort always went to Nickie. She received the highest awards in Girl Scouts and became a Girl Scout Leader. In April of her senior year of high school, she had spine surgery and managed to walk down the aisle to receive her high school diploma in June.

As a young adult, she met a TM patient and her mother at Children's Memorial. Through this family, Nickie found the TMA. The TMA gave her hope and support. Nickie became a support group leader in Illinois. She lived in Chicago. When she was able, she held support group meetings at a local hospital. Although she was not able to continue these meetings, she frequently received phone calls from new TMA patients and shared experiences. During a recent inpatient physical therapy stay, with the encouragement of her long time occupational therapist, she registered for the Dallas Symposium.

We will miss Nickie and Fran in Dallas. Her courage inspired her family and friends and she will be missed by everyone who knew her and cared for her.

John's and Nickie's passings have caused me such great sadness. Mary and Fran, we all feel so sorry for your loss. John was such a good man. Nickie was such a good, kind and positive spirit.

Transverse myelitis is rare. It impacts so few people as compared to many other illnesses and disorders that people can experience. What we do and what we are able to accomplish depends so much on the willingness of people to get involved in helping others. John and Nickie were just the perfect examples of this generosity, compassion and selflessness. They had such complicated symptoms to deal with every single day, but in the midst of these challenges, they were always able to find the time and the energy to reach out to help others. They were both always there to help me.

It is my hope that we can get many more people involved in volunteering to do this important work -whether that help comes in the form of joining or leading a support group network or participating in an awareness or fundraising campaign or getting involved by helping us with a special skill or talent that you possess that might help our organization achieve our important goals. There could be no better way to honor John's and Nickie's memories than by working to improve the quality of lives of those people who John and Nickie cared for from our community; from John's and Nickie's community.

May their memories be a blessing.

Please take good care of yourselves and each other.
Sandy

As your child prepares to begin the new school year, it is important to make sure that his or her educational needs are met. Demyelinating diseases, like TM, NMO, or ADEM, often present unique challenges to students and schools alike. Because of the rare nature of these conditions, most school personnel will not be familiar with your child's medical condition or understand his or her unique needs.

WHAT DOES THE LAW SAY ABOUT STUDENTS WITH DISABILITIES?

The Individuals with Disabilities Education Act (IDEA) is a federal law designed to ensure that public schools serve the educational needs of students with disabilities. IDEA requires that every eligible student receive a "free appropriate public education," which means that schools must:

1. Identify and evaluate students with educational disabilities
2. Develop individual education programs (IEPs) for these students and provide them with special instruction and services
3. Maintain records, resolve complaints, and involve parents in decision-making processes.

Some examples of disabilities covered under IDEA include: autism; visual impairment; emotional, intellectual, or learning disability; or other health impairment (OHI) such as traumatic brain injury, epilepsy, or demyelinating diseases. Students with TM, NMO, or ADEM may qualify under the OHI designation.

Section 504 is a portion of the Federal Rehabilitation Act of 1973 designed to ensure that children with disabilities have equal access to an education. While Section 504 does not require the school to provide a plan as comprehensive as an IEP, it may still grant the child access to accommodations. In order to qualify under Section 504, the child must have a record of physical or mental impairment which "substantially limits" at least one major life activity (e.g., learning). Determining qualification for services is completed by the school. Please see the resources list on page six for more information on special education and Section 504.

WHAT TYPES OF SERVICES MAY ASSIST MY CHILD IN THE CLASSROOM?

Given difficulties associated with cognitive, physical, and fatigue-related symptoms, students with demyelinating diseases may require support in a classroom setting. Examples of academic support services include preferential seating, assistance with note-taking, extended time for assignments and/or exams, regular breaks, vision assessment/intervention (e.g., enlarged print), and assistive technology (e.g., laptop, dictation software). Services to address physical needs may include providing an extra set of books (one for home and one for school), utilizing an elevator pass to avoid stairs, allowing extra time to travel between classes, providing a permanent bathroom pass, and adapting physical education activities. Social-emotional supports may also be needed in the school setting. Such services may include counseling and/or in-service training for staff.

Guides summarizing information on TM and ADEM have been provided by Linda McCowen (blog post author), teacher and educational consultant from the Children's Medical Center Dallas School Services Department. She has created individual "School Guides" for TM and ADEM, which provide a brief summary of the medical condition and importantly, how it may impact a student in the classroom. Of course, we know that every student is different and theses guides are not meant to suggest a one-size-fits-all approach. Rather, this information often provides a useful starting place for families to share about their child's medical condition and his or her needs. From there, parents and the students themselves must advocate for the student's individual needs. Links to these guides are provided below.

HOW CAN I ADVOCATE FOR MY CHILD?

Partnering with your child's school early in the school year will be important when advocating for your child. Regularly communicating with teachers and other school personnel is recommended to establish services as well as to monitor progress and the ongoing (possibly changing) needs of your child. If needed, consider enlisting the support of your child's medical team including physicians, therapists, psychologists, and/or educational consultants. This can be very helpful for conveying information about your child's medical condition. It is likely that the school will require medical documentation so it will be important to collect this information and/or arrange to have it sent directly to the school.

WHAT IF MY STUDENT IS IN COLLEGE?

College students with disabilities are also protected under the federal law but there are some differences in accessing services between high school and college. The Americans with Disabilities Act (ADA) extends coverage of Section 504 to the higher education setting. Students with disabilities may qualify for academic accommodations (e.g., extended time for exams); however, unlike the K-12 setting, modifications (e.g., modifying exams) are not offered in higher education, as the student is expected to meet the same academic standards as his or her non-disabled peers. Another key difference for students moving from high school to college is that the student, who is now most likely an adult, is expected to serve as his or her own advocate. This means learning to articulate information about the disability and its functional impact. In other words, the student must be able to understand and describe how TM or ADEM impacts learning and academic performance. This information, in addition to documentation provided by the student's medical team, will serve as the basis for accommodations provided to the student. A common concern is related to confidentiality so it should be noted that disability records are protected by the Family Educational Rights and Privacy Act (FERPA) and are in no way linked to the student's transcript. For more information on ADA, see the resource list on the next page.

RESOURCES

School Guide for Students with TM: http://bit.do/student-guide-tm
School Guide for Students with ADEM: http://bit.do/student-guide-adem
For more information on special education services and the law, visit: http://www.wrightslaw.com
For more information on Section 504, visit the website for the Office for Civil Rights:
http://www2.ed.gov/about/offices/list/ocr/504faq.html
For more information on ADA, visit: http://www.ada.gov
Visit the website of your state education agency

Authors

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2013 RARE NEURO-IMMUNOLOGIC DISORDERS SYMPOSIUM

The 2013 Rare Neuro-Immunologic Disorders Symposium focused on **Repair and Recovery: Today and In the Future** will be held on Oct 25-26, 2013 at the University of Texas Southwestern Campus, Dallas, TX. The goals of this education program are to inform patients, caregivers and families about the current research and future repair and recovery strategies in development.

We have invited speakers from Johns Hopkins University, University of Texas Southwestern, Kennedy Krieger Institute, Children's Hospital Colorado, and Shriners Hospital Pediatric Research Center to share with us their experience, knowledge and research projects.

Dr. Anjali Forber-Pratt, Paralympic Ambassador and Elite Wheelchair Racer, will be the Keynote Speaker. Dr. Forber-Pratt is an inspiration to so many – her journey with Transverse Myelitis began when she was less than six months old. She was recently honored by President Obama as a Champion of Change for embodying the next generation of leadership within the disability community and her commitment to the promise of the Americans with Disabilities Act.

If you are not able to join us in person, the symposium will be recorded and made available on our website. For any questions about the 2013 Rare Neuro-Immunologic Disorders Symposium, please email us at info@myelitis.org.

Agenda, registration and logistics information can be found on our website http://myelitis.org/2013rnds.

IN A GALAXY FAR FAR AWAY...

That was the theme of our annual TMA Family Camp at the Center for Courageous Kids (CCK), which was held the last week in July. Everything about our summer camp was absolutely spectacular and true to the theme ... from the weather, to the families that attended, to the great camp staff, to our special guests, to our incredible medical people, to the awesome program, to the great food...it was a journey to the moon and back!

We had 36 amazing families at our camp from across the United States and from Canada, Scotland and South Africa whose children had been diagnosed with ADEM, NMO and TM. There were children at camp who had been diagnosed more than a decade ago, and some who got their disorder only months ago. Roberta Pesce who works with us at the TMA joined us from Madrid, Spain. Our camp was truly a national and international affair!

In order to accommodate 36 families into 30 cabins, a few families shared space in the lodges, which turned out to be very special for the families and we look forward to expanding these opportunities at our future camps. We had one cabin with four Moms and four daughters, all of similar age and all with transverse myelitis who formed a special bond with each other.

Special thanks to Debbie and Michael Capen who rented a van to help families with transportation to camp from the airport in Nashville and back!

We invited Dr. Allen DeSena (University of Texas Southwestern), Dr. Teri Schreiner (Children's Hospital Colorado), Dr. Doug Kerr (Biogen Idec), Dr. Daniel Becker (Kennedy Krieger Institute), Dr. Lana Harder (University of Texas Southwestern), Dr. Meredith Budai (Kennedy Krieger Institute), Audrey Ayers (University of Texas Southwestern) and Maureen Mealy (Johns Hopkins University) to join us and spend time with the families during camp and to participate in the education program for parents and older teens in the afternoons. The program was held as an informal panel to enable an interactive session. Topics covered all of the neuro-immune disorders and included acute therapies, long-term therapies for NMO, symptom management issues, emotional, psychological and cognitive issues and rehabilitation. There were extensive and interesting discussions during these presentations between the parents and medical volunteers and among the parents too! A great deal of critical information and perspective was exchanged. The medical volunteers made themselves available to speak with families outside of the education program during the camp day ... at meals, on the dance floor, in the swimming pool, in the horse barn, at the fishing and boating pond. In addition to the education sessions, Dr. Lana Harder, a pediatric clinical psychologist, who specializes in these rare neuro-immune disorders, spent one afternoon leading discussion sessions with siblings and the next afternoon with the children who have ADEM, NMO and TM.

We are especially grateful to all the medical volunteers for their willingness to spend a week at camp with our families. Dr. DeSena is in the last year of TMA's James T. Lubin Fellowship and will begin his specialization and clinical practice in rare neuro-immune disorders next year. It was a wonderful opportunity for our families to get to know Dr. DeSena on a more personal level. There's just nothing like covering a physician in warm purple oatmeal to facilitate a meaningful relationship, and that is precisely what occurred during the "messy games" at camp. It was wonderful to spend time with the medical professionals from the TM and NMO Centers at Johns Hopkins University and University of Texas Southwestern. We also established a very important relationship with Dr. Teri Schreiner at camp this year, a pediatric neuro-immunologist at Children's in Denver, Colorado. From Dr. Schreiner's participation in the education program, to her relationship with the families at camp to her courage and valor during the messy games, it was apparent that Dr. Schreiner would be an important resource and partner in our community for many years to come.

On Friday morning, Dawna Callahan (Manager of the Paralympic Sport Outreach and Development Programs) and Dr. Anjali Forber-Pratt (Paralympic medalist who has participated in both the London and Beijing Paralympic Games) from the US Olympic Committee joined us. Dr. Forber-Pratt holds a doctorate in education. Both Dawna and Dr. Forber-Pratt got TM when they were very young children. They gave a very inspirational presentation and our families were so thrilled to have them attend our camp.

The families had a great time at camp. The fun is non-stop ... dancing after breakfast and dinner, arts and crafts, the music room, fishing and boating, archery, bowling, playing different games in the gym, swimming, horseback riding, and evenings full of great family activities, including the fabulous messy games.

THANK YOU CCK for your warmth and generosity! It means a lot to us and the families!

We are so thrilled to announce that the TMA Family Camp will be back at The Center for Courageous Kids from July 23-27, 2014. We hope more families will join us next year!

The camp was supported by grants from The Roles Family Foundation, Biogen Idec, The Reeve Foundation's Quality of Life Grants Program, and through the generosity of our members who held fundraisers in their communities and made donations to support camp. To read more about camp and stories from campers and families, please visit our blog at http://myelitis.org/tma-blog.

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.

NEED FOR CAUTION ON SOCIAL MEDIA

Recently, we have been made aware of events concerning some of our pediatric patients with disabilities being approached online through social networking sites by child predators. We have always felt that social networking sites provide unique opportunities for getting families and patients together to share experiences. However, we strongly encourage all families, especially those with children, to ensure that their privacy settings are set appropriately so that strangers do not have access to any personal information. Also, we need to be wary of any individuals that are aggressively seeking to "meet up" with you and/or your children. Often, these people may appear to be friends and/or may masquerade as patients themselves. If you hear online from a suspicious individual, we recommend that you contact the authorities immediately and cease contact with the individual. Thank you.

2014 TMA GOLF OUTING

SAVE THE DATE! COMMEMORATING OUR 20TH YEAR WITH A GOLF OUTING

As we enter our 20th year and reflect back on when we started the TMA in 1994, we have come a long way. We have more peer-reviewed publications on these diseases than we did in 1994, we have two medical Centers of Excellence– at Johns Hopkins University School of Medicine and at the University of Texas Southwestern – dedicated to the study of these rare neuro-immunologic disorders, we have a growing physician network, we have awarded more than $470,000 in grants to fund pilot research projects, research centers and support clinical training, we have established the James T. Lubin Fellowship dedicated to the training of medical professionals focused on these diseases along with education programs, quality of life camps and more to support and advocate for our over 9900 members worldwide. But we are still far-off from where we need to be – we still don't understand what causes these diseases, we don't have biomarkers that would allow for more rapid diagnoses or tests for who is at risk for an acute demyelinating attack, we don't have new therapies for repair and recovery. We have a strategy and plans to get us there, but we need your help.

Save the date for our first golf fundraiser in Ohio to raise awareness and funds for these rare neuro-immune diseases. More details on the date and venue are coming soon! We are in the very early stages of our planning and would like to invite you and your friends and family to play and to help us with the planning of this event to mark the 20th Anniversary of the TMA. **100%** of the funds raised from this event will be used for research focused on developing new therapies to restore function after a demyelinating attack.

We are looking for volunteers to help us make this event a success! If you live in Ohio or one of our neighboring states, please get involved. You don't need to be a golfer to get involved in supporting this important event. If you would like to help with the event planning including volunteering on the day of the event, please get in touch with Sandy Siegel at either ssiegel@myelitis.org or at (855) 380-3330 ext. 1. If you would like to play, please respond to the Save The Date Form by going to: http://bit.do/golf-signup.

If you have friends and family who you think might be interested in playing, please talk to them about it, make sure the date is on their calendar, and please ask them to complete the form. Formal invitations with details about registration fees will be sent out in January 2014.

Please join us at our first-ever Golf Awareness and Fundraiser event to support the research and development of novel therapies for these rare devastating disorders.

SECOND ANNUAL FLORIDA AUCTION AND WALK

Honoring Sarah Robbins

We are proud to announce that we are hosting the **2nd Annual Central Florida Auction and Walk on May 2-3, 2014 in honor of our daughter Sarah Robbins** to raise awareness and funds to benefit the Transverse Myelitis Association (TMA).

It was November 2011 - our 10-year old daughter, Sarah, walked into our bedroom in the morning after she awoke and within 30 minutes collapsed in front of our eyes. Our already mentally challenged daughter, was now paralyzed and life had forever changed. We were told we were lucky that the acute onset was not in the cervical part of her spine or she may have needed permanent assistance to breathe. We were not feeling lucky. The world for our family changed that day and now we were faced with the everyday challenges of raising our paralyzed daughter. We tried to comprehend the doctor's explanation that currently there is no medicine or treatment plan available to heal this child or anyone else suffering from this disorder. We were told she could possibly walk with constant and consistent physical therapy, or she might not. Now, our mission has begun. Please join us in this mission to support the TMA - support ongoing research, provide families with information and support and to continue to raise awareness for these rare disorders. We cannot fight alone and need your help!

Stay tuned for more details on the TMA website – http://myelitis.org

Gratefully,
The Robbins Family

TMA WALK-RUN-N-ROLL
AWARENESS CAMPAIGN

A big thank you to our community! The TMA Annual Walk-Run-N-Roll National Awareness Campaign, which started in April 2013 with events in NJ, GA, PA, FL along with the upcoming walks in MI and IL has raised over $80,000* this year! Thank you to all the walk leadership teams for your hard work and commitment!

* The amount raised noted is at the time the newsletter went to print

SUPPORT R US

Allen Rucker

I never really got behind the idea of support groups. I could see how they might benefit others, such as grieving spouses or recovering addicts, but I never thought it would be comforting to tell my woes in front of a group of strangers. In fact, in my mind, it would be discomforting. I didn't want to listen to the whining and complaining and declarations of victimhood of others, and I didn't want them to listen to mine. I guess I took my emotional cue from that astute observer of human behavior, Tony Soprano:

"Whatever happened to Gary Cooper?" he tells his shrink, Dr. Melfi, "The strong, silent type...he wasn't 'in touch with his feelings' – he did what he had to do...once they got Gary Cooper in touch with his feelings, they wouldn't be able to shut him up!. And then it's dysfunction this, and dysfunction that, and dysfunction ma fangul!" When I became paralyzed, I figured that I would Gary-Cooper my way out of it by force of will and refusal to whine or lay the blame on anyone but myself. I did it my way and after years of despair and confusion, it worked out okay. Only later was I asked to join a group of other transverse myelitis (TM) survivors in an occasional get-together at an independent living center in Orange County. I initially went out of some misplaced obligation, I guess, and since it was a long drive for me, often simply weaseled out of going altogether.

But then I saw the light. Last Saturday's TM support group lunch-and-talkfest turned me completely around. It took seventeen years, but I finally got it.

The meeting, run by TM soulmate and chair user Cindy McLeroy, started out in much the same way – someone brought little sandwiches, someone else the macaroni salad and the hot dip, and we ate and kibitzed. First I was surprised at the turnout – 13 or 14 people with the disorder plus a couple of caregivers thrown in. Remember, TM is as rare as hen's teeth, as they say back on the farm. There are maybe 1400 new cases a year in the US. Divide 316 million by 1400. It's .00000-something.

The format of discussion was much the same as any such group: you go around the room and everyone tells their story, or an update on their story, and yes, there is plenty of ####ing about bad doctors and wrong meds and such. But beyond that – way beyond that – were a series of engaging, insightful stories by a group of engaging, insightful people who would never have met under any other circumstances. On my right was my good friend, Robert Slayton, a distinguished history professor at Chapman University. On my left was Rick Benson, the administrative supervisor of Mariposa County on the southern edge of Yosemite. A couple of seats down was Nicole Magner, a former Olympic-level competitor in the bobsled. I guess that if this were a board game, she'd be The Athlete. There was also The Librarian, The Nurse, and The Eighty-Seven-Year-Old Wonder Woman. It was a good group.

TM is a weird disorder – it attacks people in a hundred different ways. No one in this circle had the same clinical profile. But there were some common themes that kept popping up, themes that I had never fully grokked before then. Here are three:

1. Pain. Everyone, those in wheelchairs and those who looked otherwise "normal," had some variation of neuropathic pain, meaning pain that comes from damaged, unstable nerve cells, often in an area that is otherwise paralyzed. This kind of pain is often described as burning, squeezing, pinching, or pins-and-needles prickly. It's hard for outsiders to know what you are talking about. Neuropathic pain seems particularly susceptible to the glib, "all in your head" diagnosis. Since it doesn't have a direct source, like a broken arm or aching back, it must be psychosomatic. Change your attitude, so this dismissive thinking goes, and lose the pain. That is, in a word, a crock.

2. The Invisibles. Those with TM whose impairment and pain is invisible – they don't need wheelchairs, canes, or walkers – are the ones who face the greatest skepticism from outsiders. Looking at it from their perspective, it's almost a blessing to have a prop like a chair to validate your condition. The Invisibles have to constantly explain and justify their behavior, like they were on trial for malingering. They are also the ones often challenged by self-righteous chair users when parking in a disabled spot. "Hey, what's wrong with you, bud, you look perfectly healthy to me!" Never judge a neurological disorder by its cover.

3. Fatigue. Systemic fatigue, as experienced by damn near everyone with TM or MS, is not "fatigue" in the I'm-all-tuckered-out sense, in the same way that clinical depression is not the same as feeling bad after your girlfriend leaves town. And as this group unanimously, and vociferously, agreed, persistent fatigue is the hardest thing to get across to the uninitiated. One lady, I think it was The Librarian, tried to explain to her teaching colleagues her chronic fatigue, and they just hooted and hollered. "Hey, join the club – we're all exhausted from this job!" I get the same reaction when I tell friends that I take a daily nap. "Really? Boy, you're living the life!" Even when I try to explain, it sounds like an elaborate excuse to goof off. It makes you want to scream.

Initially, I thought I'd duck into this TM whine-athon, down some pizza and lemon pie, and hightail it back to LA and the Dodger game. Four and a half hours later, I was in no rush to go anywhere. These fellow TM'ers weren't there to cry in their soup. Unbeknownst to them, they were there to help me unburden myself from some unseen sources of guilt and frustration. I don't like to cross Tony Soprano, but maybe if he had found a mobster support group and gotten in touch with his feelings, he wouldn't have had to whack so many people to get his point across. But, then again, the next time someone blithely announces that "everybody" has pain and fatigue, I may, in Tony's words, "do what I gotta do."

– Allen Rucker

Allen Rucker contracted TM in 1996 at the age of 51, and was paralyzed from the attack at the T-10 level. Allen published a memoir about his life after getting TM; "The Best Seat in the House." It is now available in paperback. As his memoir so brilliantly conveys, Allen is on a journey. That journey has taken him into a life as a speaker and an advocate for the transverse myelitis and disability communities. Through his many speaking engagements, his appearance on the Montel Williams Show, and as a contributing writer for ABILITY and New Mobility Magazines, Allen is raising awareness about transverse myelitis. He is the author and co-author of numerous books of humor and non-fiction. "The Sopranos Family Cookbook," one of three books he's written about the Sopranos, was a New York Times #1 bestseller. Allen is the chair of the WGA Writers with Disabilities Committee. He lives in LA with his wife, Ann-Marie. They have two sons. Follow him on Facebook and visit his website for more information.

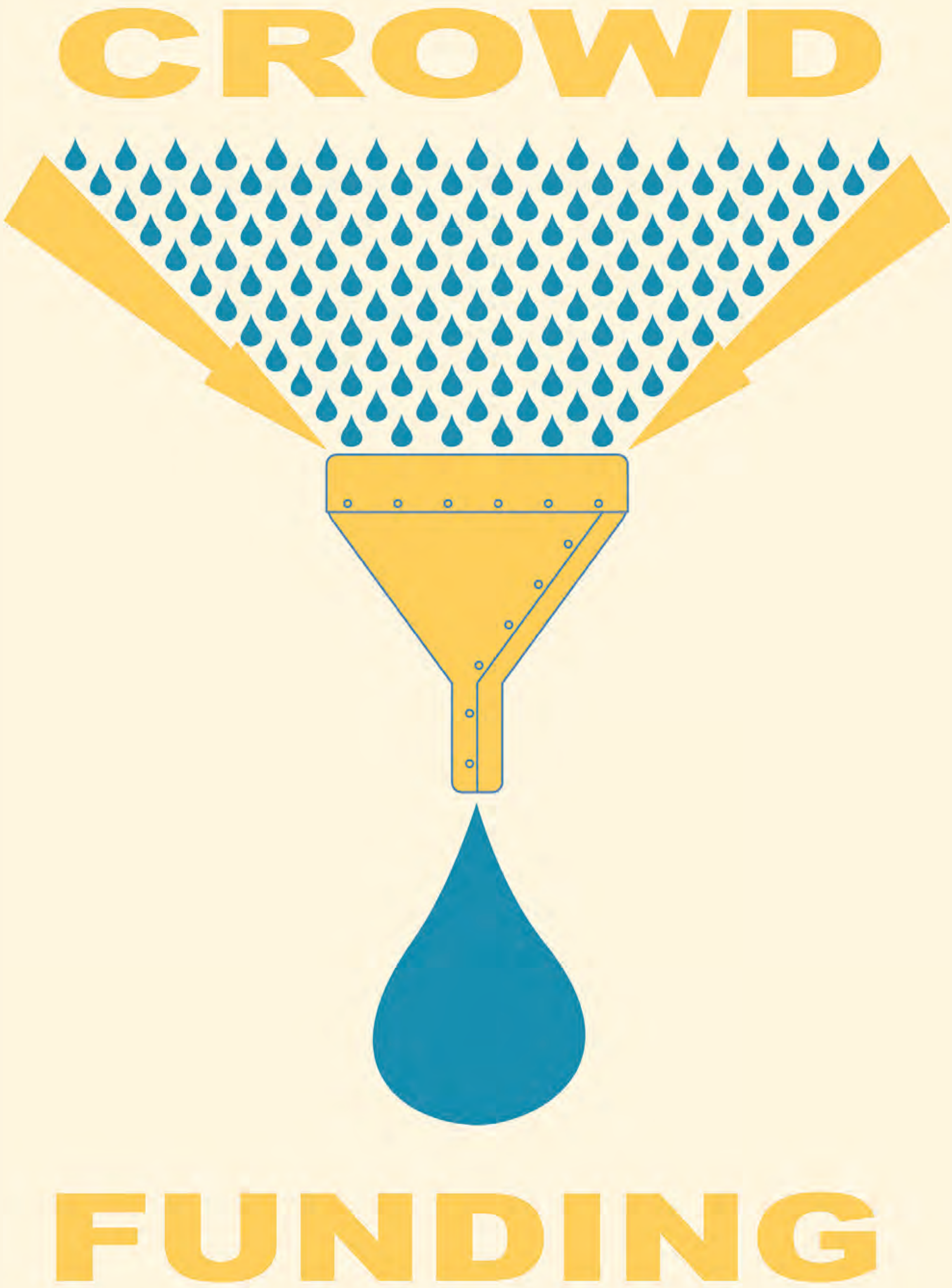
This blog was originally published in the Life After Paralysis blog series on the Christopher and Dana Reeve Foundation website. http://bit.do/allen-rucker to view the original article.

IN THEIR OWN WORDS ARTICLES

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

FACEBOOK

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



AN INNOVATIVE COLLABORATIVE PROJECT WITH CONSANO

consano
Hope. Honor. Heal.

We are pleased to announce a new collaborative project we are embarking on with Consano (www.consano.org), a non-profit crowd-funding platform for medical research based in Portland, Oregon. Consano's mission is to provide a platform to enable individuals to donate directly to specific medical research projects, advancing medical progress and empowering individual action. The goals of this collaborative project are to involve you - our community - in identifying research priorities that are most important from a patient perspective; provide an innovative platform where you can directly fund new research ideas that are meaningful to you; and promote and share novel research ideas with our community.

Earlier in the month of September, we reached out to physicians, researchers and institutions in our global network to propose innovative research pilot projects focused on rare neuro-immune diseases – Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON) and Transverse Myelitis (TM). We have asked them to submit projects that are focused on issues important to patients, and have a realistic milestone-driven funding goal. Based on the proposals we receive, we will seek the opinions of our more than 9900 members to learn about and identify your research priorities through a survey. We realize that research priorities will be different for individuals who have been recently diagnosed compared to those who have been living with the disease for a while. Our hope is to identify two research priorities identified by you for crowdfunding through Consano. We will inform you when the survey is available to share your opinions. This should be around mid-October. We will share the results of the survey with you, as well. Based on what you have identified as priorities that are important to you, the final selection of two or three projects for crowdfunding will be made by an independent group comprised of Consano's and TMA's Scientific Advisory Board.

As a patient, caregiver or relative, we greatly appreciate your support and ideas. We are excited to embark on this new approach to engage you in the research process and to raise awareness and involvement in funding research on these rare neuro-immune diseases!

CROWDSOURCING NEURO-IMMUNE DISORDER SPECIALISTS

One of the most frequent requests we receive at the TMA is a referral to a specialist who understands TM, ADEM, NMO or ON. Finding these specialists is critical and also a challenge. It is a challenge because these disorders are rare and there are few centers and physicians who focus their specializations on these disorders. Finding the specialists is critical to people's care, because there is very little published in the medical literature that offers definitive guidance about clinical care based on scientific studies. Today, almost all clinical care, including acute treatment, is based on expert judgment. A physician becomes an expert by caring for a large number of patients with these disorders and thus developing expertise.

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

The most exciting feature of this new resource is that the members of our community will be able to participate in expanding and growing our network of physicians. The TMA physician network includes the TM and NMO Centers at UT Southwestern and Johns Hopkins University and specialists from Multiple Sclerosis centers at major academic hospitals across the country. We want to hear from you! If you would like to share information about your physician or medical professional in your area who has been able to offer you excellent care through your journey with one of these rare neuro-immune disorders, please add them to the network and help us expand it. The link is www.myelitis.org/resources/physician-network. Using a community collaboration platform to grow our network of physicians and specialists, we can all participate in ensuring that everyone in our community receives care for their disorder. Please don't forget to ask your doctor for his/her permission to be added to network. The TMA will verify the information that is provided and will confirm that the physicians and specialists added to the network have an open practice and are seeing new patients. Thus, there will be some time between the submissions from our community and when they are posted on the network.

By adding physicians who are offering you great care to the Physician Network, other people in your area will be able to receive excellent care from a specialist. The second very important benefit is that by being identified as a physician or medical specialist in our Network, the medical professional will begin to see and care for more people with these disorders, and thus will develop a more intensive and extensive experience with these disorders. As expert judgment guides acute and long-term care, the development of this experience is of critical benefit to everyone in our community.

It is important to keep in mind that finding a physician in your 'area' is going to be a challenge or impossible for some of you. If you live in a rural community or in a state such as Montana or Alaska, that have very few neurologists, scattered across very large distances, you are likely going to have to travel to a different state to find an expert.

Please join us in growing our network. If you have a physician that you think should be on our network, please add him or her to the list by going to www.myelitis.org/resources/physician.network. We look forward to hearing from you and are excited about the potential to improve medical care!

ANNOUNCING 2014 TMA FAMILY CAMP

We are thrilled to announce that TMA Family Camp will be back at The Center for Courageous Kids in Scottsville, Kentucky from July 23 – 27, 2014. Please visit our website (http://myelitis.org/education/camp) where we will announce when the application is available. We have limited space, so we encourage you to apply early! Camp will accept the first forty completed applications from TMA members for review. The electronic, online portion **and** the medical portion of the application must be completed in order for camp to consider it for review. The subsequently submitted applications will be placed on a waiting list in order of receipt and will only be reviewed if one of the first forty applicants decides that they cannot come to camp. Please do not procrastinate – apply early to experience the magic of camp at CCK in 2014!

TWO GIRLS
ONE TRUE STORY

Most young girls spend their time riding their bikes, playing soccer, doing cartwheels, and other fun activities. Sarah Todd Hammer from Georgia and Jennifer Starzec from Illinois were no different. That is, until they both became paralyzed from the neck-down from an autoimmune condition called Transverse Myelitis (TM).

On April 19th, 2010 when Sarah Todd was 8-years old, and on August 16th, 2011 when Jennifer was 13-years old - their lives changed. Sarah Todd was diagnosed with TM with a lesion from C2-T1 on her spinal cord, and Jennifer's diagnosis showed she had a lesion from C1-T1. Becoming ordinary young girls that weren't stuck in a wheelchair and totally dependent on others- seemed nearly impossible.

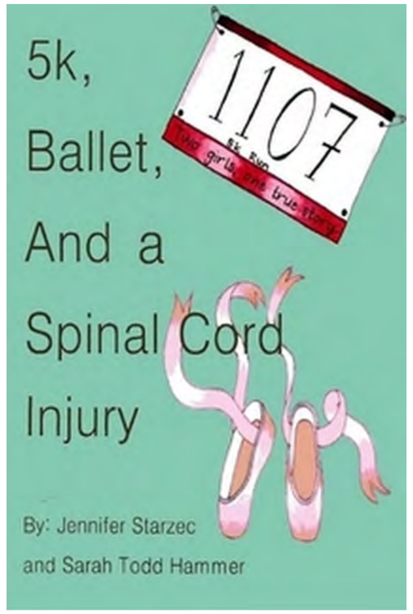
However, after a lot of hard work they made amazing recoveries - both were able to walk again and went back to doing what they loved. For Sarah Todd, it was dancing, and for Jennifer, it was running.

“ *These two girls are us.*

In the beginning, we lived far away from each other and had no knowledge of one another. However, a common friend connected us on Facebook, and our friendship began. We talked about transverse myelitis and were able to relate to each other, as well as our love for our hobbies.

Over time, we became more like sisters than friends. We still lived on opposite sides of the U.S., but we kept in touch all the time through text message and FaceTime. We told each other almost everything, and enjoyed very special moments together. It was like we clicked; we knew that we were supposed to meet each other. Transverse myelitis wasn't something we were glad to have, but we were glad that it brought us together.

It was only a matter of time before we realized that very few people know about transverse myelitis. We knew that awareness for this disease was crucial. So, we decided to write a book about our journeys and experiences with the disorder and combined our stories into a book, entitled "5k, Ballet, and a Spinal Cord Injury."



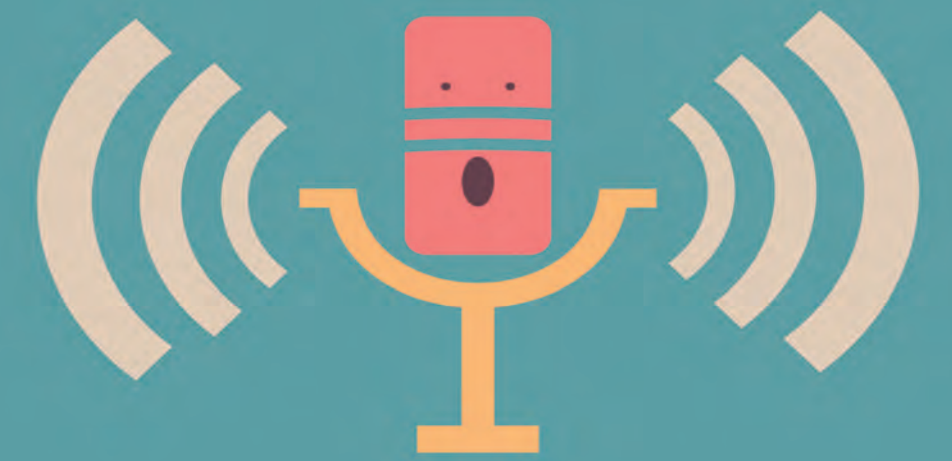
Transverse myelitis might not be the highlight of our lives, but we know it was meant to be. Raising awareness using our book may help other TM patients get diagnosed and treated quicker, aiding in a faster, better recovery. Plus, we got to know each other, and we know that life is rich; full of little secrets that only certain people are able to see."

We have also created this video to share our story and help spread awareness about Transverse Myelitis. You can watch it by going to http://bit.do/tm-awareness-video.

Don't forget to pass it along and advocate for all those suffering from rare neuro-immunologic disorders! ”

By Sarah Todd Hammer and Jennifer Starzec

Through their passion – ballet and running – and with strong support from family and friends, Sarah Todd and Jennifer fought hard to recover and to pursue their dreams. They have shared their story with all of us in their book, "5k, Ballet, and a Spinal Cord Injury", a must read inspirational story. One third of the proceeds from the sales of the book will go to The Transverse Myelitis Association. Visit the Amazon Kindle website for a digital copy or Lulu for a paperback version.



ASK THE EXPERT PODCAST RECORDING NOW ONLINE!

Thank you to our community members who joined the podcast on "Understanding Repair and Recovery After non-traumatic Spinal Cord Injury" as part of TMA's Ask the Expert podcast series on September 16, 2013. The physician-experts on the panel were Dr. Benjamin Greenberg from UTSW and Dr. Michael Levy from Johns Hopkins University.

Over 75 people dialed-in to listen to the Live Podcast, which was moderated by TMA Executive Director, Chitra Krishnan. Thank you for submitting your questions in advance as well as sharing your questions on the TMA Facebook page.

During the 45 minutes of the podcast, we were able to address most of the questions and the focus of the questions was determined by those that received the most votes by our community.

We are planning on future podcasts on topics of Fatigue and Cognition, Pain Management, and Spasticity Management. Additional podcasts will be planned to address your questions and concerns.

The podcast recording is available on our website https://myelitis.org/education/podcasts. The transcript of the session will be posted soon.

If there are topics that you would like us to address in our podcast series, you can share your thoughts by sending an email to info@myelitis.org and please use TMA Podcasts in the subject line.

Our best wishes,

The Transverse Myelitis Association

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CHANGE SERVICE REQUESTED

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ANNOUNCEMENTS

2013 Rare Neuro-Immunologic Disorders Symposium: Oct 25-26, 2013. Details inside.
2014 TMA Family Camp: July 23–27, 2014. Details inside.

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