

THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

ADVOCATING FOR THOSE WITH ADEM, AFM, NMOSD, ON & TM



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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>.



Alana Marie Swagerty Spence was born on May 7, 1989 in San Diego, California. She was a beautiful child, full of love for her family. Starting when she was 5 years old, we moved around quite a bit; first to Arizona, then to Alabama, Mississippi, Louisiana, and the San Francisco Bay area. When she was 10 years old, we finally made it back home to San Diego. Over the next few years, she had a more typical “SoCal” attitude about life, especially as a teenager – no worries, always on the go, popular and outgoing, but keeping just a few close friends. She loved school, and always did her best to make her family proud. On November 11, 2005, when she was 16 years old, her life, and ours (parents Tim and Rhonda,

her brother Darren, and sisters Savannah and Tessa) changed forever.

Within 30 minutes of feeling weak and complaining of a sore neck and shoulders, she was completely paralyzed and not breathing. Alana spent the next 8 months in 6 different hospitals in San Diego, Orange County, and Los Angeles as countless neurologists tried to determine the cause, but to no avail. All that was known was that her spinal cord had become inflamed and the myelin surrounding her spinal cord had disappeared, determined from MRI. After researching Alana’s symptoms, we discovered the Transverse Myelitis Center

THE EDITOR'S COLUMN

Sandy Siegel, PhD

*Alana's motto was
"Keep Smiling,"
and those of us
at the TMA and
all who came into
contact with her
will always do just
that whenever we
think of her.*

at Johns Hopkins, headed up by Dr. Douglas Kerr. We asked the lead neurologist at the first hospital to contact Dr. Kerr for guidance and protocols in an attempt to keep the damage isolated to Alana's spinal cord. There was fear that whatever caused the damage would spread up through her brain stem, but fortunately, no more damage occurred. During her hospital stays, she touched many people, including doctors, nurses, patients and other families. She had a special way of making people feel good through her infectious smile, strength, witty humor, intelligence, and her beautiful soul.

After being trained to care for Alana, we brought her

As with most of the young people in our community, I met Alana at camp. I had been in touch with her family before they arrived, and was looking forward to meeting the entire Spence family. This was our very first camp at Victory Junction, and Alana's presence made what was already an incredibly intense emotional experience, that much more so. It is impossible to put into words what it was like spending the weekend with Alana, Jim, Maggie, Cody and all of the other young people who made it to North Carolina for that camp.

When I received the phone call from Tim on Saturday morning, I was devastated. I usually share what I know with Pauline as soon I hear news of any kind. The social cost for not doing so is significant. But not this time. I was

home on July 6, 2006. Shortly thereafter, we contacted the TMA regarding the Transverse Myelitis Camp at Victory Junction, North Carolina on November 17-19, 2006, and Sandy put us in contact with Dr. Peter Sim at the camp. Since Dr. Kerr and his staff would be at the camp, it was an opportunity for Alana to not only meet Dr. Kerr, but to connect with other TM patients in a remarkable setting. Through extraordinary efforts by Sandy, Dr. Sim, Dr. Kerr, and the U.S. Air Force's Global Patient Movement Systems Command (Alana's father is a retired Naval Officer), we spent the weekend at the TM camp.

After over a year of isolation and fear of the unknown, our

concerned about how she would react to hearing about Alana, so I put off telling her for a couple of days. I finally found a time and place to tell her. There's just no short cuts or magic formulas for avoiding or diminishing the feelings of loss. It is a process; a long and difficult process. And the difficulty can be measured by the depth of love that one has in their heart for a person.

The sadness and grief from losing Alana has been overwhelming for everyone who was touched by this truly remarkable and beautiful child. It is one of the more incredible aspects of our lives that someone with such a positive and wonderful spirit, so full of life, can lose their life at such a very young age.

Living with quadriplegia and ventilator dependence is a precarious existence. For almost everyone I know with TM, ADEM or NMOSD who have lost motor function, being able to walk is at the top of their wish list; unless they can't breathe on their own. Losing the ability to breathe is the game changer. Doing this work over the past twenty years has introduced me to many challenging experiences and none has been

lives were forever changed by those 3 days. We remember Alana crying tears of joy upon meeting everyone there because she said it gave her hope and she was finally able to talk to people who understood what she was going through. When she heard about Stage Night, she decided she wanted to do a stand-up or what she jokingly liked to call it, a sit-down comedy routine. We remember having dinner with her that night in the cafeteria and she was really quiet. When we asked her why she was so quiet, she said she was thinking about her comedy routine. It only took her less than 30 minutes to come up with what would be a truly memorable experience. She had the whole audience laughing so hard, that it made some of

them cry. She also sang a couple of songs, and needless to say, everyone had a wonderful time.

At the camp, Dr. Kerr made arrangements for Alana to be admitted to the Kennedy Krieger International Center for Spinal Cord Injury in Baltimore, and we arrived there on November 20th. After undergoing 2 days of testing, Dr. Kerr and Dr. McDonald of Kennedy Krieger Institute determined that she should continue treatment, with physical and respiratory therapy at the Center, where she stayed until returning home on January 10, 2007.

Alana had completed her High School Junior year in



various hospitals, and returned to Valhalla High School, graduating with her class in June 2007. In another miraculous turn of events through the efforts of Dr. Kerr and the TMA, Alana was accepted as a study participant in Dr. Ray Onders' development of a diaphragmatic pacemaker, funded by the Christopher Reeve Foundation at Case-Western University Hospital in Cleveland, Ohio, in August 2007. Up until that time, Alana had been on a ventilator attached to the back of her wheelchair, with a 3 to 4-hour battery life. After implanting of the pacemaker, a device the size of a calculator with a 30-day battery by Dr. Onders, Alana was able to enjoy significantly more freedom, enabling her to go to school, to the movies

and visit friends, which expanded the quality of her life immensely.

Alana enrolled at Cuyamaca College near her home in September 2007, with the goal of obtaining a degree in Communications. After 4 years of study and tremendous effort and desire on her part, Alana graduated with an Associate Degree in Communications in May 2011, and was accepted to San Diego State University and San Diego Christian College (SDCCC) to continue to obtain her Bachelor Degree. After 3 semesters at SDCC, Alana realized she was sacrificing her health and well-being with her studies, so she decided to take some time off to

more emotionally profound for me than the entire notion of ventilator dependence and the impact this has on a person's life ... and their entire family's lives. And it is from these feelings that I think about Alana and Jim and Jonathan and the many others who live their lives thinking about and being concerned about something that the rest of us never think about and take for granted.

I think of Alana every day. I've thought of her often from the day I met her. Our thoughts and our prayers go out to her family; they've lost a very special child. And our thoughts and prayers go out to all of those in our community who have come to love Alana through her great humor, sensitivity, compassion and remarkable insights about life. We hear it often, but it is so true; life is fragile. Losing a beautiful child at the age of 26 is a stark reminder that we all need to make the best of every day we have, because each of those days is a blessing.

Alana, you will be missed by everyone who was touched by you, who cared for you and who loved you. You will be in my thoughts often ... and in my heart always.

Please take care of yourselves and each other.

Sandy

get stronger and re-focused.

She spent the last 18 months reading and writing, making videos using Dragon Voice software, making hundreds of friends on social media, and dedicating her life to adding joy to those around her. Alana wore her heart on her sleeve and loved all people, but especially her parents, grandparents, brother, sisters, and of course her cats. Wherever we went she always found somebody to compliment one way or another, because she said you never know what a person might be going through, and it made her feel good to think she may have made a difference in their day. If she saw a person in uniform, she always made a point to thank them for serving our

country. She enjoyed giving more than receiving and that would end up being her final gift, as she donated some of her organs to the Johns Hopkins Transverse Myelitis Center in hopes of finding a way to help others struggling with TM. Alana passed away peacefully in her sleep on the morning of September 19, 2015.

Alana Marie Spence will always be remembered for her positive outlook on everything about her life, the joy she imparted to everyone she touched, and the desire to always take others' displays of pity and instead turn that emotion into warmth and goodwill.

Tim and Rhonda Spence



Timeless Captures Photography

UPDATE ON IMAGING STUDY:

Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis

DR. LANA HARDER, UTSW

We are so grateful to our TMA community, in partnership with Consano, for facilitating an exciting pilot study on cognitive functioning in transverse myelitis (TM) through crowd funding! Given our previous research findings at UT Southwestern and Children's Health showing that many of our TM patients are experiencing cognitive dysfunction, we designed a brain imaging study to learn more. By taking pictures of the brain in a different way than would be usual for clinical care, we are hoping to get a better look at the brains of TM patients so that we may increase our understanding of this condition. It is because of the support of the TMA community that we are able to take this important step in research!

I am fortunate to have collaborators, Dr. Benjamin Greenberg from Neurology and Dr. Craig Morriss from Neuroradiology, who have devoted significant time and effort to design our novel pilot study. Our team and our patients have shown great interest and enthusiasm and are also making this study possible. Individuals diagnosed with TM between 8 and 18 years of age treated at the Children's Medical Center Pediatric Demyelinating Diseases Clinic in Dallas, Texas are eligible to enroll in this study. We are happy to announce that we have enrolled our first participant and will continue to enroll participants until we reach our target, when we will analyze the data and share the results with you. We are excited to learn more about TM by taking a closer look at the brain. Results from this study are expected to deepen our understanding of TM and inform treatments for our patients. Stay tuned for more on this study as we move ahead!

FOR MORE DETAILS ON THE STUDY, PLEASE VISIT THE TMA WEBSITE FOR CLINICAL STUDIES:

<https://myelitis.org/clinical-studies-and-trials/utilizing-brain-imaging-to-understand-cognitive-dysfunction-in-transverse-myelitis>

FROM THE DESK OF DR. MICHAEL SWEENEY

The TMA James T. Lubin Fellow at University of Utah

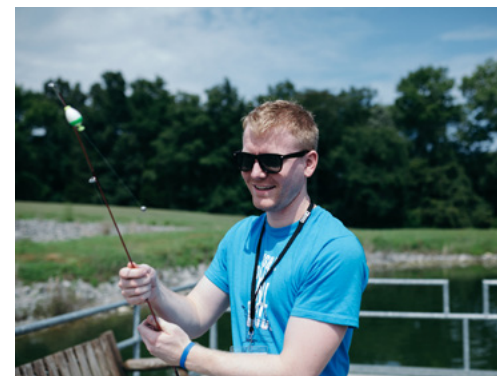
Dear TMA members,

My training fellowship is in full swing. It got off to a great start with spending a week having a blast at the annual quality of life TMA camp held at Center for Courageous Kids in Scottsville, KY. I can't say enough good things about camp. The perspective and motivation it gave me are truly invaluable. Since starting my fellowship here at the University of Utah and Primary Children's Hospital, I have been seeing many patients with complicated neurologic diseases, both in the clinic setting and also in the hospital with multiple sclerosis, NMOSD, transverse myelitis, and many other immune-mediated neurologic diseases. For the past several weeks, I have been rotating through the clinical labs at ARUP laboratories in order to gain a better understanding of the many tests that we order as part of a clinical evaluation. ARUP Laboratories is a national clinical and anatomic pathology reference laboratory and an enterprise of the University of Utah and its Department of Pathology. I am looking forward to visiting UT Southwestern and Johns Hopkins University as part of my training this coming spring to further expand my experience.

Thank you for your support,

Sincerely,

Mike





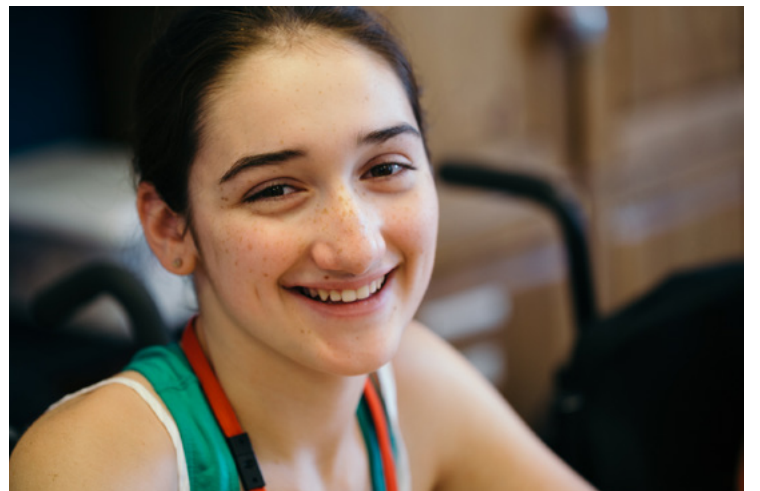
2015 TMA Quality of Life Family Camp

The Kentucky summer was thriving when the 2015 TMA Quality of Life Family Camp commenced on July 21, 2015 at The Center for Courageous Kids (CCK) in Scottsville, KY. Once again, staff and volunteers at CCK welcomed The TMA staff, volunteers, medical professionals, and 27 incredible families, with open, inviting arms. Our families represented 15 different states of the U.S. and 4 countries (Canada, Denmark, Republic of Georgia, and United Kingdom)! Regardless of any jet lag, everyone was ready for the 5 days to break away from our usual day-to-day routines and just enjoy life with other children, other families, who without introduction empathized with what makes each of our day-to-day lives unique.

It usually goes without saying within our TMA community that life is often extremely difficult because of a rare neuro-immune diagnosis. While we may seem as though we are a large group, we are still “rare” in the general population and so many, including within the medical community, cannot truly understand what it means to live with or to have a child with one of these disorders. To be able to come together with other families who understand what these diagnoses mean and

with medical professionals who have vested their time, energy and hearts into our children’s unique circumstances, is incredible. But to be able to do so at a place such as CCK, where our kids can be just that – kids; swim, fish, ride horses, paint, try archery, sing, be in a talent show, and have so many more opportunities, well, it’s nothing short of extraordinary.

TMA Quality of Life Family Camp is a unique, awesome, heartfelt opportunity for not just the kids but their parents, siblings, the medical volunteers, and The TMA staff and volunteers who attend. It is incredibly important to our community and for the well-being of our children as they grow into adulthood to be able to experience the connections and look fondly back upon their time at camp – one that they likely couldn’t or it would be extremely difficult to find anywhere else. The experience of camp wouldn’t be what it is without the support of our sponsors, our community of financial supporters, and our volunteers. Our sincere and heartfelt thanks go out to The Roles Family Foundation, our amazing medical professional community, inspirational volunteers and board members: Sandy & Pauline Siegel, Debbie & Michael



Capen, Paralympians Dr. Anjali Forber-Pratt & Amanda McGrory, and The Center for Courageous Kids. It is because of each of these individuals and organizations that camp is made possible.

We are so excited to be able to once again announce that the 2016 TMA Quality of Life Family Camp will reconvene at The Center for Courageous Kids in 2016! **Mark your**

calendars for July 31 to August 4, 2016 for a summer camp you will never forget! Be sure to stay tuned for our announcements via email, Facebook, and our website for the official announcement of when applications are live and available. We can't wait to see you in 2016! Until next time, enjoy the photos that speak volumes of the amazing time that was had this past July!



Our TMA Family Camp Adventures

Travelling all the way from Scotland to Kentucky was an adventure in itself especially for Ameera and her Gran. When we arrived at camp it took a while for us to adjust to the time difference but it wasn't long before we were having a great time. One of the things we don't realize as parents is that children are very intuitive. We think that they don't notice the little things, but they do. After we'd been staying at the camp in Kentucky for a couple of days, Ameera told me that she hadn't seen me laugh that much in years and she's probably right. As parents of children with a rare condition we are too busy worrying about hospital appointments, school and a million other things that we seem to forget how to have fun and that's what CCK is all about. I enjoyed the whole TMA Camp adventure from start to finish and will never forget the wonderful people I met along the way ... from the

parents and their amazing kids to the TMA, doctors, nurses and the CCK staff. Amanda and Anjali also gave wonderful talks on growing up with TM and what they have accomplished. I am sure this gave us all hope for our own TM Warriors and I am already noticing the difference in Ameera since she came back from camp. She is no longer afraid to try new things and is excited about the future. I can't thank the TMA enough for this experience and hope to return next year.

Lisa Ali, Parent

When I arrived at the Center for Courageous Kids I felt nervous, as I wasn't sure what to expect. I'm a shy and quiet person and didn't have much confidence until I came to camp. I really enjoyed the activities and tried canoeing, horse-riding, fishing and archery. I would never have tried any of these back home and my favorite activity was definitely archery. My

mum helped me to look for archery lessons when we came back to Scotland and we found a local club in our area. This is something I am really looking forward to. By the end of camp I felt that I could open up more and felt more comfortable talking to other people my age. The CCK staff were good fun, very friendly and easy to talk to. I loved the whole experience of being there. Messy games were brilliant and I loved the carnival and movie outdoors. I was sad when we had to leave, but I know that I'm a different person now because of the

CCK camp and am ready to try new things and meet new people.

Ameera Ali, Camper

TMA Family camp was an amazing experience that I will never forget. There were so many activities to do and it was great to be with kids who have been living with and understand what I've been through. Some of my favorite activities were messy games, woodshop, nature and archery. At camp we also had a movie night where we got to watch a movie outside with our friends, which was so much fun. Making new





friends was awesome and it was nice to feel normal once again, because we got to be with people who are in a similar situation. I would love to go back to the camp as a camp member or a counselor; the vibe around the camp is great and it's fun to be around everyone. At the end of my week at camp I came to appreciate my life a little more and I already miss my friends from the camp. The overall camp to me was great and I loved it.

Isabella Lindsey, Camper

We had so much fun at camp. It was the first time we had met anyone else with TM.

Caden got to see that there are other kids just like him. We got a much needed break from the most stressful year of our lives and Caden was able to just be a kid again. It was awesome to see him riding a horse and doing archery. That smile on his face was priceless. We met so many wonderful people. We even took our first airplane ride ever for both of us. This was also the first vacation we have ever taken in our lives. We are so blessed to be members of the TMA family. Thank you so much.

Caden Tobar & Jamie Heminover, Camper & Parent

Chloe has never been to a camp and this was an amazing first camp experience for her. She's so glad she got to go and wants to return every year. Being around kids like her and nice counselors made this summer special and more memorable than others. Horseback riding, swimming, archery and catching her first fish are just some of the pearls taken from CCK. The TMA made this cross-country road trip possible and it made a huge difference in all of our lives. What a mind-blowing group of people to bring this experience to children and families. Thanks from the bottom of our hearts!

Jill & Chloe Russ, Parent & Camper

Thank you to The Roles Family Foundation for their support in providing travel grants to families to attend the 2015 TMA Quality of Life Family Camp.





2015 ILLINOIS , MICHIGAN

SEPTEMBER 20

AUGUST 22

& MARYLAND

OCTOBER 4

WALK-RUN-N-ROLLS



A lot of laughter, a few tears and a great amount of support...

By Niki Tracy

When I received an email from Chitra Krishnan inviting me to a TMA Mom's Retreat in Corolla, NC, there was no question in my mind that I was going to attend. My three year old daughter, Rilynn, was diagnosed with TM 2 ½ years ago at the age of nine months. While she continues to make great strides in her recovery, one of the more frustrating things for me throughout this process has been the challenge in finding another mom who can relate to the stress and worry that comes along with this diagnosis. Chitra, Sandy Siegel and the rest of The Transverse Myelitis Association played an integral role in Rilynn's care immediately after her diagnosis and are directly responsible for helping us get Rilynn admitted for plasmapheresis treatments and inpatient rehabilitation when the local neurologist was telling us this wasn't an option because of her age.

The purpose of the retreat was to invite moms of kids with transverse myelitis, acute flaccid myelitis, NMOSD and ADEM to have the opportunity to sit down and discuss our ideas for ways the TMA can focus on their pediatric/young adult programs and issues. There were six "TMA Moms" who were able to participate with dates of onset for our kids ranging from 2 ½ years to 18 years ago. It was an incredible experience to spend time with this group of women – every one of us had a different story to tell and every one of our kids' recoveries has transpired in a different way. But we all had the same story to tell with regard to the TMA. The TMA has provided all of us with an incredible amount of resources and contacts that have helped in our child's recovery.

The weekend was spent talking about our lives, sharing our stories, and brainstorming about ways to expand the reach of the TMA and to provide more information and resources to our community members. One of the ideas we discussed was developing a Parent Ambassador Program to help foster communication between medical professionals, the TMA Staff and other parents/caregivers of children and young adults affected by TM, NMOSD and ADEM. We began working on developing outreach programs in locations around the country specifically targeted at the TMA's population in the form of art therapy, a weekend dance workshop, and the possibility of an adaptive sports partnership with Disability Sports USA. Advice on working with schools to develop Individualized Education Plans (IEPs) for our children was a hot topic and progress was made on developing a resource for parents. Parent-led podcasts are a hope for the future in an effort to facilitate more open communication and education in a peer-to-peer setting, as well as the ability to offer a forum for young adults with TM, NMOSD and ADEM to communicate with each other about ways to handle different issues in their lives.

Overall, it was an incredible weekend with some incredible progress on how to achieve the five-year mission that was developed in the Spring of 2014. For me personally, because Rilynn is still a little young to attend the Annual TMA Camp, it gave me the opportunity to develop relationships with a group of women who really understand what my family has gone through. There was a lot of laughter, a few tears and a great amount of support.



MY JOURNEY FROM THE WHEELCHAIR TO USING MY LEGS AGAIN

By Noshaba Malik, 21, Pakistan

It was a beautiful morning on July 12, 2010. I was in 11th grade walking with my friend down our college corridor when suddenly I felt a severe pain in my back. The pain was dreadful. I went to the college restroom and took Panadol (paracetamol/acetaminophen) and rested for an hour. After an hour, I tried to stand up but my lower limbs were unresponsive. I was taken to the hospital and diagnosed with Transverse Myelitis. The doctor gave me steroids as an initial treatment.

I was paralyzed from the belly down and also had numbness. I started walking within 2 months of my diagnosis because of the medication I was given, physiotherapy, and great care by my family. I can still remember what it felt like to stand on my feet for the first time after paralysis. It was like being a baby again, learning how to walk, how to take steps. I started going to college and continued my studies but I continue to have some problems from TM. I can't walk fast, I can't

run, and I also have problems controlling my bladder. I am still taking medication, but the numbness in my lower limbs and my urinary incontinence are not getting better.

I passed my 12th grade with flying colours and joined the field of Physiotherapy, and I

am pursuing a Doctorate in Physical Therapy. I take my limping leg and my uncontrolled bladder with me. I go out every day, I go to college, visit my friends, and go shopping. I feel that when I pass people they look at me and then they whisper to each other but I don't care about that. I know I have to struggle, I have

to study hard, and I have to get a good job.

I want to convey a message to people with disabilities: "don't confine yourself to the four walls of your home, come out and shine." I also want to convey a message to all able-bodied people: **"Disabled people don't need your money or attention, we want your respect."**

**"don't confine
yourself to
the four walls
of your home,
come out and
shine"**

TMA SUPPORT GROUP IN CENTRAL TEXAS

Gina Rodriguez, Central Texas Support Group Leader

HI EVERYONE! My name is Gina Rodriguez, and I have volunteered to lead the Central Texas Support Group. I lived in the Dallas/Fort Worth area for about 10 years, and helped Barbara Nichols with the support group there. My husband joined the Army and has been stationed at Fort Hood, near Austin, Texas. Once we found this out, I spoke with Barbara, and we decided to start a group for Central Texas. Although it's taken far too long to get off the ground, I'm excited to finally get this going!

My story is a familiar story, so I'll keep it short. In 2008, at the age of 28, I woke up one day unable to urinate. Two days later, I finally went to the ER and had a Foley catheter

put in. I saw quite a few urologists, none of whom could figure out what was going on with me. I had the catheter in for a month before I learned to self-catheterize, during which time my legs also grew weaker. It was finally determined that the cause was neurological.

The first neurologist waved me off and told me I would be fine. I saw a few more specialists and was finally put on steroids. The steroids seemed to help. The second neurologist that I saw ran more tests, and couldn't figure out what was going on with me. He finally did a spinal tap, at which time I was diagnosed with transverse myelitis. My options were to wait and see what happened next,

or he would refer me to the Clinical Center for Multiple Sclerosis at UT Southwestern. I opted to be referred to UT Southwestern (UTSW).

The neurologist at UTSW was my 10th specialist. It took two years and multiple tests and specialists to get to the right place. My diagnosis was between Multiple Sclerosis (MS) and Neuromyelitis Optica (NMO). For years, my neurologists at UTSW leaned toward NMO, although I did not yet meet the diagnostic criteria. I was officially diagnosed with NMO about two and a half years ago, although I have been treated with the NMO medications since 2010.

I have had approximately 8 flares since 2008. I have recovered from being blind, paralyzed from the waist down, and many other manifestations of this disorder. I am fortunate to have found the right doctors, and to have recovered well from flares. In 2014, my husband and I welcomed our son, Daniel, into the family. I hope to connect people with rare neuro-immune diseases, and provide a safe place to learn and support one another.

If you live in this area and would like to join our group, please contact me at tmafamily9@gmail.com.

DIFFUSION TENSOR IMAGING IN PEDIATRIC TRANSVERSE MYELITIS: A case study

Barakat et al. published a case study in 2012 about using diffusion tensor imaging in a pediatric transverse myelitis patient. Magnetic resonance imaging (MRI) is commonly used to diagnose transverse myelitis. Diffusion tensor imaging (DTI) is another imaging technique that can be used to assess the spinal cord. It looks at the diffusion of water molecules in the spinal cord and can identify white matter, differentiate between white and grey matter, and identify damaged areas of the spinal cord.

The authors used DTI to look at the spinal cord of a 7 year old with transverse myelitis, and compared his results with those of healthy controls and with others with traumatic spinal cord injuries. The child's initial MRI showed an area of myelitis, but after several years and some recovery, the child's MRI looked normal. DTI of his spinal cord did pick up abnormalities that were different from both the control group and the SCI group though, which the authors note indicates how sensitive DTI is. Furthermore, the patient's DTI results were significantly different from the results of those with traumatic SCI, once again showing the sensitivity of the imaging technique. They contend that DTI paired with standard MRI could be used to make quicker and more accurate TM diagnoses.

Original research: Barakat N, Mulcahey MJ, Pallav S et al. Diffusion tensor imaging in pediatric transverse myelitis: A case study. J Pediatr Rehabil Med. 2012;5:281-286.

*Dr. Barakat is leading a study at Boston Children's Hospital entitled **Spinal Cord MRI Research Study for Children, Adolescents, and Young Adults With Transverse Myelitis** to determine how the structure of the spinal cord in children and young adults with non-traumatic spinal cord injuries with pain involvement, specifically those with Transverse Myelitis, is different from those without back pain or spinal cord injury. For more information on the study and how to participate - <https://myelitis.org/clinical-studies-and-trials/spinal-cord-mri-research-study-for-children-adolescents-and-young-adults-with-transverse-myelitis>*

UNDERSTANDING THE ROLE OF ANTIBODY PRODUCING B CELLS IN TRANSVERSE MYELITIS

Ligocki et al. published a study in 2013 that discussed plasmablasts that have been found in a certain subset of transverse myelitis patients. Plasmablasts are white blood cells (B cells) that secrete antibodies. The authors looked at the cerebrospinal fluid (CSF) and peripheral blood of 33 patients with clinically isolated syndrome (CIS), which included 11 patients with optic neuritis (ON) and 22 with transverse myelitis (TM). Those diagnosed with CIS have a high risk of eventually being diagnosed with multiple sclerosis (MS), especially if brain lesions are present on MRI. Also, ON patients tend to have a better long-term prognosis than TM patients if they are eventually diagnosed with MS. Because of this difference in prognosis, Ligocki et al. hypothesized that TM patients would have a high expression of what are known as CD27 B cells (B cells with a unique marker known as CD27) in their CSF and peripheral blood. High expression of CD27 cells is seen in several autoimmune diseases, including neuromyelitis optica and rheumatoid arthritis.

The authors looked at the B cells in the CSF and blood of the 33 CIS patients and found that overall, B cell/plasma cell percentages and numbers were similar between those with ON and those with TM, but there was a group of TM patients who had high expression of CD27 cells in both their CSF and blood compared to ON patients. They also found a correlation between finding CD27 cells in the peripheral blood of this subset and the length of time they were not treated for transverse myelitis. Overall, 41% (9/22) of TM patients had high levels of CD27 in their CSF, and 45% (10/22) had high levels of CD27 in their peripheral blood. The authors note that the presence of CD27 cells may influence disease progression and severity in those with TM.

Original research: A J Ligocki, W H Rounds, E M Cameron, C T Harp, E M Frohman, A M Courtney, S Vernino, L G Cowell, B Greenberg and N L Monson. Expansion of CD27high plasmablasts in transverse myelitis patients that utilize VH4 and JH6 genes and undergo extensive somatic hypermutation. Genes Immun. 2013;14(5):291-301.

UNDERSTANDING VACCINATIONS AND AUTOIMMUNE DISEASES

A Synopsis

A synopsis on the topic originally broadcast on January 22, 2015 as part of The TMA's Ask The Expert Podcast Series with Dr. Benjamin Greenberg from The University of Texas Southwestern and Dr. Teri Schreiner from Children's Hospital Colorado.

*The entire podcast recording is available at:
<https://myelitis.org/resources/understanding-vaccinations-and-autoimmune-diseases>*

The education podcast was a moderated Question and Answer session with the experts based on questions from the community.

The conversation included possible theories that could explain a link between vaccinations and rare neuro-immune diseases like transverse myelitis, a discussion of the risk of demyelinating diseases after a vaccine versus after an active infection, and also addressed specific vaccinations.

These were the salient messages offered by Drs. Greenberg and Schreiner from their experiences.

ABOUT VACCINES

- They are used to prevent very dangerous illnesses.
- There are three types of vaccines available today. A live

attenuated vaccine is a weakened version of live virus that elicits a very minor immune response. Inactive vaccines are killed viruses, and conjugate vaccines include some parts of the virus and not the entire virus.

- All of these vaccines are safe, and one type is not considered safer than the other.
- The only exception is that anyone on immune-suppressants (for example steroids) or recently treated with immune-suppressants should not receive a live attenuated vaccine.

IS THERE A LINK?

- There has yet to be a study that proves a link between vaccination and rare neuro-immune disorders, but a lack of evidence doesn't mean that there is not a link, although it is unlikely.

- After a demyelinating attack, people are often given immune-suppressants. In this case, vaccines should not be given within a month or two after immune-suppressants. For children who have had their vaccine schedule interrupted by a neuro-immune disorder, the CDC has recommendations for how to get children back on track for being fully immunized (<http://www.cdc.gov/vaccines>). Otherwise, there is no need to split up or delay vaccinations. A vaccine can cause low-grade fever, so there should be a discussion about how to deal with this if an individual is still in a rehabilitation setting.
- There are two theories that describe the potential biological link between vaccines and these disorders, but neither of these theories have been proven:
- The first theory is that there is molecular mimicry between the vaccine and the human body. This theory posits that proteins in a specific vaccine look very similar to proteins found in the nervous system. The vaccine causes the nervous system to activate and then it accidentally triggers an autoimmune response in which the body causes inflammation in the brain and/or spinal cord because the proteins are similar. In this theory, a demyelinating attack could occur any time after a vaccination, even years later.
- The second theory is that there are individuals who are predisposed to having these attacks. This theory posits that some individuals have the biology to be predisposed to auto-immunity. When these individuals get vaccinated it leads to generalized inflammation that triggers demyelination. In this theory, it would be expected that someone would experience a demyelinating event within 60 days of getting a vaccination, but not too soon. This theory is highly unlikely given the extensive data indicating that vaccines are safe in individuals with established autoimmune disorders, such as multiple sclerosis.
- It is very unlikely that vaccinations are linked to rare neuro-immune disorders. In the past, rabies vaccines were grown in brain tissue, which did cause demyelinating disorders, but brain tissue is no longer used to produce vaccines. Also, while we hear of individual stories about vaccinations and TM, there does not seem to be a pattern between vaccinations and rare neuro-immune disorders when you look at an entire population. Even in those individual cases in which an attack occurred after a vaccination, it is not currently possible to prove that the vaccine caused the

attack.

ON INFLUENZA VACCINE

- Although there are two theories that could possibly explain a link between vaccines and autoimmune diseases, the potential impact on rare neuro-immune disorders is much more significant from the flu itself than it is from the vaccine. One study looking at those with multiple sclerosis and found that the risk of a demyelinating attack was significantly higher in the 3 months after getting the actual flu than it was after receiving a vaccine.
- The influenza vaccine changes from year to year to accommodate for the changing viruses in the community. No two flu vaccines are the same year to year, so if an individual had a demyelinating event after a flu vaccine, they should be able to get a flu vaccine in the future, because that particular flu shot will not exist again.

ON OTHER VACCINES

- The measles and flu are highly contagious, have serious complications, and can be deadly, so the benefits of getting vaccinated against these diseases significantly outweighs any possible risk. In children, the chicken pox vaccine is also highly recommended, because the disease can cause complications and even death.
- It is recommended that pregnant women get the pertussis vaccine, and those aged 65 years or older, and adults/children with serious long-term health problems get the pneumonia vaccine. The leading cause of death for quadriplegia is pneumonia.

ABOUT RELAPSES

- Those with rare neuro-immune disorders may experience a temporary worsening of symptoms after vaccination, but it is very unlikely that someone with one of these disorders would experience another attack because of a vaccination.

CLINICAL STUDIES

- There is currently an enrolling pediatric TM study (<https://myelitis.org/clinical-studies-and-trials/capture-collaborative-assessment-of-pediatric->

[transverse-myelitis-understand-reveal-educate](#)) that tracks whether participants received vaccinations or had an infection prior to their TM.

- There is also a longitudinal study at UT-Southwestern that is collecting vaccination data (<https://myelitis.org/clinical-studies-and-trials/a-longitudinal-study-of-neuromyelitis-optica-and-transverse-myelitis>). These studies should help us learn more about vaccinations and rare neuro-immune disorders.

ON ADVERSE EVENTS

- The Vaccine Adverse Event Reporting System

(VAERS) is a monitoring system set up by the CDC. Individuals can report adverse events following vaccination. The data are publicly available at <https://vaers.hhs.gov/index>.

Ultimately, it is important to have a discussion with your health care provider about vaccinations, so that you have a partner in the decision-making about what vaccinations you should receive. Vaccines are generally safe, and the benefits of being vaccinated outweigh the risks.

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The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

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 disorders, 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 research and findings in the field of rare neuro-immune disorders. It's easy to stay informed about the latest events, programs and activities of The Transverse Myelitis Association. You can have all of this information delivered directly to your inbox so you won't miss a thing! To receive a weekly email with our latest blog posts in your inbox, please go to <http://eepurl.com/xuoGr>.

A novel outbreak enterovirus D68 strain associated with acute flaccid myelitis cases in the USA (2012-14)

A RETROSPECTIVE COHORT STUDY

In 2014, there was an outbreak of enterovirus D68 throughout the United States. This outbreak was linked to severe respiratory infection, and also occurred at around the same time as an increase in the number of cases of acute flaccid paralysis, or acute flaccid myelitis (AFM). Enterovirus D68 has previously been detected in people with AFM. Individuals with AFM have myelitis, or inflammation of the spinal cord, but the inflammation is located largely in the gray matter of the spinal cord rather than in the white matter as in transverse myelitis. They also have flaccid paralysis, which means their limbs are weak and have reduced muscle tone.

A study by Greninger et al looked to see if there was a link between the 2014 enterovirus D68 outbreak and AFM. They included individuals with AFM who went to Children's Hospital Colorado or Children's Hospital Los Angeles from November 24, 2013 to October 11, 2014, or individuals who were identified by the California Department of Public Health between January 1, 2012 and October 4, 2014. Different types of samples (for example, nasopharyngeal and oropharyngeal, blood, cerebrospinal fluid, and stool) were taken from individuals during their time in the hospital. A total of 48 individuals were included in the study, 25 of whom were diagnosed with AFM, two with enterovirus-associated encephalitis (inflammation of the brain), five with enterovirus D68-associated upper respiratory illness, and 16 with aseptic meningitis or encephalitis and also tested positive for enterovirus. Of the 25 individuals with AFM, 11 were part of a cluster of AFM cases, and 14 were not. A cluster occurs when a group of individuals get the same illness at around the same time and in close geographic proximity to one another.

Most individuals with AFM were children and had a median age of 7 years. More than half (60%) of the cases reported were male and most (80%) reported upper respiratory illness before the symptoms of AFM started. 48% of nasopharyngeal and oropharyngeal samples from individuals with AFM tested positive for enterovirus D68. 64% of the 11 individuals who were part of a cluster tested positive for enterovirus D68.

None of the 25 individuals had enterovirus D68 present in their cerebrospinal fluid, but viruses like enterovirus are not usually detected in cerebrospinal fluid. Only one person had enterovirus D68 present in their whole blood and stool samples, but the virus was present in lower numbers than in their nasopharyngeal and oropharyngeal samples.

Those with AFM, whether or not they had enterovirus D68, had similar outcomes. All continued to have neurological deficits 30 days after onset and in 77% of the individuals, there was no or minimal improvement in paralysis.

The authors believe that the data from this study shows that there is probably an association between enterovirus D68 and AFM. This is because over a third of individuals with AFM had enterovirus D68 present in their samples, and 80% of individuals with AFM had an upper respiratory illness before their AFM, and upper respiratory illness is commonly associated with enterovirus D68. Also, enterovirus D68 was the most common virus that was detected in samples and no other enteroviruses that have been previously linked with AFM were detected. The authors also noted that the samples were collected more than a week after the onset of URI (upper respiratory infection) which probably decreased the numbers of the virus present in samples. Also individuals who were negative for enterovirus D68 had their samples collected later than those who were positive, so this may have made it less likely that the virus would be detected. They also identified a pair of siblings who had the same strain of enterovirus D68. Both siblings had an upper respiratory illness, but one went on to develop AFM. The authors state that this indicates that the way individuals react to enterovirus D68 and how severe their reaction varies from person to person.

Greninger AL, Naccache SN, Messacar K et al. A novel outbreak enterovirus D68 strain associated with acute flaccid myelitis cases in the USA (2012–14): a retrospective cohort study. Lancet Infect Dis. 2015;15:671-82.



PEDIATRIC MYELITIS OUTCOMES STUDY

“CAPTURE” STATUS REPORT

STUDY ENROLLMENT GOAL: 180

CURRENTLY ENROLLED: 43

ENROLLED IN THIS STUDY AS OF OCTOBER 2015



8 CHILDREN ENROLLED



3 CHILDREN ENROLLED



The Children's Hospital of Philadelphia®

8 CHILDREN ENROLLED



1 CHILD ENROLLED



International Center for Spinal Cord Injury
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3 CHILDREN ENROLLED



21 CHILDREN ENROLLED
(VIRTUAL PARTICIPATION)

If you are not eligible for participation in the study, help us succeed by sharing this study on social media, with your physicians and therapists and with newly diagnosed families who contact you!

To learn what our future could look like and how this study could impact the TM and AFM community, listen to the **Town Hall CAPTURE Podcast** (<https://myelitis.org/resources/town-hall-capture-study>) held on September 2nd with Dr. Benjamin Greenberg of UTSW, Dr. Brenda Banwell and Dr. Sarah Hopkins of Children's Hospital of Philadelphia, moderated by nurse research coordinator, Patricia Plumb of UTSW.

The study funding is at risk! As much as we stand to gain from this opportunity, we also stand to lose.

Spread the word! Travel is not necessary to participate in the online cohort. A family may enroll and complete the surveys from their own home or wherever they may be seeking therapies.

CONTACT

Questions about the study
and to enroll:

REBECCA WHITNEY

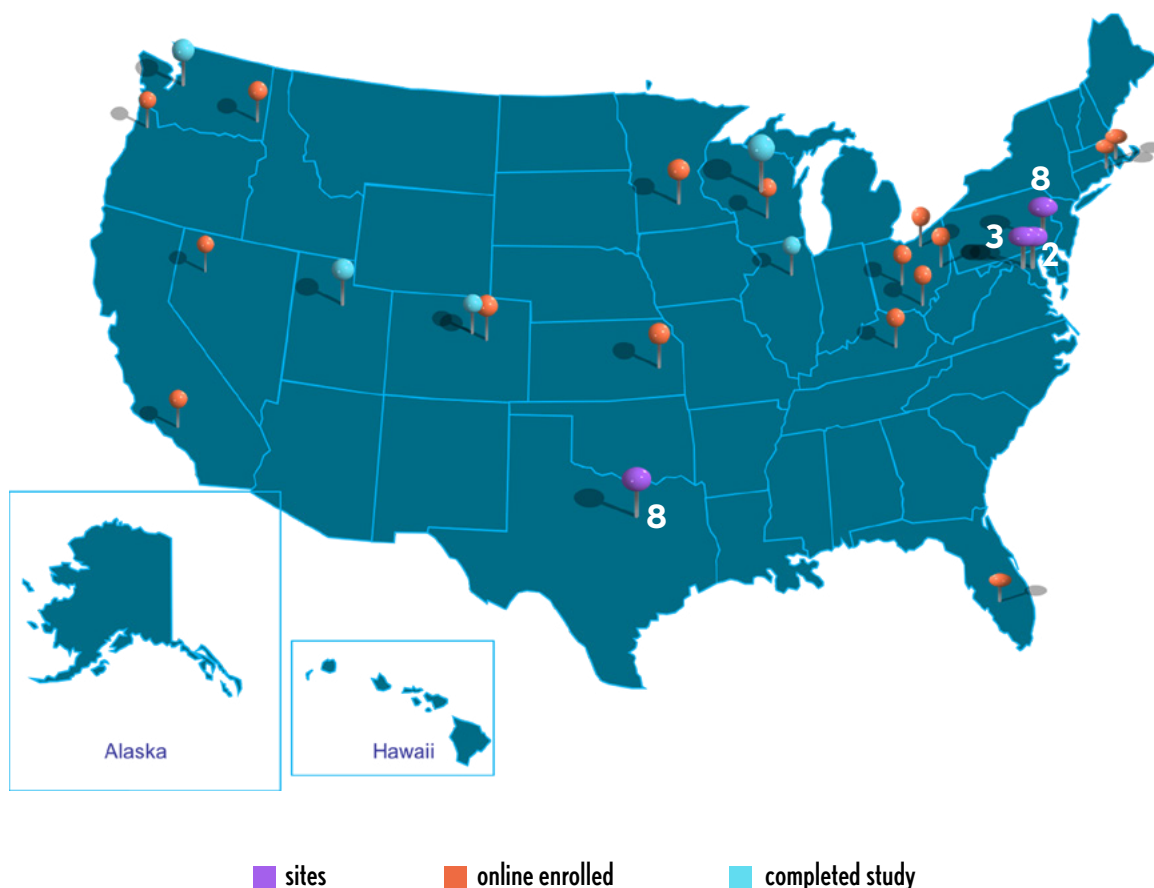
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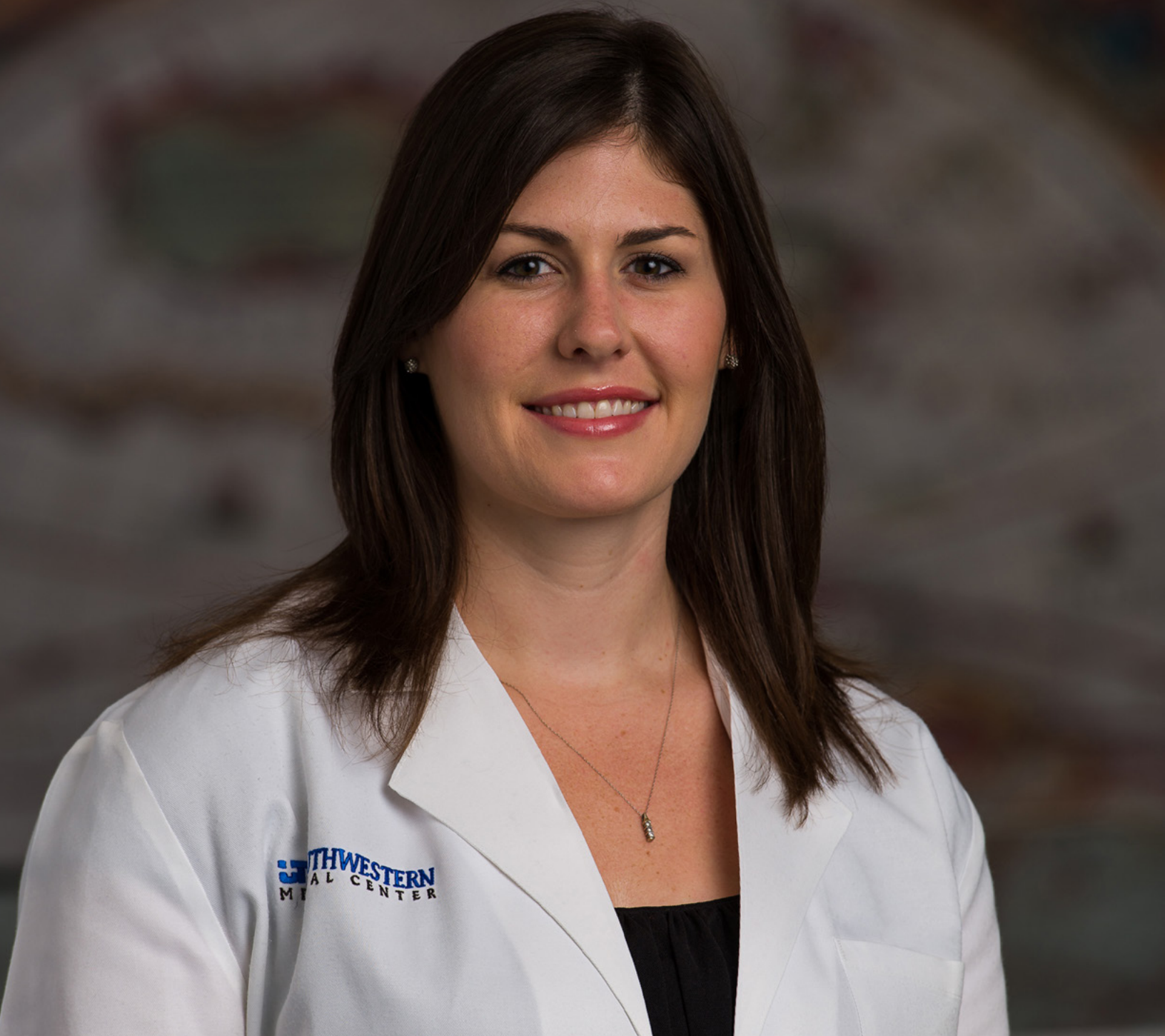
My introduction to neuroimmunology and the challenges that inevitably accompany the diagnosis of chronic neurological diseases and rare disorders came with my sister's diagnosis of multiple sclerosis in my home country of Pakistan. Since multiple sclerosis is rare in Pakistan, our initial and subsequent experiences (as I learned much later) had a striking resemblance to those of patients and families with rare neuro-immunological disorders here in the US. We soon learned the importance of educating ourselves using the right resources and advocating for ourselves as we navigated the health care system and life in general. Inspired by my sister's bravery and hoping to safeguard her interests, I set out on my journey to train as a neurologist and subsequently as a neuro-immunologist in the US. This was over eight years ago and since then, in addition to my sister, I have been inspired by countless patients with both MS and rare neuro-immunological disorders.

Today, at the conclusion of my training in neuroimmunology at University of Texas Southwestern in Dallas and as I embark on a career as a neuro-immunologist at Billings Clinic in Montana, I am the product of my experiences as a family member and part of a health care team providing care to patients

with neuro-immunological disorders. Over the years, I have come to believe that our goal as a health care team (which should include family members) is not just to ensure good health care for our patients but ultimately to assist them in leading fulfilling lives in spite of all the challenges that come with these diagnoses. This requires educational resources with the right information about conditions, support groups, forums connecting patients and families to each other, access to latest research etc., all critical elements as we attempt to achieve our goals for patients. My introduction to The Transverse Myelitis Association came from watching Dr. Greenberg's team working relentlessly for The TMA during my neuroimmunology fellowship. However, my real education about the impact that TMA has on patients with rare neuro-immunological disorders came from hearing their stories firsthand in clinic. As they recounted their initial experiences, it became apparent to me that more awareness is needed in our health care system about these conditions along with neurologists with the expertise to care for these patients. Another important lesson during my training was the importance of having the courage to embrace and manage patients with unclear diagnoses (not uncommon in rare disorders) and to solicit opinions from other experts to provide the

best possible care for them. Given that these conditions are rare, it is also critical to connect individuals working in this field to facilitate communication between them in order to expand knowledge and move research forward. TMA is a huge resource for patients, their families and health care teams as they strive to improve care and advance research in this discipline.

Having come full circle now, I can see how my own view of the field of neuroimmunology has evolved immensely over time. Almost a decade ago, as I stood at the crossroads and made the decision to train in neuroimmunology, I was discouraged by well-meaning individuals in healthcare from going into a specialty with 'so little hope'. Today, I can say with much conviction that nothing could be further from the truth! Even with existing resources, we can (sometimes after much persistence) almost always make things better and even though much remains to be accomplished, the future looks very promising! I feel privileged to be part of the world of neuroimmunology in these exciting times and honored to have the opportunity to work with The TMA in extending its impact to more patients and to build on the hard work of those before me.



Young people desire autonomy, but may not have the foresight or the aptitude to know how to reach their goals. The best way to start is to ask questions. I have learned there is rarely a consensus among the patient, parent/caregiver, and healthcare provider when discussing a teenager's ability to do a task independently, such as remembering to take medications. Awareness of ability, or lack thereof, is crucial in order to create a plan towards independence.

BUILDING CONFIDENCE FOR TRANSITION OF CARE

There are three main components to transition of care: knowledge of health needs, being prepared, and taking charge. Listed below are skills needed to independently care for one's own medical condition.

1	Ability to explain one's own diagnosis
2	Understanding medications including indication, dose, potential side effects and surveillance
3	Communicating with the healthcare team
4	Refilling medications
5	Making appointments
6	Knowing when to call providers or seek emergency care
7	Understanding patient rights
8	Understanding/managing insurance

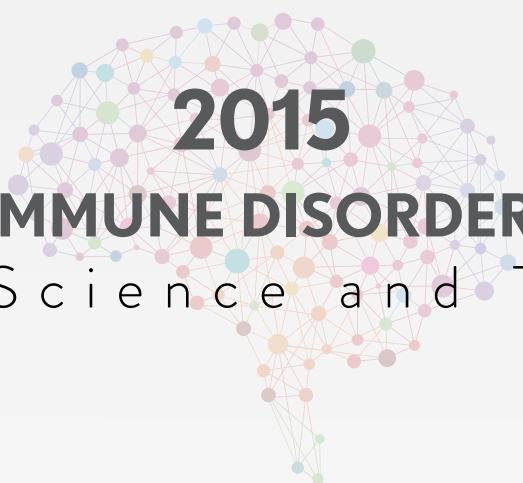
When we think of all the knowledge and skills necessary for self-advocacy and healthy behaviors, our first thought probably is to hide under the covers for a few days. Do not panic! Most caregivers acquired the skills and knowledge to navigate the healthcare system over time, and many times through trial and error. In the safety of the home, it is important to teach our teenagers and young adults how to be experts in their disease, communicate with others independently, and build foundational skills to care for themselves. Building confidence by mastering skills at a young age is expected to increase independence and decrease anxiety. By making smaller attainable goals and accomplishing them, the teenager will feel a sense of accomplishment over time, which will enable the teenager to feel empowered. It is important to remember that there will always be competing priorities; so working on these goals over time will help realize these skills.

ACTION STEPS

- Talk about these topics with your teenager
- Encourage your teenager to pick 1-2 items that are the biggest priority to them
- Ask your teenager to make a plan to reach their goal
- Choose a time frame to reassess the goal and modify the plan as necessary

This is the second blog in the series on Transition of Care. Audrey Ayres, RN, BSN, MSCN is a clinical nurse at University of Texas Southwestern Department of Neuro-immunology. She was recently awarded the 2014 Excellence in Nursing Award by the Dallas magazine. Audrey provides care for adult and pediatric patients with Multiple Sclerosis, NMO, TM, AFM, ADEM and Limbic Encephalitis. She is also the primary nurse for the Pediatric Demyelinating Disease Clinic for Children's Medical Center in Dallas, TX.

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THE SPINAL FUSION EXPERIENCE

Amanda McGrory



Dr. Anjali Forber-Pratt

Paralympian medalists Amanda McGrory and Anjali Forber-Pratt were diagnosed with transverse myelitis at a young age. Dr. Anjali Forber-Pratt is a member of the TMA Board of Directors.

Spinal fusion surgery is something we've been hearing a lot of parents talk about, and we would like to share our stories and perspective. Spinal fusion rod surgery is fairly normal for any child growing up using a wheelchair (due to SCI, spina bifida, TM among many others). Developing scoliosis and at some point needing rods is just part of our developmental trajectory and it is not something to feel totally blindsided by. Your child can, and will, lead a very active healthy life post-surgery. Yes, it is a major surgery, and with any surgery there are risks and so forth, but we hope that by sharing our stories it will be a helpful perspective for all to consider.

AMANDA: I was admitted to A.I. duPont Institute in July of 2000 for a full spinal fusion – stainless steel rods beginning at T1, and running all the way down my spine where they finally anchored into my pelvis. As a 14-year-old competitive wheelchair racer and basketball player, I was pretty sure my athletic career and dreams to compete at the Paralympic Games were going to be left on the table in the operating room.

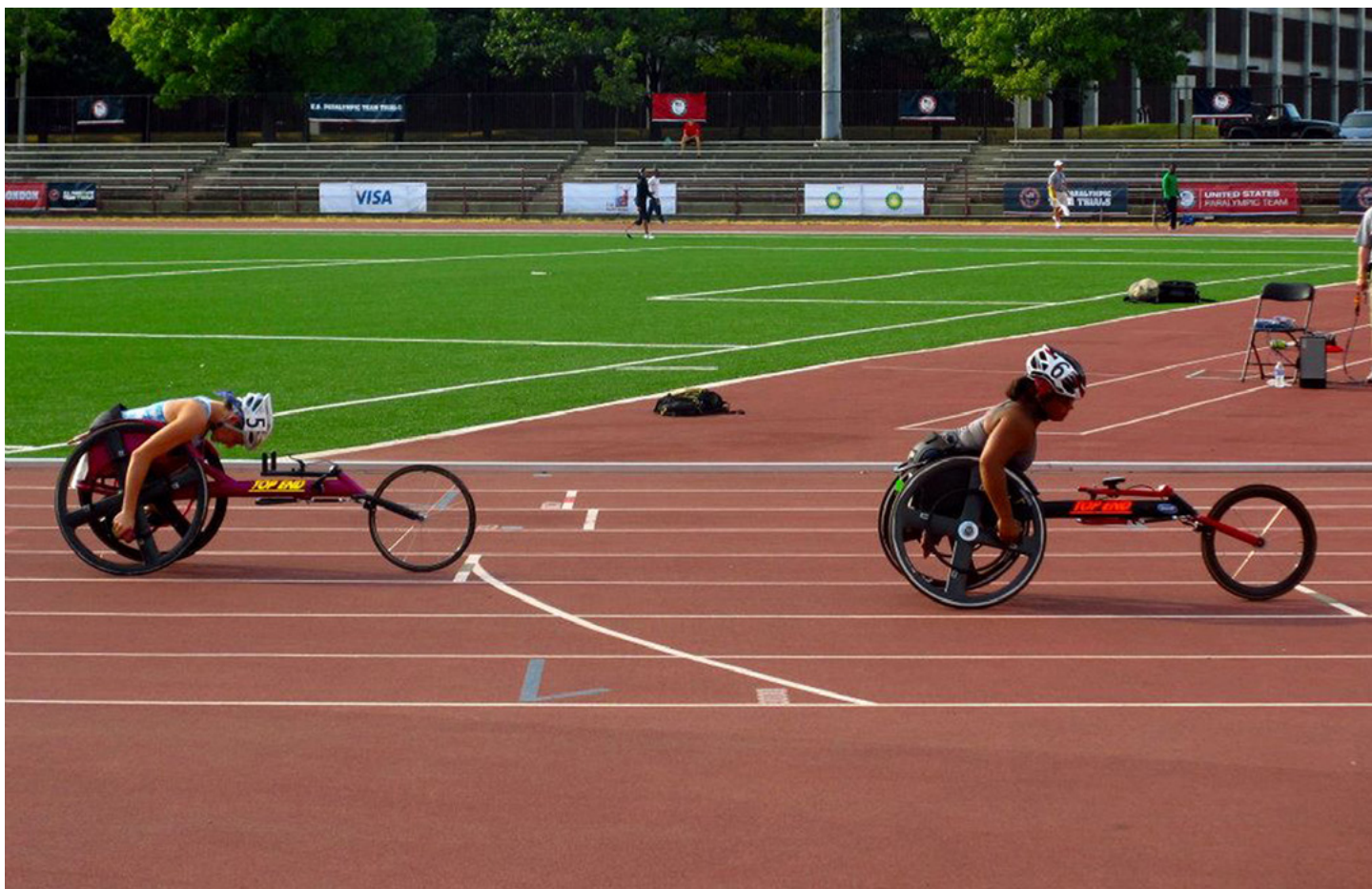
ANJALI: I was scheduled for my spinal fusion in November 2000, and we had medically put off this surgery until the last possible moment. My curve was 120 degrees and I was not sleeping at night due to pain. The original surgical plan was to have top to bottom rods the whole way down my back. Unfortunately, days before my scheduled surgery my surgeon had a heart attack and died, so I had to quickly find a new hospital, new surgeon and start the process over again. I was fortunate to be quickly established with an orthopedic surgeon at Boston Children's Hospital and this new surgeon was extremely reluctant to do any type of rod surgery on me, and ended up proposing an entirely different surgical approach which was to fuse only the worst of my curve from T11-L4 in the middle of my back and to leave both my upper and lower curve as is.

AMANDA: I was diagnosed with transverse myelitis when I was five years old in October of 1991. Scoliosis was a concern for my doctors from the start. Although my sensory level fell between L1 and L2, my motor function declined steeply at T9 – without those strong core muscles, my doctors feared that as I neared puberty, I wouldn't be able to properly support my quickly growing body, and they were right.

ANJALI: I got sick with TM as a baby at T10, at 4.5 months old in November of 1984. My parents always knew that scoliosis was going to be an issue because I was so young and developmentally still growing without the benefits of a strong core and the ability to properly engage those muscles. I was always told that sometime after puberty when most of my growing was done, I would need rod surgery.

AMANDA: Over the course of 6 months, my curve increased from single digits to over 50 degrees, in an "S" shape – I had no pain, but the top part of my curve was putting pressure on my heart and lungs. My general practitioner immediately recommended I see an orthopedic surgeon, who in turn immediately recommended I have surgery to correct the curve. "The sooner we do the operation," they told me, "the better the chance we can fully correct the scoliosis and minimize the damage to your internal organs."

ANJALI: My new surgeon spent over an hour with me having me get up off the ground, roll over, open a door, push my wheelchair etc. He was watching and saw that I actually used my curve to be able to increase my functional abilities. I adapted to my curve and had pretty remarkable balance considering how skewed my x-rays looked. My orthopedic surgeon was also highly concerned that my active lifestyle, which involved wheelchair racing, swimming, tennis, basketball, skiing etc. would be greatly compromised by this surgery. The doctor told me I would lose flexibility in my



back, have to relearn how to balance and sit and do all of these things, and that there was no guarantee that the movements that I was reliant on to be a competitive ski racer would be the same. However, at this point, my pain was unbearable and there was growing concern that my organs were going to be crushed soon if we did not intervene.

AMANDA: Both my parents and myself were hesitant to schedule the surgery right away. I had qualified to compete at the 2000 National Junior Disability Championships (NJDC), and because no one could give us a definite answer on whether or not I'd be

able to continue competing after the fusion, we decided to push the surgery back a few months until after the competition.

Talking to other athletes at the NJDC about spinal fusions, I learned that everyone had a different experience—some recovered immediately, some went through a lengthy rehab program, some felt stronger and gained function, others lost balance and stability. What I took away from those conversations is that just like disabilities, there is no universal experience, no universal diagnosis, no one right answer. It varies from person to person, and it's most important to make

the best choice for your own unique body.

ANJALI: Growing up with other families of kids with disabilities who were active and involved in sport was a blessing. At NJDC and in my home community too, I also learned quickly that everybody's medical experience and process of going through the fusion surgery itself and the recovery was different. But, the thing I learned most was that this surgery was inevitable, and it was not coming about because of anything I did wrong, not because of anything that my parents should have done differently, and not because I didn't work hard

enough at strengthening my muscles. This just is a normal process that all kids growing up with spinal cord disabilities have to go through. My parents had a hard time with it too—I was constantly harped on for not sitting up straight, for sleeping in a ball, for leaning to the left when watching television, but the truth of



the matter is, growing in combination with weak muscles from TM, these issues were bound to happen. It is nothing that you as parents, or you as kids with TM are doing wrong.

AMANDA: Speaking with my surgeon after the competition, he presented me with a few different options. The biggest, of course, was the length of the rods to be put in. Shorter rods would result in fewer changes to my body – they wouldn't be attached to my pelvis, so my balance wouldn't really be affected, but with them, it would be impossible to fully correct my curve, and I would most likely need to have a second fusion when I was older after my body finished growing. Longer rods could affect my ability to compete, as I would lose the use of most of my core muscles, but the chance of needing to return for a secondary operation was very slim. My parents let me make the decision on my own, and in the end I chose to go for the full fusion – T1 to my pelvis. The idea of returning for an almost guaranteed secondary surgery after a few years more of competitive athletics sounded much worse to me than just diving in all at once.

ANJALI: For me, I trusted my surgeon who was proposing the alternate surgery of fusing only the worst part of my curve knowing that this would buy me about 10 years of competition and that I would likely need to have my rods lengthened to address the lower part of my curve and anchor into my pelvis at a later date.

AMANDA: The surgery itself went very well. The rods were inserted, screwed into my pelvis, attached to my spine with twisty ties (seriously), and the spaces between were filled with powdered cadaver bone. I spent three days in the ICU, three days on the

rehab floor, and was then sent home. I remember the incision being painful and having difficulty transferring and sitting upright for the first couple weeks, but I healed quickly. In fact, the day I was released from the hospital, my family and I drove to Maryland for a weekend at the beach. To be completely honest, I mostly stayed inside and played Nintendo between naps, but still).

ANJALI: This was one heck of a long surgery. I believe I was under for 11+ hours, as when they got in they found blood vessels in places that didn't belong so it took them a lot longer to clean that all up before placing the rods and screws. Then, after the fusion part was done (they took bone from my rib), they were getting ready to wake me back up and gave me IV dose of pain medicine and I flat-lined due to anaphylactic reaction to the medication. Needless to say, this earned me a first class ticket to the ICU where I stayed for several days. When I eventually woke up, the first thing I did was punch a nurse (in my defense, they did kill me!) so I woke up in a 5-point restraint, still intubated and quite swollen from the whole affair. I moved to a regular hospital room and had pretty strict precautions on what I could and could not do.

AMANDA: I had one small setback during recovery with a minor infection in the incision, but everything was fully healed and my staples were removed in time for me to begin 9th grade. I was told to wait a few months before returning to sports, just to be sure that the fusion was healed enough to handle the stress and impact. I began playing basketball again in the fall, and racing that spring.

ANJALI: Because of the surgical

approach used and that there was no strong anchor point for the rods, I was not allowed to make any unassisted transfers for 6 months after surgery. I was not allowed to lift anything heavier than a one-subject notebook and I was not supposed to push up ramps/curb cuts without assistance. I did not have a brace after the surgery, but had to obey the precautions so that the fusion would "take". I grew 7" in one day from this surgery! As a short person, this was highly exciting for me. But, I did have symptoms of vertigo because of this, and I had trouble eating food off of my plate because the food felt too far away from my brain, and things like the location of door knobs were weird for my brain to interpret for a couple months because of this instant growth. I was able to learn ways to safely return to self-transferring as long as my legs were supported, once I reached about the 3-month mark. I was lucky that at my 6-month appointment, I was fully healed and allowed to return to all activities with no restrictions at that point. While my doctor did take a very conservative approach to this recovery, I understood why these precautions needed to be in place.

AMANDA: The doctors were right in assuming that my balance would be affected by the rods, but it in no way affected my ability to be competitive in sports. In both basketball and track, my classification was adjusted to reflect my slightly wobblier status – from a 2.0 to a 1.0 in basketball, and a T54 to a T53 for track. I continued with both sports through high school, and attended the University of Illinois on a wheelchair basketball scholarship. I stopped playing basketball after I graduated, but I am currently a member of the US Paralympic Team for track and road racing, and a four time Paralympic medalist.



ANJALI: My balance was greatly affected by this surgery, as was predicted. My classifications for sports did not change, as I was already a T53 in track and LW10 in skiing. I went on, as many of you know, to make my first national team for wheelchair racing in 2007 and competed in the Beijing and London Paralympic Games and I am a two-time medalist.

Just prior to the London 2012 games, I started having lower back pain and problems, which was almost like clockwork, 11 years after my initial fusion. I worked with my doctors to put a plan in place to delay the inevitable rod lengthening surgery so that I could still compete in the London Games. I went in for surgery 10 days after the games to have my rods lengthened L4-S1. The surgery itself went fine, but post-surgery I began having life-threatening complications and did in fact code a week after surgery. I spent a month in the hospital and for four weeks there was nothing but questions and very little answers about what was going on. I only knew that something wasn't right. This additional fusion exacerbated issues due to a tethered spinal cord that we didn't know I had until this fusion revision. I have had multiple surgeries since then to correct the untethering surgery (May 2013), had another spinal fusion revision (October 2014) and most recently have had a trial and permanent spinal cord stimulator placed (June 2015) to help with pain management.

AMANDA: I have never, in any way, regretted my decision. The full spinal fusion was definitely the right choice for me and I'm glad I was able to weigh my options and make the decision for myself. It, like any surgery, was scary – both for myself and my parents, but I feel confident that my quality of life now is much higher than it would be had I not gone through with the operation.

ANJALI: My story has unfolded with more complications than Amanda's, but I have never regretted my initial decision to take the risk on the partial fusion surgery. I was able to be a normal kid and experience the joy of sport and thrill of competition in between my two surgeries. I also do not regret going in for the fusion revision in 2012; it was the best decision for me at the time. I was able to make informed decisions on what path to take. I fully believe that it was a perfect storm of sorts and that none of these complications could have been predicted or avoided and while I wish that I hadn't had all these recent complications and issues, I am confident that I am now on a path to a greater quality of life and healthier living. I certainly do wish that my athletic career had not been halted due to these medical issues, but I'm grateful to still be able to live independently, work and enjoy the happy moments in life.

WHAT ARE THE ODDS?

By Kenneth Buck

My name is Kenneth L. Buck. I reside in Galloway, NJ. I am married with three kids. I am a retired Detective from the Galloway Police Department. In September of 2003, I was shot in the line of duty while investigating a homicide. This horrific incident led to my disability retirement due to PTSD. After my retirement from the Galloway Township Police Department, I was still capable and allowed to work in a different career. My last job before becoming ill with Acute Transverse Myelitis was at Mainland Regional High School in Linwood, NJ, where for 6 years I was assigned as a one-to-one aide to work with disabled students in the high school.

On January 17, 2015 in the middle of the night, I was suddenly hit with what was later diagnosed as Acute Transverse Myelitis. I received IV steroids and had IVIG. I was hospitalized for 21 days, including in-patient rehabilitation at Jefferson University, Philadelphia, PA, where I had to learn to walk again. After being discharged, I went to outpatient therapy and still to this date, I continue to fight this horrible disease on my long road to recovery.

On July 18, 2015, while resting at home in my recliner, my wife, Christy Buck, alerted me to one of my friends' Facebook page, Richard Solkin, who resides in Tampa. Rich had shared a gofundme page for a Pasco County



Firefighter, Pete Bignotti, who also suffers from PTSD and now has a rare disease; Transverse Myelitis. My wife encouraged me to reach out to Pete and to help him through his illness. I looked him up on Facebook and I sent him a message via Facebook.

Hey Pete my name is Ken. I am friend of a friend of yours, who lives in Tampa and owns Kickin' Wingz. Your story and mine are very similar. I am a retired detective shot in the line of duty in 2003. I have suffered from PTSD many years thereafter. Now after everything settling down and getting married with three kids I was hit with TM in Jan of 2015. I know exactly what you're going through brother. I had a five-day treatment of steroids and three intense days of IVIG. While I was in the hospital I ended up having AFIB, as if there wasn't anything else I needed to go wrong. Here I am 6 months later, fully disabled and still on the road to recovery. I have pins and needles daily. I am fatigued, depressed, my knees are in severe pain, and my lower back hurts. I am fortunate to have a

good support system and I am going to try to get down to Florida to see you. I have to warn you that the heat and humidity does not help if you have TM. If you would like to chat, please feel free. I barely sleep when I should be and haven't slept in bed in a while. I now sleep in a recliner. Hope you get well soon and keep in touch. Sending many prayers from NJ!

After Pete read this message, we started chatting on a daily basis. I coached him through some of the hard times he was having while hospitalized and in rehab. Encouragement and prayers were being sent to Pete from me daily. Almost everything I told Pete about my experience, he too experienced, even the same time frame with our hospital stays and inpatient rehab.

We have so much in common. We are both married, three kids, wives are teachers, both former police officers involved in shootings, both suffer from PTSD, both have transverse myelitis, both have Maine Coon cats. The odds of this are far beyond hitting the pick 6 lottery. The odds alone for TM are between 1 and 8 cases per million per year. There are only approximately 1,400 people a year that get this disease. Currently, there are about 33,000 people who have TM in the US. That tells you how rare this disease is and the coincidence of meeting Pete with all our similarities is beyond amazing.

I have been sleeping in a recliner since I came home from the hospital. I have severe back pain and cannot lay flat or on my side. I needed a Tempurpedic bed but couldn't afford to spend \$10,000. For my 40th birthday and to help with my medical condition, my wife put together a gofundme page. She by far exceeded any expectations of her set goal. Family, friends, anonymous donors, and people I never met donated to my cause. We raised \$12,465 in less than three weeks. The amount in the picture was the total before my 40th birthday. We were so blessed and Pete and his family were still in need, so I decided to fly down to Tampa to pay it forward to Pete! Here is the page my wife created to raise money for my cause: <http://www.gofundme.com/bedforbuck>.

On August 27, I flew with my wife and three children to Tampa. We stayed at my friend's house, Richard Solkin, who owns a restaurant in Hudson, FL called Kickin' Wingz. Pete previously had a gofundpage that was created by a friend in his fire



department. His family had no way of updating and correcting the page's errors. That gofundme page had to be closed. We helped his wife, Gail, to set up a new gofundpage for Pete (www.gofundme.com/helpmywarrior). We also worked with his wife to set up a benefit on November 21, 2015 at Kickin' Wingz restaurant in Hudson, FL. Here is the link to the fundraiser <https://www.facebook.com/events/545969105550331>.

So for two days in Tampa, before I met Pete, we worked on his new campaign and fundraiser. Pete had no clue I was in town. He still continued to contact me, while I was in Tampa, and I just played it off that I was home and just had normal conversations. On August 29, 2015, my family and I surprised Pete and his family at my friend's restaurant, Kickin' Wingz! He thought he was going there to discuss having a fundraiser. ABC news was there. They had covered Pete's story when he was in rehabilitation learning to walk again. Pete didn't think this was suspicious because he believed they were going to promote his fundraiser. They started interviewing Pete and that's when I walked out and gave Pete a surprise of his lifetime. I believe the ABC news article covered it very well. Here is the news story link: <http://www.abcactionnews.com/news/region-pasco/strangers-bond-through-social-media-to-cope-with-rare-disease>.

I started off the donations on his new gofundmepage with a \$250 donation and my friend, owner of Kickin' Wingz matched the same amount. Then they held a 50/50 and the person who won donated all the money back to Pete. During our time together at the restaurant we shared stories, listened to our children sing karaoke, and then we watched the news story together at 11PM.

Pete didn't want the night to end! On Sunday, August 30, 2015 our families got together again. We spent the day at my friend's community pool. The kids all had a blast swimming. Afterwards, we had a nice family BBQ back at the house, before my family and I had to depart for the airport to head back to NJ. Pete had the surprise of his life. This was a priceless experience for me to be able to help a complete stranger that I knew for just about a month. Because I was so blessed for my 40th birthday and because of the generosity of so many kind people who donated to my wife's gofundme page for the medically needed therapeutic bed, I felt I had to pay it forward. When I was hospitalized, I only wished I had someone to reach out to me about transverse myelitis, that could have shared their experience with me. A little bit of encouragement and inspiration goes a long way when you are ill!

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