the transverse myelitis association

newsletter

spring 2016

advocating for those with ADEM, AFM, NMOSD, ON & TM

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

THE EDITOR'S COLUMN

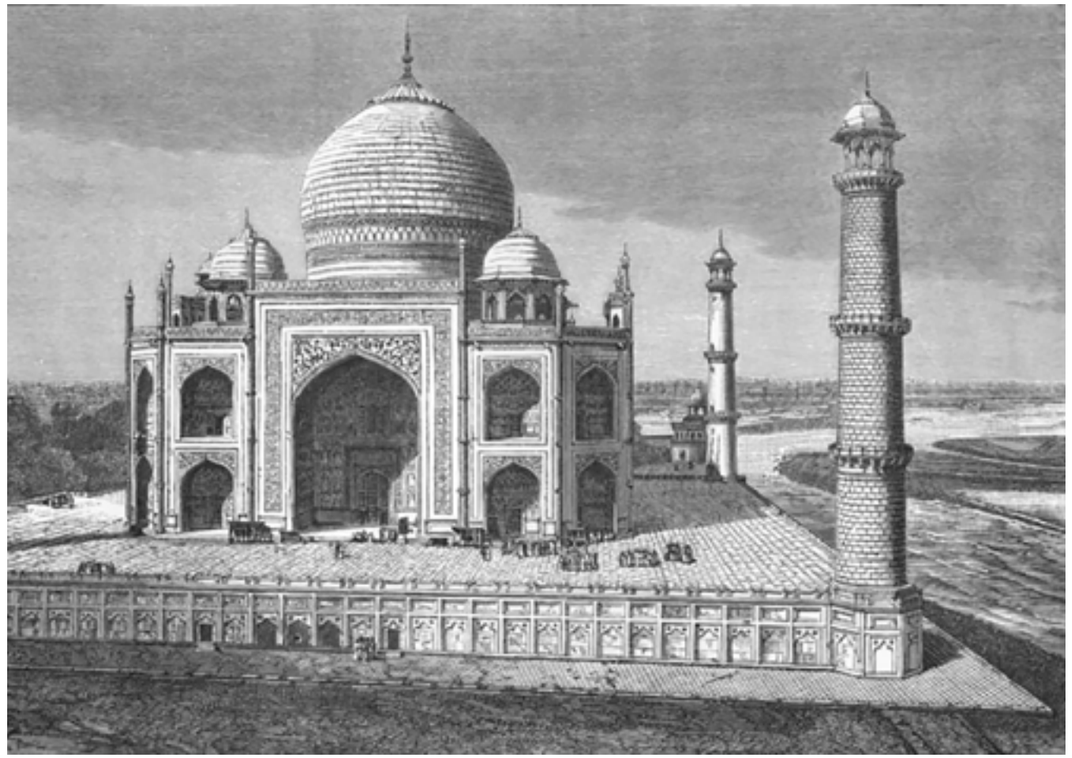
The members of The Transverse Myelitis Association represent such incredible cultural diversity. Because I am ethnocentric, like everyone else on earth, I have to be reminded periodically that all of life doesn't revolve around my head like the sun; that the people who read our newsletters and everything else we publish think about, find meaning, and arrive at conclusions from an entirely different point of world view than that which emanates from my head, i.e., my language and culture.

Our members come from more than 90 different countries, which represents many more different societies and cultures.

Our members have come together because they share one incredibly important life experience; so important, in fact, that this experience will shape almost everything about how they and how their families live the rest of their lives. They got ADEM, NMOSD, ON or TM. But those impacts and those 'shapes' will be so significantly influenced by the culture and the society from which a particular member belongs. Nowhere can this diversity be more manifestly apparent than aging with one of the rare neuro-immune disorders. How people age and how a society treats their aging family members is very different from one culture to the next.

I am going to share some observations about aging with one of these disorders bearing in mind that many of you who are reading this column won't share the practices, the values, the traditions or the world views that are represented by what I am describing.

I'm going to start this discussion about aging by relating a personal experience (because life does, in fact, revolve around my head). My father passed away about three years ago. Since that time, my mother lived alone in her home which was located about 25 miles from me. I called my mother more than once each day to check in on her. Our conversations were about her sadness, the leaking gutters, the snow and ice on the driveway between her front door and the mailbox, and what she should do with the paralyzed baby deer in her backyard. I ended each conversation by thinking, 'why is my mother living alone in this house?' My mother is 90 years old. She is fiercely independent and in great health, but the arrangement was not a good one for her. She is also a very social person and she was totally isolated from people; except for me. I am not a sufficient surrogate for my mother's social life. After falling and breaking her nose, her knee and a thumb, and after being cajoled by me unrelentingly, she finally went along with the idea of me forcing her out of the house against her will. It was a horrible ordeal in every direction; and caused so much emotional turmoil for my mother. She and my father were married for almost 70 years, and they shared this home together for about 25 of those years. Lots of memories.

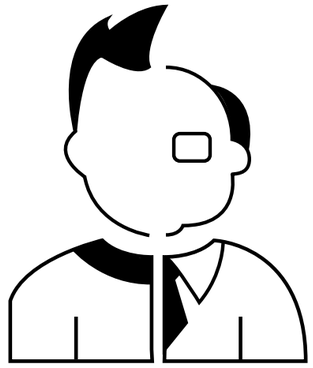


Taj Mahal, Agra, antique print c1885

She currently lives in the orthodox Jewish assisted living version of the Taj Mahal. She has a beautiful apartment, the meals are strictly kosher, they have their own rabbi and all of the holidays and Shabbos are celebrated, and they have a vibrant social program that runs all day and every day. She is a short walk from her shul and from the Jewish community center. In the six months she's been there, she's made so many wonderful friends and she spends every day surrounded by really interesting and caring people. I still call her multiple times each day to check in on her, but she's never home. The situation is absolutely perfect for her, so I get to feel only moderately guilty about her being in an assisted living apartment. Hey, it's not a facility and it isn't a nursing home.

Most of you who are reading this who belong to a different society and practice a different culture are likely asking, why isn't she living with you? Great question. Two generations ago, she would have been living with me. My grandparents lived with their children when they got to be old enough that it wasn't safe for them to be alone. And for people who share my culture, that might have been the last generation that cared for the elderly in that way. For subsequent generations, all of life revolves around our heads.

For a large segment of the cultures that make up American society, the family has become a very independent and self-sufficient unit. When I was a child, all of my many aunts and uncles stayed in the same city as their parents and all of them made weekly pilgrimages to our grandparents; every weekend; no exceptions. When my grandparents needed help of any kind, their children were there for them. The social and psychological pressure to be there to help one's parents was pretty intense. It was a commandment, it was a mitzvah, and if you didn't deliver, there was an abundance of guilt and shame from all directions.



And then our culture very rapidly and dramatically changed. It became acceptable for children to move to Timbuktu – no offense to our members from Timbuktu; it looks like a lovely place. The forces operating to encourage social, economic and geographic mobility have been very strong in our society and the resultant changes to the family have taken place in just a short generation. The nuclear family has become so independent, that the traditional practices involving help for the extended family have become somewhere between confused, diffused and non-existent. In my parent's generation, no one lost touch with a sibling or a parent. It happens today.

I am observing the repercussions of this change all around me. One of the most obvious is the number of assisted living facilities (okay, it is a facility) and nursing homes that exist and that are being constructed around us. I am aware of about eight of these places being built within five miles of my home (and none of them are going to have a rabbi or kosher meals).

For many of you, and particularly those of you outside of my society and culture, the extended family will likely care for you while you age. Often this responsibility is dictated by social norms, and often it is dictated by resources. It is something of a luxury to contract out this familial responsibility to a private, third-party entity. Most of the world's societies don't have that luxury. Families care for the elderly, at times, because there is no viable alternative.

And interestingly, in our own society, even when the resources aren't available, we've created a system whereby the alternative for sub-contracting this familial responsibility exists. It is called Medicaid. Many people in our society can't save enough during their lifetimes to amass the resources required to pay for assisted living and nursing home care. Many people in our society can barely live on what they earn, let alone save anything. Many people in our society don't carry long-term care insurance; and truth be told, most policies only cover relatively short periods of time. Thus, long-term care can work great, if your plans involve dying in about five years of needing it. Most people can't afford long-term care insurance premiums anyway. The option for many becomes buying their way far enough into poverty to become eligible for Medicaid.

For those of you reading this column who do not share the culture being described, the options for you might be better, but they aren't going to be idyllic either. There is much about aging that is a wonderful experience, and there is much about it that is a challenge. While there is much about aging within an extended family that is a positive social and psychological situation, it also isn't a perfect environment. There are times when being cared for by a trained professional is a very good thing. None of these situations is going to be perfect for people who are aging.

Regardless of your society and culture, almost all people aspire to grow old. For most of humanity, we want to experience as much of life for as long as we possibly can. It is wonderful to be able to share in the lives of your grandchildren, if you can find them or afford to travel to Timbuktu. It is awesome to be able to choose what one is able to do with one's time and energy. But aging often comes with a cost. Few of us are able to grow old without experiencing the health issues which result from the evolutionary clock that is genetically built into our bodies. Many healthy people are going to develop various kinds of pain from the wearing out process. Many healthy people are going to develop various kinds of bowel and bladder problems. How do I know this? Television commercials. There must be an enormous market composed of aging people with bowel and bladder issues. Many healthy people are going to develop mobility issues.

My head is immersed in these aging issues because of my experiences with my parents, because many of these problems are occurring in my own body, and because Pauline has been experiencing these issues for more than twenty years, since she was diagnosed with transverse myelitis. And now Pauline is beginning to age. She's had a head start on all of these 'aging' issues. What is going to happen to all of Pauline's health issues as she ages? Does her head start mean that her issues are going to stay the same, or does aging with these issues mean that they are going to get worse? Clear answers to those questions aren't readily available. One of the reasons for this paucity of information is that there's never been a study or even a systematic collection of information on the subject. Another reason might have something to do with the ways we deal with aging, and more precisely, dying in my culture. Perhaps in your culture, aging is associated with dignity and you are valued for your wisdom about all of life. Dying may be considered a natural and beautiful outcome of life or

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a continuation of the cycle of life. My culture isn't doing very much of any of this kind of stuff. From my anthropological observations, I would say that my generation is doing about everything in its power to reverse all of the incredible damage that we caused to our bodies during the course of the first thirty or so years of our existence. Whose idea was it to have the 1960s and 70s? Can eating organic grapes do anything to combat the effects of eating kishka and grievens throughout the first ten years of my life? In my culture, the elderly aren't valued for their wisdom like in the olden days or in your culture, because life has become more about valuing change and innovation than valuing tradition. And when it comes to dying, the people around me might be dropping like flies, but I have no intention of dying. I think about death only in my weakest moments, for very short periods of time, against my will, and then I return to my beautiful, peaceful state of denial. When forced out of denial, I think about my and Pauline's life, and ask myself, how do we prepare for all of this? I have nothing more than common sense to throw at the issue, so I'll try that approach.

How do we prepare for all of this? I have nothing more than common sense to throw at the issue, so I'll try that approach.

If one of your symptoms from the spinal cord attack was a neurogenic bladder, I don't think that experience is going to inoculate you from having your prostate grow to the size of a small grapefruit. If you experienced significant muscle weakness in parts of your body or paralysis, I don't believe that you can, therefore, avoid problems that arise from arthritis, stenosis or connective tissue problems associated with aging. Having had permanent spinal cord damage doesn't mean that you can't develop diabetes, cardio-vascular problems, cancer, or any of the other crap that happens to the human body as one ages. Such is life. Aging will be a challenge for me in many ways. I think it will be a bit more of a challenge for Pauline. As noted, she's had a head start in this arena.

So, what do we do about all of this? Well, you can try denial; our culture offers lots of tools for that approach. Does anti-wrinkle cream and hair dye help at all with denial?

Or you might try accepting reality and doing what you can to maintain your health for as long as possible. And I believe that it is possible to do so. Again, relying on common sense, it is likely that exercise, stretching, keeping one's weight under control, following your doctor's recommendations about what is a good diet, and finding good coping methods for managing stress can possibly help to maintain quality of life even for people who have had a head start on the ravages of aging. See, aging comes with ravages!

And as important as eating brussel sprouts, doing squat thrusts and meditating, it is probably a great idea to start having serious conversations with any of the loved ones you haven't lost touch with about what is going to happen with you when all of those ravages get out of hand and you need some help. If you live in a society where this entire process is well defined for you and you know just how this scenario is going to play out, I envy you. Your traditions are truly a blessing, and I am certain that you find great peace and comfort in the certainties that surround how getting old is going to work for you. If you are a member of my culture, I'm pretty certain that all of your traditions evaporated along with the notion that kishka and grievens were a good idea. It is more likely that the only plan for aging is going to be the one you come up with and for which you prepare. And since we're such an independent and self-sufficient people, you're going to be pretty much on your own; you'll be doing a lot of pulling yourself up by your boot-straps and rubbing dirt in it.

The process is going to start with education. What is possible, and what are you going to be able to afford. These conversations with your loved ones and with yourself are also going to entail figuring out what you need and want through this process. Of course, your wants and needs will have to match your resources. And you definitely don't want to have all of this process just happen to you in the middle of an emergency. You are going to want to decide your plan, prepare your plan, figure out how you will pay for this plan, set aside the money to make that happen, and then let someone responsible know all of this while you have total control over your life. For many people, it doesn't occur this way, and I feel very badly for them. And the reality is that we don't have any control over when we might lose control over our lives, so that planning should start immediately. It doesn't matter if you are eighty or thirty; you need to think about it. And if you are eighty, you might want to do a lot more than just think about it.

I love the whole notion of growing old with Pauline. I want to be able to share as much time with her as I possibly can, and with both of us having the highest quality of life that is possible for each of us. And we are doing as much planning and preparing as we possibly can, while we both have control over our lives. We love our sons dearly. They are sweet, caring, wonderful human beings. But the reality is that sometimes they can go for weeks without calling us; what are the odds that they're going to be changing our diapers? That's what I'm talking about; we're saving for the nursing home and hopefully we can afford the one with carpeting.

There has to be a more compassionate way to treat people who are aging and going to be aging with one of these very complicated, chronic conditions.

Many of the people from our community have suffered tremendous losses in their lives across a whole spectrum of concerns. Obviously, health issues have been at the forefront of their losses. Another very significant loss for many in our community has been the economic misfortunes that so often accompany having a challenging disorder. I don't know if we have the best medical system in the world. I do know that we have the most expensive medical system in the world. Many of the people in our community are unable to work. Many people in our community under-earn because they are no longer able to perform the jobs for which they were educated or trained. Many people in our community have suffered financial losses because of medical bills or from having to make modifications to their home that are not covered by any kind of insurance program or social service agency. I know that all of this happens to people in our community, because people have been calling me and sharing their stories for more than 20 years. They lose their homes, they lose their livelihoods and they lose their hopes and dreams. Our society doesn't do a very good job or a very compassionate job of helping people who have chronic illnesses with challenging lifelong symptoms. We do a lot ... but we could do so much more, and we could afford to do so much more.

There's no way that most of these people are going to be in a position to save what is necessary to plan much of anything. It disturbs me to no end that there will be many people in our community who are not going to be in a position to make and execute the plans that they deserve. They aren't going to have the resources to attain anything but the bare minimum of care in the bare minimum of places. I think that just totally sucks; particularly living in the wealthiest country in the history of humankind. There has to be a better and more humane way to care for the elderly in our society. There has to be a more compassionate way to treat people who are aging and going to be aging with one of these very complicated, chronic conditions.

The current system cannot possibly be sustained. The entire notion of warehousing and caring for the baby boomers, many of whom lack the resources to afford this care on their own is going to create a significant economic burden for our society. There is a lot of debate going on about social security, Medicare, Medicaid, and taxes that will determine the future of our health care system. The impact of these discussions is going to have a tremendous impact on the people from our community. I sure hope our leaders get all of this right. Whether they do or they don't, please take as much control over your future as you possibly can. Please do what you can to keep yourself healthy. Educate yourself as much as you possibly can about your options. Talk to your loved ones and try to figure out for yourself what you want and need as you begin or experience the process of aging. And do as much as you can to prepare yourself for all of the eventualities of the future.

Please take care of yourselves and each other.
Sandy

From The TMA's Vice President

LINDA MALECKY

Dear TMA Members:

I am very honored to be nominated as the Vice President of The Transverse Myelitis Association by the Board of Directors. As Vice President, I will work with Chitra Krishnan and Sandy Siegel to meet the needs of our members, both now and in the future. Specifically, my responsibilities involve planning, community development, raising awareness, and fundraising.

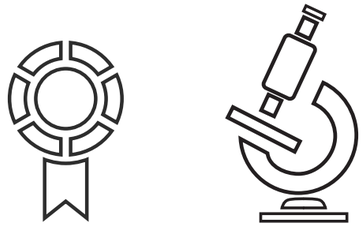
My involvement with The TMA began in 2002 with the Columbus Children's Workshop, which I attended with my daughter and mother. It was at the workshop that I first met Sandy, Pauline, and Debbie, as well as the parents of other children with TM and felt the benefit of sharing our story with other parents and patients who were experiencing the same thing.

When Chitra and Sandy approached me about becoming the Treasurer of The TMA in 2012, I was excited to help. It was not until I became intimately involved with The TMA that I understood the amount of effort that was needed to successfully and responsibly manage this organization. We are so fortunate to have volunteers, employees and medical professionals who put in countless hours to support our community and work to provide the education, emotional support, patient care, and research that enables a better quality of life for our community.

I urge you to **get involved with The TMA**. There are many ways to help – start or attend a support group, organize an awareness and fundraising event in your community, or sign up for clinical research. Some volunteer opportunities require a significant time commitment, but some are as easy as answering a survey. In addition to volunteering, **stay educated**. Things change frequently in The TMA world – new therapies, new medical professionals dedicated to treating those with these disorders, new events to interact with others in our community. It is only with the whole TMA community joining together that we are going to have the opportunities to achieve the quality of life that we want for ourselves and our families.

If you have any questions, concerns, or ideas, please feel free to email me at *lmalecky@myelitis.org*.

ANNOUNCING THE 2016–2018 JAMES T. LUBIN CLINICIAN-SCIENTIST FELLOWSHIP AWARDS



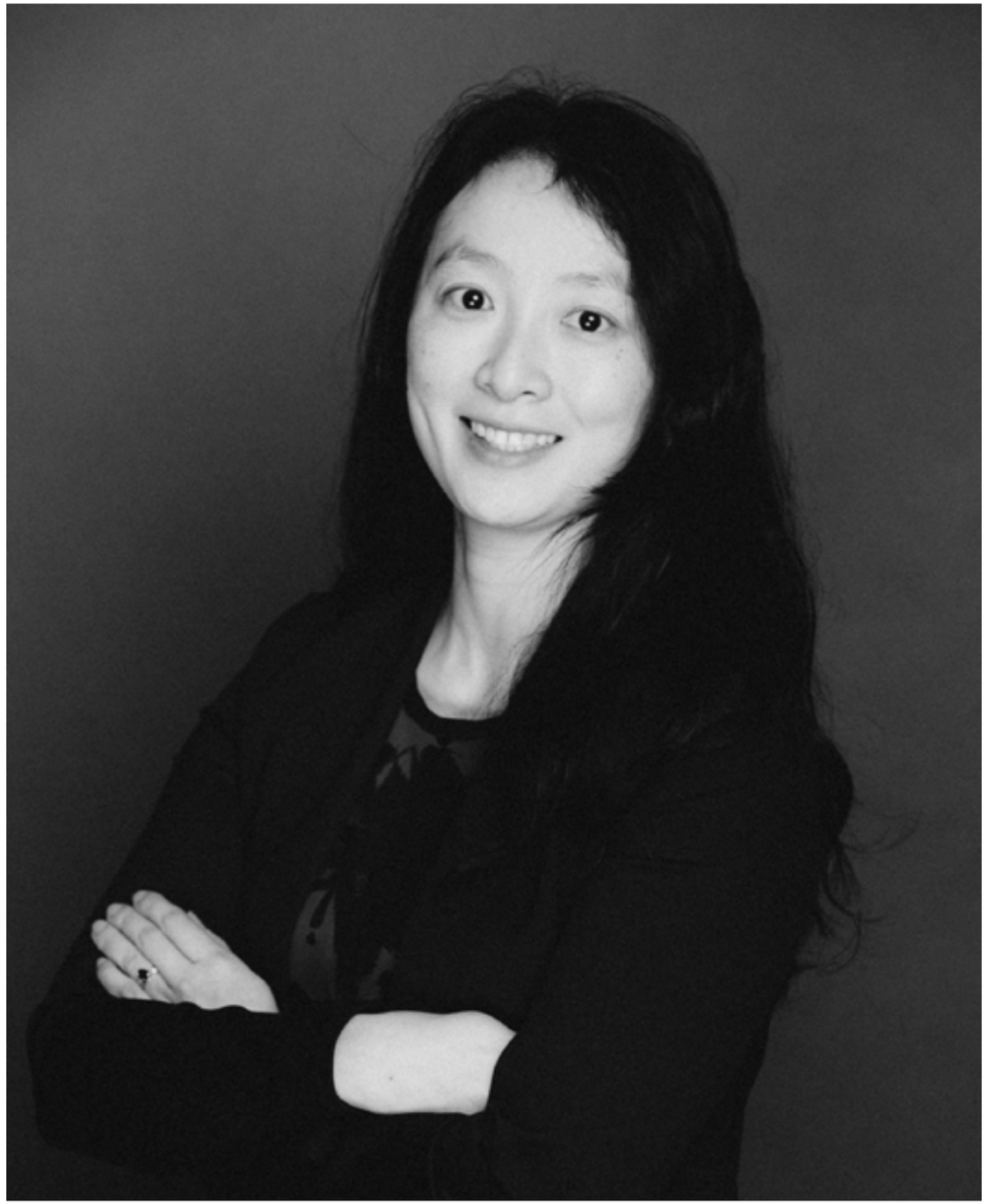
The Transverse Myelitis Association is pleased to announce that our Board of Directors have approved two TMA James T. Lubin Fellowship Awards to Dr. Cynthia Wang at The University of Texas Southwestern in Dallas and Dr. Elena Grebenciucova at The University of Pennsylvania.

The Transverse Myelitis Association is pleased to announce that our Board of Directors have approved two TMA James T. Lubin Fellowship Award recipients this year, Dr. Elena Grebenciucova and Dr. Cynthia Wang. Dr. Elena Grebenciucova will receive clinical and research training under the mentorship of Dr. Brenda Banwell at the Perelman School of Medicine of The University of Pennsylvania and Dr. Cynthia Wang will be mentored by Dr. Benjamin Greenberg at The University of Texas Southwestern and Children's Health.

The James T. Lubin Clinician Scientist Fellowship Award supports up to two years of clinical care and research training in an environment where clinicians learn to use the most current scientific tools to treat and advance knowledge about rare neuro-immune disorders, that include TM, AFM, ADEM, NMOSD, and ON. After completing the program, Fellows are prepared for a combined clinical and research career in academic medicine, directing robust research programs important to rare neuro-immune disorders.

Dr. Grebenciucova received her medical degree from East Carolina University in Greenville, North Carolina. She then completed a neurology residency at the University of Chicago in Chicago, Illinois. Dr. Grebenciucova has been interested in autoimmune disorders of the central nervous system, including rare neuro-immune disorders, since medical school. She hopes "... to be able to study how clinical features at the time of presentation and over the course of the disease, as well as their biochemical and radiological correlates can be used to prognosticate patients' motor outcomes and predict future relapses."

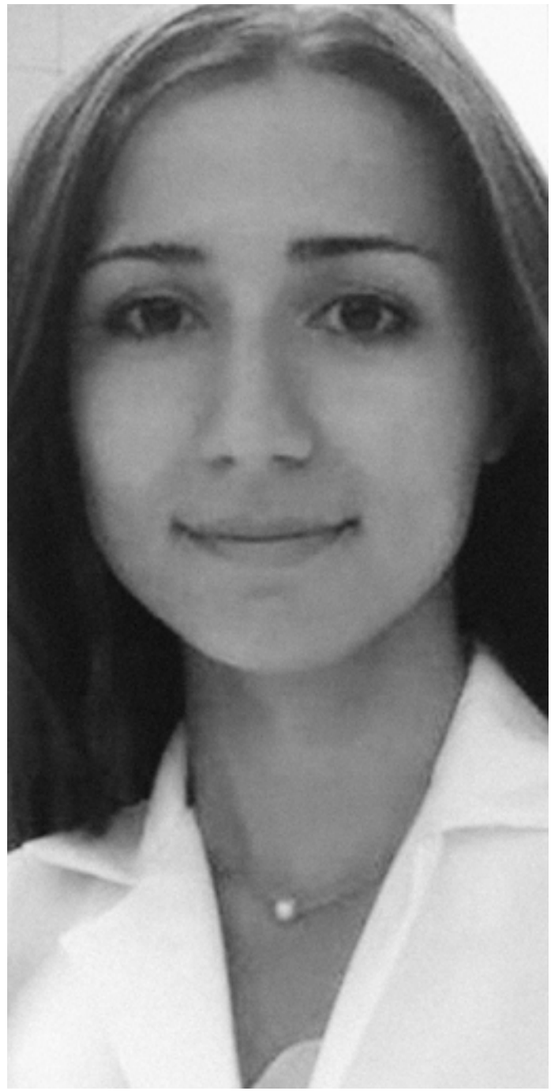
"We are very grateful for the support provided by the TMA. Training top clinician-researchers is an essential step towards accelerating research and to improve-



Dr. Cynthia Wang from The University of Texas Southwestern

The TMA is thrilled to have Dr. Wang and Dr. Grebenciucova as the James T. Lubin Fellows; they are both exceptional physicians and will ultimately make a tremendous difference for our community. They will be trained as clinicians and researchers over the next two years by leaders in the rare neuro-immune discipline. Under the mentorships of Dr. Benjamin Greenberg and Dr. Brenda Banwell, respectively, we know that they will receive the best training. There is nothing that I am more proud of than the James T. Lubin Fellowship – and in my mind, this is one of the most important programs that we support. Through this fellowship, we make available the best possible clinical care to the people in our community, we facilitate the opportunity for critical research, and we develop teachers who can motivate this passion in their students to pursue this important discipline. It is so fitting that this fellowship is named to honor Jim Lubin. He is a remarkable human being. He has been a full quad and vent dependent going on 27 years. In spite of his challenges, he has made the most profound contributions to the people who have these rare disorders and their families.

Dr. Sandy Siegel, President of The TMA



Dr. Elena Grebenciucova from the University of Pennsylvania

ments in care for individuals with TM. Our program at UPenn specifically addresses the impact of TM in children and adults, in order to understand the needs of all patients, even the youngest infants," shared Dr. Brenda Banwell, Professor and Chief of Neurology at Children's Hospital of Philadelphia.

Dr. Wang received her medical degree from University of Texas Southwestern Medical Center in Dallas, Texas and completed a pediatrics and pediatric neurology residency at Mott Children's Hospital, University of Michigan Health System in Ann Arbor, Michigan. Dr. Wang's goal "...is to work in an academic setting to provide excellent clinical care to children with demyelinating disorders and engage in clinical and translational research that will lead to therapeutic advancements in this field." Dr. Benjamin Greenberg, Associate Professor and Director of the TM and NMO and Pediatric Demyelinating Disease Program at UTSW shared, "We are excited to have Dr. Wang join our team at UT Southwestern and Children's Health here in Dallas. The support from the TMA is incredible and makes it possible for us to train future specialists and expand both our clinical care and research programs. Dr. Wang's involvement in the clinic and focus on ADEM research will benefit many and we are grateful to all of those in the TMA community who made it possible." Her research study is a prospective, longitudinal study on acute disseminated encephalomyelitis (ADEM) to identify the clinical characteristics, treatment methods, and follow-up interventions that are associated with better and worse patient-centered outcomes.

We Are Hiring!

The Transverse Myelitis Association is seeking to hire a full-time Community Partnerships Manager who will be responsible for developing, engaging and managing The TMA community support network, and projects related to raising awareness and furthering education both within and outside The TMA community. Their work will significantly impact the efforts to fulfill our five-year strategic mission.

The main role of the Community Partnerships Manager is to direct and grow The TMA's global support group network and a newer ambassador program; design, develop and implement local community based education, awareness and fundraising events and identify new partners and champions to lead and help achieve our strategic mission.

If you have a desire and ability to relate to and learn from the community of people and families affected by our rare disorders, like to travel, have education, training and experience in the field of community organizing, events management, marketing, health care and working in a non-profit environment, we encourage you to apply. Please go to *http://bit.ly/tma-careers* to learn more about the position and apply! Please spread the word!

We are excited to announce that The TMA will be hiring a Community Partnerships Manager. Support, education, networking and advocacy are core functions of our Association and are critical to what we offer to our community. All of the staff and volunteers currently contribute to these activities on a daily basis. If you have contacted The TMA by phone, through emails, participated in local support group meetings, attended awareness events, or any of our numerous education programs, then you are familiar with the significance of these programs. Small organizations with limited resources require that everyone contribute to all programs; there is little opportunity to specialize. Through the generosity and dedication of our members, you have provided us with the opportunity to fill this position. This focus will have a very direct and positive impact on our members by making us more responsive to our community, by expanding how we are able to communicate with and help our members, and by creating a more sophisticated network of support. This person will also develop and grow our network with other advocacy organizations, medical and rehabilitation centers and academic centers. Through this work, we will become more effective in our advocacy for you and find ways to enrich quality of life for the people in our community by expanding services.

We will hire the most qualified person. It would be wonderful if this were a person from our community. Our members most intimately understand how these disorders impact our lives and our families' lives and they have an understanding of these rare disorders. Our members know The TMA's mission and programs and they would bring a fundamental and intense passion for our cause. If the job and the qualifications match your skills, your abilities, education and experience, we hope you will apply. The person who performs these important tasks will have the opportunity to make a transformative difference in our community.

Sandy Siegel, President, The TMA

A Letter from Dr. Allen DeSena

Dear TMA Members:

Greetings to all supporters and members of The TMA community!! It has been almost two years since my arrival to Cincinnati Children's Hospital and Medical Center (CCHMC) and University of Cincinnati. A lot has been going on in the past several months specifically.

From a clinical standpoint, the clinic at Cincinnati Children's continues to grow, and I am seeing more and more patients that have been diagnosed with transverse myelitis, NMOSD and other related disorders. We have changed the culture with respect to aggressively managing acute cases of transverse myelitis in the hospital setting. In addition, our clinic continues to be supported by other very proactive sub-specialists. The Physical Medicine and Rehabilitation providers at CCHMC and the Orthopedic Surgeons (who have performed nerve transfers in a couple of TM patients) have continued to provide excellent care to the TM community. As the TM clinic moves forward, it is so vitally important to have highly engaged experts in other areas in order to provide the highest level of care possible, and I am grateful to have such enthusiastic and knowledgeable colleagues at our disposal. In addition, the Neuroimmunology subsection of Neurology at CCHMC was highlighted for its clinical endeavors in one of its mailings and correspondence that goes out to providers across the country.

I have been working with basic science researchers at both CCHMC and at other major centers on projects that are in early phases of planning and will hopefully shine more light on neuro-immune disorders. I believe that there are some exciting things that could come out of these projects. In addition, I am working with a colleague from Ophthalmology for CCHMC to be included in a large, multi-center study about patients who present with optic neuritis. Lastly, I am happy to say that we are going to be a site for the CAPTURE study of which many of you are familiar!

One of the things that I am the proudest of so far here at Cincinnati is that it is a place where both adults and children with TM can come for expert assessment. Of course, I am hoping it will evolve into so much more than that, both clinically and from a research standpoint. I am excited to see what the following year brings, and I continue to support The TMA in all its endeavors.

Sincerely,

Allen DeSena

Cincinnati Children's Hospital Medical Center
Adult Neurology Clinic at (513) 475-8730
Pediatric: (513) 636-4222

Structural and Functional Features of Central Nervous System Lymphatic Vessels

It was previously thought that the central nervous system did not have a connection to the immune system through lymphatic vessels, but Louveau et al. recently discovered lymphatic vessels in the dural sinuses of the brain in mice. The dural sinuses drain blood from the brain. Lymphatic vessels are part of the lymphatic system, which is part of the immune system. The lymphatic system carries lymph from tissues in the body, and lymph contains white blood cells which protect the body against infections. Previously, little was known about the connection between the central nervous system and the immune system, but now there is evidence about how they are connected. The authors also found that the newly discovered lymphatic vessels drain cerebrospinal fluid, which is fluid that cushions the brain. The authors note that a malfunction of these vessels might be the cause of several neurological disorders that are influenced by the immune system, such as multiple sclerosis and Alzheimer's disease. Dr. Benjamin Greenberg, Director of the Transverse Myelitis and Neuromyelitis Optica Spectrum Disorder Program at the University of Texas Southwestern, stated that "For patients with TM and NMO this research is meaningful. We are constantly trying to gain understanding into the biologic basis for inflammatory events. Recognition of a lymphatic system within the central nervous system allows us to pursue new theories about how and why inflammation occur."

Original publication: Louveau A, Smirnov I, Keyes TJ. Structural and functional features of central nervous system lymphatic vessels. Nature. 2015.

Systemic administration of a drug called epothilone B promotes axon regeneration after spinal cord injury

Ruschel et al. published an article in 2015 that described the effect of a drug called epothilone B (epoB) on the spinal cord of rats with spinal cord injuries (SCIs). To repair SCI, a drug needs to reduce scarring that takes place after an injury, inhibit the chemicals that prevent repair from naturally occurring, and activate the growth of nerve cells. After an SCI, scar tissue made with fibrous proteins called fibronectin and laminin forms where the injury is, and this scar tissue contains chemicals, including chondroitin sulfate proteogylcans (CSPGs) that inhibit the repair of the spinal cord.

The rats given eopB after SCI had a reduction in scar tissue, including fibronectin and laminin, and a reduction in CSPGs. The epoB treatment reduced scar tissue by stopping microtubules from migrating to the lesion site. Microtubules are structures within a cell that help create the structure of the cell and they play a role in movement within a cell. The authors also tested the locomotion abilities of rats with SCI that were treated with epoB and found that treatment with the drug improved the walking ability of rats – it increased the stride length and gait regularity of the rats, and reduced the amount of external rotation present in their hind paws. The authors concluded that epoB might be a promising treatment for SCI.

Dr. Benjamin Greenberg, Director of the Transverse Myelitis and Neuromyelitis Optica Spectrum Disorder Program at the University of Texas Southwestern, stated that "While this medication was tried in a model of traumatic injury, the same scar tissue forms after myelitis. Developing ways to reduce this scar formation will be critical for recovery in our patients. Future trials will need to consider using this medication in non-traumatic models of spinal injury."

Original research: Ruschel J, Hellal F, Flynn KC. Systemic administration of epothilone B promotes axon regeneration after spinal cord injury. Science. 2015;348(6232):347-352.

The ZIKA virus and its Relation to Rare Neuro-Immune Disorders

The Zika virus was discovered in 1947 in Uganda. The virus was then linked to the neurological disorder Guillain-Barré during an outbreak between 2013 and 2015, and in October 2015, scientists in Brazil noted its association with microcephaly. On April 13th, 2016, the CDC confirmed that Zika can cause microcephaly. There have also been reports of Zika and related cases of acute myelitis[1] and acute disseminated encephalomyelitis (ADEM).[2]

In March 2016, a case study was published about a 15-year-old girl from the Caribbean Island, Guadeloupe, who had presented with acute myelitis from Zika in January. Then, on April 10th 2016, several news articles were published about a study showing a link between Zika and acute disseminated encephalomyelitis (ADEM). Dr. Maria Lucia Brito and colleagues presented research on 151 patients who had been infected with arboviruses, including Zika. Arthropod-borne viruses (arboviruses) are transmitted to humans primarily through the bites of infected mosquitoes, ticks, sand flies, or midges. Six of these patients tested positive for Zika and developed autoimmune disorders: four developed Guillain-Barré and 2 developed ADEM. It is still unclear why Zika virus is associated with autoimmune disorders. The TMA will continue to follow and share reports of Zika and its associations with rare neuro-immune disorders.

For more info, follow these links:

(1) *http://thelancet.com/journals/lancet/article/PIIS0140-6736(16)00644-9/fulltext*
(2) *http://www.reuters.com/article/us-health-zika-brain-idUSKCN0X70VP*

Certification in Rare Neuro-immune Disorders for Medical Professionals!

Patricia Plumb, Research Nurse at University of Texas Southwestern, Dallas

I am relatively new to rare neuro-immune disorders. The opportunity to accept a position as a research nurse for children with rare neuro-immune disorders presented itself about 2 years ago. I jumped at the chance with both feet. I have learned more everyday about ON, ADEM, TM (including AFM), NMOSD, and limbic encephalitis just by observing and asking questions.

I heard about the Certification in Rare Neuro-immune Disorders (CRND) via word of mouth from my colleagues. Again, opportunity knocks. Answer the door, friends! I viewed this examination as a way to gauge what I have learned and what else I can do to further my education. As a practitioner engaged in research for rare neuro-immune disorders, I knew I had knowledge gaps in physical therapy and rehabilitation. However, I am able to answer questions about patient advocacy and how research plays a part in rare neuro-immune disorders. I knew the CRND would be a great way for me to understand what I am missing to further advance our mission to assist families with rare neuro-immune disorders.

For the families we serve as practitioners, the CRND certified medical professional has taken a few more steps in their education than the average medical professional for immune mediated disorders. This is a brand new opportunity for our community; as practitioners, we need to advocate for the certification examination to our colleagues. We also need to raise awareness to our families we serve that we are learning more and more daily. I would like to let our families know that although they have a rare disorder, so much is being done behind the scenes to enhance their lives. And it all starts with signing up to further a medical practitioner's education by taking the CRND certification. Please spread the word!

More information : https://myelitis.org/continuing-medical-education/#crnd

OUR ACUTE FLACCID MYELITIS STORY

Elisa Holt

I'll never forget the morning of June 19, 2013 when I took a pregnancy test that was positive! Just to be sure, I took two more! All positive. That afternoon I picked my husband, Mitch, up from the train station with a gift for him revealing we were expecting! We were both ecstatic for the new journey we were about to embark on.

We prepared like most first-time parents do; setting up the nursery, reading books on birth, schedules, sleep and more! I completed the genetic screening, glucose test, anatomy/organ development ultrasound which all came back normal. Mitch and I felt as ready as we were ever going to be as first-time parents. What we never prepared for was what happened on October 3, 2014.

Our beautiful baby boy, Noah, arrived March 2014. Ten fingers, ten toes, perfect from head to toe! We survived the first few months of sleepless nights and soon enjoyed a daily rhythm. We enjoyed getting into the groove of becoming a family of three. September rolled around and sweeping the news were stories about enterovirus D68 (EV-D68). Noah had come down with quite a few colds that month. With a combination of EV-D68 in the news and Noah's colds, we became frequent flyers in our pediatrician's office. Noah presented with a very typical upper respiratory infection and because he wasn't wheezing, there didn't seem any reason to be alarmed.

It was a sunny Friday morning on October 3, 2014. It felt like any other day, why shouldn't it be? I put what I thought was a healthy baby to bed the night before. We woke up just before 8 am and I got Noah out of his crib for his morning feeding. Like every morning, I brought him in to my bed to nurse him. After eating, I went to sit him up and he fell backwards. Puzzled, I tried again, but again he fell backwards. My initial thought was he was full and sleepy but I quickly realized, as I looked him over, he wasn't moving his legs, feet or toes. Everything from the waist down was torpid. Immediately, we placed a call to our pediatrician who directed us to go to the hospital. The Beverly Hospital emergency department was alerted that we were on our way and they didn't waste any time examining Noah. Within 15 minutes of our arrival, an ambulance was waiting to take Noah to Boston Children's Hospital (BCH). To the emergency physician on duty that day, **thank you!** Thank you for not wasting our time and going with your gut and sending us right to Boston. She knew upon arrival that Noah needed more specialized care and this was a time sensitive medical emergency. I remember her apologizing to me for not knowing what was wrong with him as we were preparing to depart for BCH. I know in my heart without her impulsive decision to move us as fast as she did, Noah would not be where he is today.

When we arrived at Boston Children's Hospital, Noah was examined and his blood was drawn. In the thick of the EV-D68 outbreak, the medical community was on high alert and knew they were racing against the clock to make a diagnosis and start treatment. EV-D68, as you may know, can mask itself as many other illnesses. It's crucial for someone with this virus to receive treatment as fast as possible. A spinal tap was done at bedside and soon Noah was sedated for an MRI. Once these tests were completed, it was time to wait for the results. Waiting, waiting, waiting... waiting to get answers. Waiting to hear what our future holds. Waiting to see if the day we just had would ever make sense. Waiting to hear if this paralysis would be reversible. We waited.

While we were waiting, we cuddled our baby boy. We held him ever so tightly so he felt comforted in our arms and we were comforted by him. As parents we felt helpless. How could we have not protected him from whatever this is? Every decision, moment, event that happened went through my head. What could possibly cause this? How did we end up here? Was it cancer? EV-D68? Guillain-Barre Syndrome (GBS)? Can it be fixed? We just had to wait for answers.

We had made it through the day in survival mode. My aunt, who was a nurse, was with us, being a third set of ears for us and helping us navigate the nightmare that was unfolding before us. The emergency room physician came in to inform us the possible diagnoses were GBS or a type of myelitis radiculitis caused by EV-D68. A nose swab, stool culture and spinal tap would be sent out for testing to see if EV-D68 was present. These two possibilities were overwhelming and terrifying. What do you hope for? Both were life changing and only time would tell as far as a prognosis. We were told the initial treatment for both illnesses had the same protocol and they would start immediately.

What could possibly cause this? How did we end up here? Was it cancer? EV-D68? Guillain-Barre Syndrome (GBS)? Can it be fixed? We just had to wait for answers.

After a 10-hour day in the emergency department, we were moved up to the inpatient neurology floor where we were told our stay might last a few months. How did my six-month old baby who was meeting all his milestones early all of a sudden become paralyzed over night? How did we get here?

We got settled into our room that overlooked the city. Outside life was happening and inside our hospital room (it felt like) time stood still. It was as if we weren't a part of the world that was going on around us anymore. We were in a nightmare and couldn't get out. Mitch and I could only fix our eyes on our faith – we clung to it with every fiber of our being.

The overnight physician arrived shortly after we got settled into our room. She explained to us the two types of treatment that would be started. Immunoglobulin therapy (IVIg) and intravenous steroids would be given simultaneously throughout the night. Shortly after the first round of IVIg was started we found out Noah was allergic and it had to be discontinued. He spiked high fevers throughout the night and was unable to continue the treatment because the dose he was receiving was already being given at a very slow pace. Unable to tolerate the IVIg and spiking such high temperatures, the physician came back in to inform us they would monitor him closely, but if he got worse or needed more assistance they would be moving him up to the ICU. Every 15 minutes his vitals were taken and we watched his monitors closely. Night turned to day as the sun came up over the city and the world outside kept on moving. In our world, time continued to stand still.

The start of the second day - a new type of IVIg was administered and thankfully there was no allergic reaction. Noah was able to tolerate the new drug and dosage at an average infusion rate. We met with the inpatient attending and resident who took over Noah's case while we were there. The radiologist who reviewed Noah's MRI the previous day wanted another MRI to confirm a possible diagnosis. The second MRI concluded Noah had Acute Flaccid Myelitis (AFM), a subtype of transverse myelitis.

Noah would finish the protocol for the IVIg and continue steroids for another few weeks. When the doctors told us of Noah's diagnosis, they said since Noah's paralysis was sudden and medical intervention happened within 24 hours of onset, they caught this early. In the midst of a parent's worst nightmare, these words were anything but comforting. No one could tell us what Noah's future would look like and if the paralysis would be permanent, but we were to remain hopeful. Only with time would we truly know the aftermath of AFM. We were told the United States was in the thick of the outbreak and it would be months or longer before we knew how other children recovered from AFM.

Overnight our nurse noticed Noah's mouth started to slightly droop on one side and the next morning they decided they would place a nasogastric tube (NG-Tube) to avoid pulmonary aspiration. During our first few days, it felt like we continued on a downward spiral. Pretty soon though things started to turn around. We started to see gradual improvement. The turnaround seemed pretty quick for an AFM patient. Noah's mouth, neck and arms regained their mobility and control. As for the waist down, we watched and waited for any signs of movement.

As the week went on, Noah's upper body continued to regain control. We constantly watched his lower body for any signs of movement. The NG-tube was removed by the end of the week. Since his upper body was improving daily and the NG-tube was out, they decided that he could go home. As for prognosis, no one knew. Everyone hoped with time healing would occur. After initial treatment of IVIg and steroids, the next step was physical therapy. Typically, an AFM patient would be transferred to a rehab facility but because Noah was only 7 months old (Noah turned 7 months old during our stay), everyone felt it was best to discharge him home and proceed with outpatient physical therapy.

After an eight-day hospital stay, it was time to go home. We couldn't believe it especially since we had prepared ourselves for a long-term stay. We were more nervous bringing him home than the day he was born. Our lives changed overnight and now it was time to adjust to a new normal.

Once home, it was time to focus on Noah's recovery. We started outpatient physical therapy at a facility near our home within the first week or two. Slowly and ever so slightly we saw movement coming back. A sign of hope! After being home a little over a month, we were enrolled with the Northeast Arc – Cape Ann early intervention, a program that provides services to children ages three and under with disabilities and developmental delays. We discontinued our outpatient therapy, because in-home therapy would be provided through the new service. Through the Northeast Arc we were assigned a physical therapist, Dr. Jenna Elie

(PT, DPT) who also is our case manager. She initially saw Noah once a week, but quickly started coming twice a week and added a developmental specialist for supplemental physical therapy because of the progress and improvement she saw in Noah every week. Three months into our three sessions a week therapy regiment, Noah was accepted into the aqua therapy program, bringing our weekly sessions up to four.

On top of our weekly therapy sessions, Mitch and I were taught how to work with Noah throughout the day to incorporate therapeutic play in Noah's daily activities. Each week we saw progress. After consulting with a leading physician in AFM who supported and encouraged an intensive physical therapy regiment, Dr. Elie was quick to bring on board an occupational therapist for more supplemental physical therapy. In Noah's case, our weekly therapy sessions were continuing to make Noah stronger. Hippotherapy and music therapy were also brought on board in early 2016. Dr. Elie said we have to, "Think outside the box in the treatment plan. After all these children are 1 in 2.7 million, they are unique and their therapy services should be as well". She couldn't be more right! We collaborated together advocating for many types of therapy services, which have proven in Noah's case to be just what he needed in his recovery. Noah is now a year and half post onset and walks with a posterior gait trainer! Noah's recovery team consists of neurologists, urologist, physiatrist, physical therapists, developmental specialist, occupational therapist, hippo therapist, orthotist, orthopedist, pediatrician, and music therapist. We couldn't be more grateful to our dedicated team and to Dr. Jenna Elie who helps us advocate and coordinate Noah's care.

A Journey of Teamwork

Jenna Elie, PT, DPT

Physical therapists have certain expectations for themselves, and from others. We specialize in the human body, including restoring it, managing or preventing conditions, and achieving the patient's best physical condition given the person's current state. So what happens when a patient is referred to us with a rare neuro-immune disorder that we have never heard of before? Families are scared, and are looking to us for answers. So how do we treat these patients with conditions that are of the "unknown?"

Patients continue to teach medical professionals on a daily basis. I thought I would share one particular experience that has profoundly improved me as a clinician. Please note that not every patient responds to therapy in the same manner, so the recovery process varies for each individual. What has worked in this case may be different for others given the presentation and severity of the diagnosis.

I have had the pleasure of working with a family, whose 7-month-old son was referred to me after a diagnosis of Acute Flaccid Myelitis (or AFM). According to the CDC, "from August 2014 to July 2015, CDC has verified reports of 120 children in 34 states who developed acute flaccid myelitis." With roughly 319 million people in the United States, that is .000038% of the population. Like most patients, I initially thought that I should be able to tell the family what to expect and exactly what to do. However, since this is such a rare condition that is still being researched, I quickly re-

alized that is not what I am here to do. We are all in this learning process together.

The first thing all medical professionals should do when coming across a diagnosis that they have never treated before is to educate themselves. Thus, I did my research to find out what AFM was and how to go about treating it. Unfortunately, there is no treatment protocol, per se, and the long-term prognosis is unknown. No one is able to directly state whether or not these children will be able to walk again.

So, what next?

TREAT WHAT YOU KNOW

Although these rare diagnoses can be daunting, it is important to remember to treat what you know. The diagnosis may be new, but the impairments that come along with it are often impairments that we have seen before, and know how to treat. Breaking down the diagnosis into structural and functional impairments will guide the treatment plan.

KNOW YOUR LIMITS

Along with treating what you know, it is just as important to know your limits and ask for help or other opinions when necessary. Even if we are "pretty sure" we are doing all that we can do, it is best to get others opinions just in case there is something out there that we are not aware of. This is especially true with cases of rare neuro-immune disorders that we do not see everyday. Asking co-workers, recommending consults with other disciplines, and really taking into consideration the input of others will help guide the plan of care. In this manner, we can expand our current knowledge, share ideas, and best treat our patients.

GO AT THE FAMILY'S PACE

The patient and family are always our number one priority. We need to be very cognizant of their emotional state throughout this process. Imagine a child who has met all of his motor milestones now all of a sudden loses all mobility from the waist down. This experience is incredibly traumatic and overwhelming. Once home from the hospital and medically cleared, we step in to start outpatient services. The family is scared, and therapy is their hope. There are many things to discuss, and a long road ahead. However, it is important not to overwhelm them during this sensitive time; meet them where they are emotionally, and go at the family's pace. Take the time to physically show them every small improvement that is observed; this can help them emotionally cope with their feelings of loss.

The first thing all medical professionals should do when coming across a diagnosis that they have never treated before is to educate themselves.

BE AN ADVOCATE

After researching AFM, I learned that intense physical therapy is the best treatment, after the acute treatments of steroids, intravenous immunoglobulin (IVIg), or plasmapheresis. Each medical treatment will vary depending on the individual. Starting therapy services as early as a child is medically cleared to do so, will help to prevent atrophy and bone loss that can be seen with any paralysis. It is our job to advocate for these patients who do not fall within the normal protocols of therapy, and strive for multiple therapy sessions per week. Advocate for these intense services, including getting other disciplines involved. Or, recommend activities such as swimming, gymnastics, horseback riding, music therapy, and dance classes. I am fortunate to be working for an early intervention program, which gives children access to many different services. I know this is not the case everywhere, and that is why supplemental activities are important. Any appropriate activity that challenges the body in different ways can be an option. Think outside the box in the treatment plan. After all, these children are 1 in 2.7 million -- they are unique and their therapy services should be as well.

EMPOWER THE FAMILY

In addition to advocating for services, it is important to realize that we will not always be there with the family. Therefore, we need to empower the family to advocate on their own, and teach them how to do so. Giving them the tools to advocate and know how to manage their child's care is important, and it will make all the difference. The patient and family will be managing the child's care on a daily basis, and we need to make sure they are comfortable doing so. It is important to organize the child's environment to promote therapeutic play throughout the day. A child will do whatever it takes to get to what he or she wants, which allows us to promote challenges in the natural environment. For example, if you are working on standing activities, help the family arrange their household environment so that all of the child's toys are up high (on a table, easel, play kitchen, etc.). This makes therapeutic play more natural.

The child I see participates in seven structured therapy services per week, as well as therapeutic play throughout his day with his family. This can be overwhelming for families, so guiding them on how to manage their time is beneficial. Designate one person to organize the team, and develop a specific plan for therapeutic play or exercises, including what to prioritize. This can relieve a lot of the stress for families wondering where to start on their long list of activities.

With all of these services, the child is now 2 years old and walking with a posterior gait trainer. He has been receiving services now for over 1.5 years and continues to show progress on a weekly basis. Patients may hit plateaus, so trying a different approach can be what is needed. That is not to say all cases should have these exact services or will see the same progress; as I have stated before, every patient's road to recovery is different. However, advocating to give them the best possible chance is essential. The neurological system is an incredible and beautiful system that has the ability to regenerate for years to come with continued hard work. It is never too late to start.

While thinking about writing this post, the one word that continues to pop up into my head is "teamwork." It is remarkable to watch so many people come together to support one patient on their journey with a rare neuro-immune disorder. Each individual is just as invested as the next. I will never forget looking around at an appointment with over 10 medical professionals watching this now 2-year-old walk down the hallway. All of us were so proud of how far he has come, and hopeful of where he is going. We are regularly in contact with each other and discuss our ideas, questions, and concerns. The family's perspective and priorities are always of utmost importance. The families we serve are strong, and continue to unify us as a medical team. This is what makes a success story. I truly attribute the outstanding progress with this "unknown" diagnosis to the fact that every single person is working together in harmony to do whatever is necessary for this child to continue to grow and thrive as he deserves.

So, treating a patient with a rare neuro-immune disorder is not really scary. It's something that we are all prepared to do if we take a step back, slow down, and work together to complete the puzzle. It is a beautiful journey of hope, perseverance, teamwork, dedication, and love.

CLINICAL STUDIES & TRIALS

For more information, please visit bitly.com/tma-trials

1 **CAPTURE: Collaborative Assessment of Pediatric Transverse Myelitis; Understand, Reveal, Educate**

Principal Investigator: Benjamin Greenberg, MD, MHS
Lead Study Site: University of Texas Southwestern
Study includes online and multiple study sites

2 **Efficacy and Safety Study as Monotherapy of SA237 to Treat NMO and NMOSD**

Study Sponsor: Chugai Pharmaceuticals

3 **Safety and Efficacy of Sustained release Dalfampridine in Transverse Myelitis**

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University

4 **A Double-masked, Placebo-controlled Study With Open Label Period to Evaluate MEDI-551 in NNMO and NMOSD**

Study Sponsor: Astrazeneca

5 **Spinal Cord MRI Research Study for Children, Adolescents, and Young Adults with Myelitis**

Principal Investigator: Nadia Barakat, PhD
Study Site: Boston Children's Hospital

6 **A Safety, Tolerability and Efficacy Study of V158866 in Central Neuropathic Pain Following Spinal Cord Injury**

Principal Investigator: Christine N. Sang, MD, MPH
Study Site: Brigham and Women's Hospital

7 A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis

Principal Investigator: Benjamin Greenberg, MD, MHS
Study Site: University of Texas Southwestern

8 FES Impact on CNS Growth Factors in TM, NMO and other, Neuroinflammatory Disorders

Principal Investigator: Daniel Becker, MD
Study Site: Hugo W. Moser Research Institute

9 The PREVENT Study

Study Sponsor: Alexion Pharmaceuticals

10 The Effect of Pregnancy on Neuromyelitis Optica

Principal Investigator: Eric Klawiter, MD
Study Site: Massachusetts General Hospital

11 Neuroimaging and Neurobehavioral Outcomes of Pediatric Neuromyelitis Optica: A Pilot Study

Principal Investigator: Ana Arenivas, PhD
Study Site: Johns Hopkins Medicine

12 SCI-Hard: Evaluating the Effectiveness of a Mobile Game to Improve Self-Management Skills of Teens and Young Adults with SCI and other Spinal Cord Impairments

Principal Investigator: Michelle A. Meade, PhD
Study Site: University of Michigan

13 Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis

Principal Investigator: Lana Harder, PhD
Study Site: University of Texas Southwestern

1

An innovative, multi-center, pediatric transverse myelitis study led by Dr. Benjamin Greenberg, MD, MHS, Director of the TM and NMO Center at UTSW in Dallas, TX. The study is the first to combine assessments from health care providers and patients relative to pediatric TM outcomes. The collaboration involves multiple health care centers across North America, the Transverse Myelitis Association and most importantly, patients. The study is designed to assess the current state of Pediatric TM (including AFM or Acute Flaccid Myelitis) in terms of diagnosis, treatment and outcomes. Ultimately, it will lead to an improved understanding of the current status of care for individuals afflicted with TM and reveal what are the current best practices. Patients will educate clinicians and the study will educate the broader health care system about what outcomes are important and achievable. It will develop a multi-metric outcome measure based on combined patient generated and provider generated data that can be used in future controlled trials. Participation in this study may involve travel to one of the five participating centers, whichever is closest to the patient geographically (or enrollment into the virtual cohort if travel is not possible), at 3 month, 6 month, and 12 month intervals. It will include a review of treatment records, imaging, and an examination by a physician. Internet access is required for completion of questionnaires by the child and/or parents.

2

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

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

3

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

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

All study participants will be randomized for the first double-blinded 8-week part of the study with 25-foot timed walking assessments every 2 weeks. At the conclusion of this first 10-week trial, subjects will be crossed over to the other therapy for another 8 weeks and 25-foot timed walking assessments will again be done every 2 weeks.

4

The main objective of this study is to determine if MEDI-551 can significantly delay the time it takes for a new NMO/NMOSD attack to occur. This is a multinational randomized, double-masked, placebo-controlled study with an open-label period. "Double-masked" means that neither the patient nor the study staff (for example, the doctor/nurse) know the identity of the study drug they are receiving (either MEDI-551 or placebo). Placebo-controlled means that some patients will receive MEDI-551 and some will receive placebo, an inactive substance designed to look like MEDI-551. Eligible NMO/NMOSD patients will be "randomized" in a 3:1 ratio to received either MEDI-551 or placebo. This random selection is made by a computer and will give a 25% (1 in 4) chance of getting placebo and a 75% (3 in 4) chance of getting MEDI-551. "Open label" means a period in the study where there is no placebo arm and all patients receive MEDI-551.

After being enrolled in the study, patients will be first followed for 28 weeks; this period is called the placebo-controlled treatment period. During the placebo-controlled treatment period, MEDI-551 or placebo will be given in the vein (intravenous infusion) on Day 1 and Day 15. Patients will have the option to enroll into the open-label period if a confirmed NMO/NMOSD attack occurred during the placebo-controlled treatment period. Subjects who complete the placebo-controlled treatment period without experiencing an attack will also be given the option to enroll in the open-label period. During the open-label period, MEDI-551 will be given on Day 1 and Day 15 and then every 6 months thereafter until the end of the study. During the study, the study doctors are allowed to treat NMO/NMOSD attacks with standard rescue medications.

5

Our objectives are to better understand pain involvement in children with myelitis and to develop diagnostic imaging techniques to detect different demyelinating stages of myelitis. The study takes place on-site at Boston Children's Hospital and includes pain sensitivity testing and two MRI scans of the spinal cord, without contrast injections. Each study session takes approximately 3.5 hours. Participants will receive a $100 Visa gift card. They will also receive an additional $10 gift card each time they refer a friend who qualifies for the study as a healthy volunteer.

6

V158866 is an active inhibitor of FAAH1, an enzyme that metabolizes the endocannabinoid called Anandamide (AEA). It is hypothesized that inhibition of FAAH1 can decrease pain without generating side effects in non-activated pathways. Therefore, the primary objective of this study is to investigate the safety and tolerability of V158866 in subjects with central neuropathic pain following spinal cord injury (both traumatic and non-traumatic) and evaluate its analgesic and anti-hyperalgesic effect. The study will consist of four overnight visits to the hospital. All travel to and from the hospital will be reimbursed.

7

This observational study seeks to determine the biologic causes of inflammation in patients with Neuromyelitis Optica (NMO), Neuromyelitis Optica Spectrum Disorder, Transverse Myelitis and Optic Neuritis. While patients will be treated according to decisions with their treating physician, this study will collect data and samples from patients prospectively to gain a better understanding of the disease. The study is seeking to understand why some patients respond to medications, while others do not; and what happens biologically, preceding relapses. Gathering these data and samples will allow researchers to identify new ways of diagnosing and treating these diseases. Data and samples will be shared with researchers around the world to support collaborative efforts to treat these conditions.

8

This research is being conducted to evaluate change in function (spasticity, strength, and sensation) in individuals with inflammatory myelopathies in response to functional electrical stimulation (FES) cycling therapy. The study will also evaluate the changes in CSF growth factors, neurotrophins, and inflammatory cytokines in response to FES stimulation. A correlation between changes in function and changes in the cerebrospinal fluid (CSF) neurotrophic/inflammatory milieu will provide evidence of biochemical changes that may mediate neurological repair following FES cycle therapy. This data will be crucial for the design of a phase 2/3 clinical trial evaluating the efficacy of FES in patients with inflammatory myelopathies.

9

Alexion Pharmaceuticals is conducting a clinical trial called the PREVENT Study. The primary objective of the study is to assess the efficacy and safety of an investigational medicine as a potential treatment to prevent relapses in NMO and NMO Spectrum Disorder (NMOSD). This is a randomized double blind study, where participants will receive investigational medication or placebo and neither the participant nor the study doctor or their staff will know who received the drug or placebo. In this study, 2 out of 3 participants will receive investigational medication and 1 out of 3 participants will receive placebo. The medication is given intravenously at the study doctor's office or infusion center.

10

This research is being conducted to study the effect of pregnancy on Neuromyelitis Optica (NMO). It commonly affects females of childbearing age. To date, women's health issues in NMO have not been studied in detail. Determining the effect of pregnancy on the NMO disease course is of great importance in counseling patients on family planning. Information will also be gathered on the incidence of complications of pregnancy and the incidence of miscarriages.

11

The primary objective of this study is to determine how well specific neuroimaging modalities detect the different aspects of anomalous white matter development associated with pediatric NMO. Our purpose is to acquire data using neuroimaging obtained at 3.0 Tesla as well as neurobehavioral data to better characterize neuroimaging features and function in this rare population.

This study takes part in two phases. For the first part, participants will undergo neuropsychological (cognitive) testing and have a "mock" or practice magnetic resonance imaging (MRI) scan". The purpose of this "mock" scan is to improve comfort, decrease potential anxiety, and to train you to lie still while in the scanner. After the "mock"/practice scan, participants will have the MRI exam. The MRI scan could take up to 1 hour. Participants are in this study for one day for approximately 3-4 hours.

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SCI Hard is a mobile game designed to help teens and young adults with spinal cord injury (SCI) and other spinal cord impairments improve their ability to manage their health and interact with others. The game can be downloaded to Apple or Android mobile devices and takes about five hours to complete. The goal of the game is for players to be able to manage their health and prevent complications so they can achieve independence, get out into the community, and save the world.

We are currently recruiting research participants, 13 to 29 years old, with transverse myelitis, SCI, spina bifida, or related impairments of the spinal cord. Participants will complete a set of online surveys three times over three months and will be expected to download and play their assigned mobile game (either SCI Hard or another game). If they complete all parts of the study, they will be eligible to earn up to $100.

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Based on previous research showing cognitive problems in transverse myelitis, a pilot study was designed to further investigate this observation. This is a study that utilizes brain imaging to understand cognitive dysfunction in transverse myelitis. Data will be acquired through MRI scan of the brain, optical coherence tomography (OCT), and neuropsychological evaluation.

ASK THE EXPERT PODCAST RECORDINGS AVAILABLE ON ITUNES!

The TMA's Ask the Expert Podcast Series in the first quarter of 2016 included conversations with clinical professionals and experts from our community on a range of topics from diagnosis to pain management, to living with Acute Flaccid Myelitis from the perspective of parents.

IN JANUARY...

Dr. Benjamin Greenberg and Dr. Izlem Izbudak spoke about diagnosing TM, NMOSD, and ADEM from both the neurological and neuro-radiological perspective. They discussed the various tests used to diagnose rare neuro-immune disorders, including an in-depth discussion about MRI and its role in diagnosis. They also talked about ongoing monitoring through follow-up MRIs to check for new inflammatory attacks. They stressed the importance of having physicians on a health care team communicate with one another, because different specialties may use different language to describe the same thing, such as the words "inflammation," "lesion," or "white spots." Dr. Greenberg studies the use of biomarkers to improve the care of patients, and Dr. Izbudak uses diffusion tensor imaging to study rare neuro-immune disorders. Dr. Greenberg also encouraged listeners to participate in research about rare neuro-immune disorders.

IN FEBRUARY...

Dr. Greenberg was joined by Dr. Richard Robinson, a clinical psychologist, to talk about the management of neuropathic pain. Dr. Greenberg gave an overview of neuropathic pain, and the differences between neuropathic pain and pain caused by physical damage. Dr. Robinson talked about how pain is processed by the brain and how mindfulness can control the way we process the pain we feel, the role a psychologist can play in helping to manage patients' pain, and the various strategies psychologists use. They encouraged patients to thoroughly describe their pain to their physicians to help them better assess what kind of pain they are experiencing and how to treat it. They discussed medical marijuana, opiates, and spinal stimulators for treating pain. They also talked about alternative treatments and supplements, and the potential dangers of supplements.

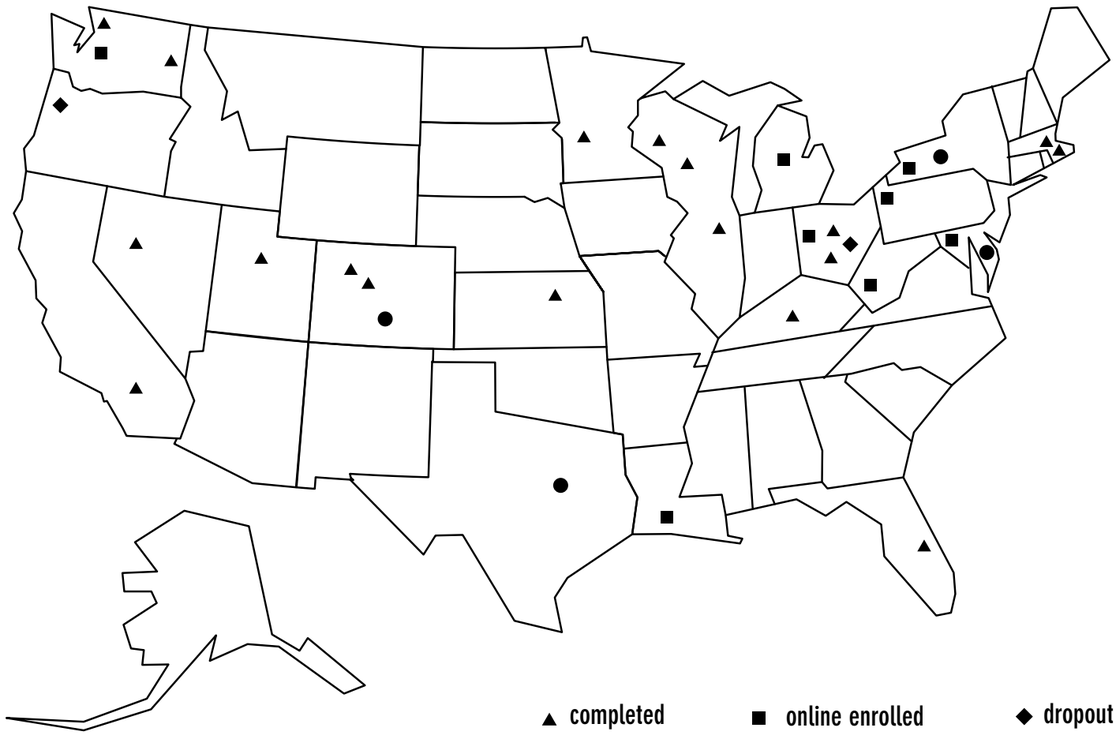
IN MARCH...

Rebecca Whitney, The TMA's Pediatric Programs Manager, spoke with Elisa Holt and Courtney Robinson who are mothers of children with acute flaccid myelitis (AFM), a subtype of transverse myelitis. Elisa talked about her son Noah's experience with AFM, and Courtney talked about her son Kingston's experience with AFM. They talked about their children's symptoms and their experience with diagnosis and treatment. They also talked about rehabilitation, and alternative forms of rehabilitation, such as horseback riding and swimming. They shared how social media allowed them to connect with other families living with TM and AFM, and how this helped support them through the diagnosis. Recovery from AFM takes time and is a marathon, not a sprint. Parents should try to be patient while at the same time, never losing hope.

All of the past podcasts are available on our website. To listen to these podcasts and to join upcoming podcasts, please visit: http://bit.ly/tma-podcasts

AN UPDATE FROM THE CAPTURE STUDY

Current distribution of participants in the study



● **sites:** CHOP: 11 enrolled | UTSW: 10 enrolled | Kennedy Krieger Institute: 4 enrolled | Johns Hopkins: 2 enrolled

● **sites:** The Hospital for Sick Children: 2 children enrolled

We are still enrolling. If you or someone you know meets the criteria below, please contact us.

Children diagnosed with Transverse Myelitis or Acute Flaccid Myelitis between the ages of 0 to 18 years (or 17 years at onset) within 180 days of the initial onset of symptoms.

Contact Us

Rebecca Whitney
(855) 380-3330 extension 5
rwhitney@myelitis.org

Tricia Plumb
(214) 456-2464
Patricia.plumb@utsouthwestern.edu

ANNOUNCING THE 2016 TMA ANNUAL QUALITY OF LIFE FAMILY CAMP

We are excited to announce that our TMA Family Camp will be held Sunday, July 31 through Thursday, August 4, 2016 at The Center for Courageous Kids (CCK) in Scottsville, KY.

How to Apply?

Application is now open at bit.ly/2016-camp-app.

Step One: Online Application

1. Please complete the form for Family Retreat by going to *bit.ly/2016-camp-form*.

Select Transverse Myelitis Association Family Camp (July 31 to August 4) in the drop down menu for Camp Session Requested. If you do not immediately receive an email, then your Step 1 has not been submitted. After you complete Step 1, continue to Step 2.

Step Two: Print Application

2. Download and print the Family Retreat application from *bit.ly/2016-camp-print-form*.

Please complete the form, ask your physician to sign it and return to CCK by mail or fax at the address below:

The Center for Courageous Kids
Attn: Camper Admissions, 1501 Burnley Road, Scottsville, KY 42164; Fax: (270) 618-2902;
Phone: (270) 618-2912

Application Process

Step 1 and Step 2 application forms must be completed before an application can be reviewed.

International families will be reviewed and notified on an immediate, rolling basis prior to final review date. This is necessary for families to make the appropriate accommodations and meet requirements for international travel.

Round 1 review

CCK will begin immediate review of new families on a rolling basis in the order in which the completed applications are received. All other completed applications will be reviewed March 7, 2016.

Round 2 review

Applicants reviewed the week of March 7, 2016 will be informed of their acceptance in the order they are reviewed and accepted by March 14, 2016.

Completed applications received after March 14, 2016 will be reviewed on a rolling basis in the order in which they are received until 30 families are accepted.

Round 3 review

Remaining applications, after the first 30 applications will be waitlisted and reviewed beginning on April 4, 2016 based on availability of space and willingness of families to share space. The review of the waitlisted applications will be on a rolling basis in the order in which the completed applications are received. Families will be informed of their acceptance in the order they are reviewed and accepted by May 2, 2016.

Please note that CCK has 4 lodges with 8 dens in each lodge (with either 6, or 8 beds in a den), and more than one family can be accommodated in one den based on family size, diagnosis and age of children. Families may identify another family they would like to share with when submitting the application.

If your child has special needs, is in a chair and unable to stand and transfer, or you are unable to assist your child in making these transfers, please let us know on your application.

Eligibility

1. Families with children diagnosed with ADEM, NMO, TM, ON and Acute Flaccid Myelitis (AFM) who are 5 to 17 years are eligible to apply to camp.
2. Applications are welcome from older and younger children, who may be accepted on a case-by-case basis.
3. Siblings and up to two adults living in the same household as the camper may participate in camp
4. All applicants must be members of The TMA. Membership is free.

Arrival and Departure information

1. Families will receive detailed information about arrival and departure times along with their acceptance information from CCK. In general, most families arrive at camp around 3:00 pm on the first day of camp, Sunday, July 31, 2016. Camp closes at noon on Thursday, August 4, 2016.
2. The closest airport is Nashville, Tennessee. For help with ground transportation between the airport and camp, please contact The TMA at *tmakids@myelitis.org* with travel information. Please do not make plane reservations until you receive an acceptance letter from CCK.

THERE IS STILL TIME TO APPLY! PLEASE MAKE SURE TO COMPLETE STEP 1 AND STEP 2 OF THE APPLICATION TO BE CONSIDERED FOR REVIEW.

Cost

3. There is no cost for families to come to camp besides personal travel expenses. The TMA and CCK have a partnership under which we cover the cost of camp.
4. TMA will be able to offer some financial help via travel grants to families. All accepted families will receive an email with an application form and guidelines to apply for this funding in approximately May, 2016. They are offered on a first come first serve basis until grant funds are no longer available.

Education Program

Medical professionals and specialists from our medical community will be joining camp and provide a three day education program for the parents and any of the children, teen or young adults who attend camp and are interested in the education program.

Special Requests

If your child has special needs, is in a chair and unable to stand and transfer, or you are unable to assist your child in making these transfers, please let us know in advance.

2016 REGIONAL

RARE NEURO-IMMUNE DISORDERS SYMPOSIUM

August 13, 2016
The University of Colorado Hospital, Denver

An education and advocacy conference for families, caregivers and individuals diagnosed with Transverse Myelitis (including the subtype Acute Flaccid Myelitis), Neuromyelitis Optica Spectrum Disorder, Optic Neuritis and Acute Disseminated Encephalomyelitis.

This conference hosted by The Transverse Myelitis Association (TMA) and The University of Colorado, Denver is dedicated to the exchange of information regarding diagnosis, research and treatment strategies and to providing an opportunity to bring together the community of individuals diagnosed with these rare neuro-immune diseases, families, caregivers and the medical professionals who have interest and are specializing in these disorders.

For more information on the program, logistics and to register, please visit https://myelitis.org/event/2016-rnds

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

Announcements

2016 Ohio Walk-Run-N-Roll: May 21, 2016

2016 TMA Quality of Life Family Camp: July 31 to August 4, 2016

2016 Regional Rare Neuro-Immune Disorders Symposium: August 13, 2016

2016 Massachusetts Walk-Run-N-Roll: October 15, 2016

Contact us

The Transverse Myelitis Association

1787 Sutter Parkway
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info@myelitis.org
855-380-3330

myelitis.org