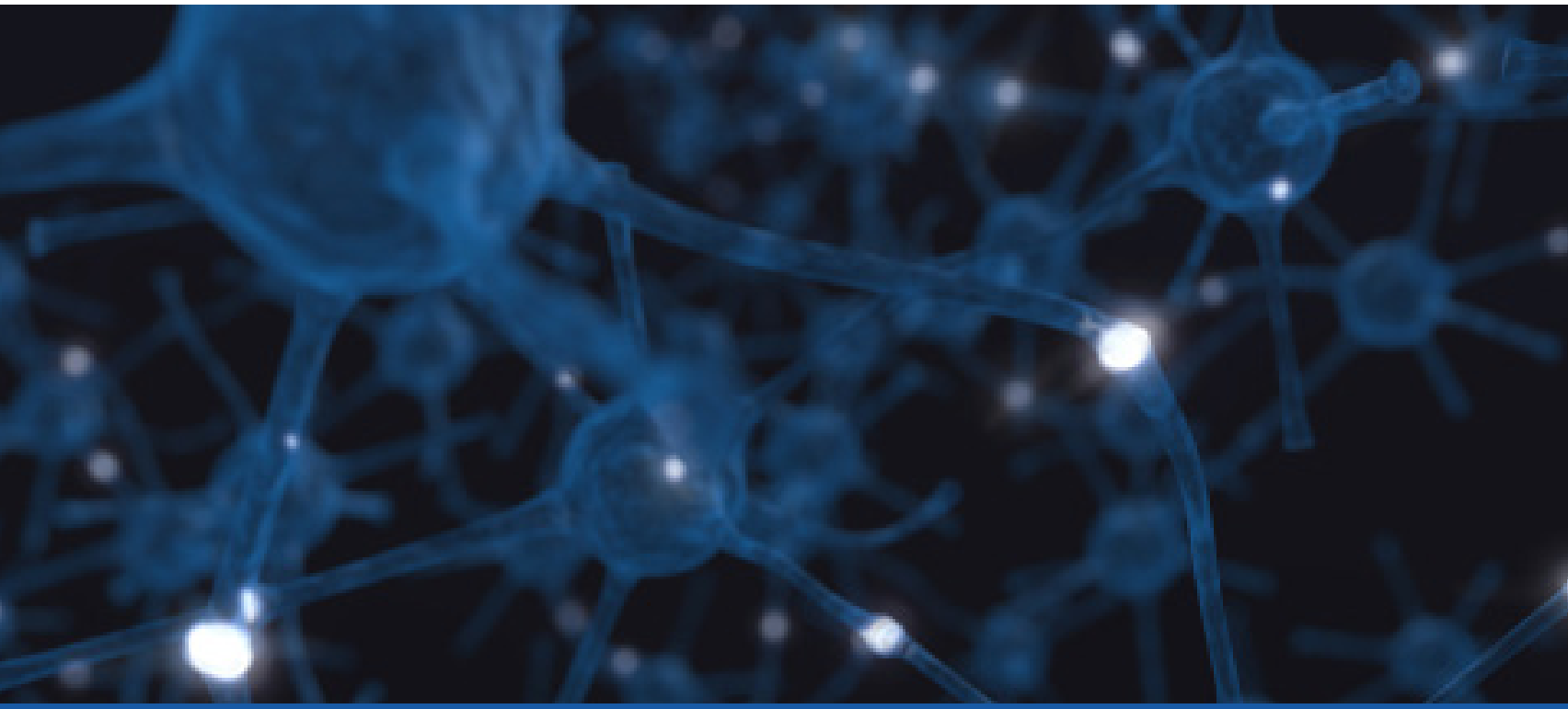
THE TRANSVERSE MYELITIS ASSOCIATION

NEWSLETTER

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

Spring 2013



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THE EDITOR'S COLUMN

Sandy Siegel, PhD

IN HONOR OF MY REMARKABLE FATHER: DANIEL MARLIN SIEGEL

My father passed away on February 18, 2013. He had Alzheimer's disease; we had our very long good bye. It was a blessing and a miracle that my father was given 90 amazing years. He was such a unique and remarkable man. He was so filled with talent and skills, he was so smart and filled with uncommon common sense, and he had an amazing character and values. He was most definitely one of the greatest of the greatest generation. His three children, his daughters and sons in law, his four wonderful grandsons and his three beautiful great grandsons will miss him terribly. But no one will miss him anything like my mom who had a 70 plus year love affair with this man. They were married for 69 years.

He grew up during the depression and the family was dirt poor. He learned the value of hard work; it was impossible to out work my father. He so believed that if you are going to do something that you do it right... he never did anything half way. He served in the Army Air Corp as a cryptographer during World War II and was stationed in North Africa and Italy. He was so proud of his service. He was a world class problem solver. He lived an amazingly challenging and difficult life. A lesser man would have been totally ground up and spit out by the significance, the number and the severity of the events that happened to my father. His health issues were staggeringly complex. And he never stopped fighting. They didn't make them any stronger than my father.

He was so proud of his education. He was married and had three children when he went to Western Reserve University for a business degree. He went to school on the GI Bill and completed his bachelor's degree in three years.

I learned so much from my father and he had such a profound influence on my character and values. He had an incredible sense of justice ... he was always for the little guy and he couldn't stand to see someone get taken advantage of or wronged. It made him crazy. It was through my father that I learned the importance of healing the world; that one has a responsibility to care for their family, their community and society. I inherited my great passion for life and my sensitivity, compassion and kindness from my father. He taught me to be honest and to always try to do the right thing. He taught me to be a responsible person. He valued my thoughts about everything. He never put me down or belittled anything I thought or felt or did. He was always my greatest defender and supporter - even when he wasn't wildly enthusiastic about my choices. He was accepting of his children in all ways, and that acceptance came from the deep love and respect he had for us. Our father was so openly proud of everything his children accomplished in their lives ... large and small. Our deepest respect for our father never came from fear ... our respect came from our relationship with him and from our understanding of the kind of human being that he was. He truly defined and embodied the meaning of unconditional love of one's children.

Pauline and I had no greater supporters in the work we were doing for The Transverse Myelitis Association than my mom and dad. Not only were they so proud of our efforts, they regularly rolled up their sleeves to help us with the work. For years, we performed our own bulk mailings until our membership was well over thousands of people. My mom and dad would go through the sorting instructions and would place the thousands of mailing labels onto each envelope. They proofread everything we wrote for the newsletters and journals. They helped us with all of the clerical and administrative work and offered regular advice and support through every challenge. My parents also had the greatest admiration and respect for Pauline. They were among her most loyal cheerleaders. They offered encouragement, love and care; my father so loved Pauline. And my father was Kazu's best buddy. He loved Kazu and marveled at his smarts and his sweetness. He would have fed Kazu from his plate at every meal, if Pauline had allowed it.

My father's devotion to his family was paramount in his life ... nothing else came close. He was an incredible example for us of what it meant to be a good person, what it meant to be a good husband, and how to be a good father. He set the bar so high for us. You couldn't match his selflessness or his loyalty or his devotion but he made us want to try to be like him in these ways. I will carry my dearest father with me in my life every day; because he made me into the person I am today.

Life is so fragile, please cherish every moment.

You can help me celebrate my father's life and honor his memory by making a donation to The Transverse Myelitis Association in his honor and memory. Thank you!

Please take care of yourselves and each other.

IN LOVING MEMORY OF DANIEL MARLIN SIEGEL

SAFETY AND EFFICACY OF SUSTAINED RELEASE DALFAMPRIDINE IN TM

INVESTIGATOR: MICHAEL LEVY, MD, PHD | JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD

COLLABORATOR: ACORDA THERAPEUTICS

Study Details

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

The clinical trial will focus on monophasic idiopathic 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.

Eligible Participants

Patients (18-65 years) diagnosed with idiopathic transverse myelitis confirmed by MRI will be eligible to participate in this study.

Diagnosis of any other recurrent CNS disease including multiple sclerosis, recurrent myelitis, or neuromyelitis optica is an exclusion criteria for the study. Other exclusion criteria include:

- History of seizure(s).
- Pregnancy or positive pregnancy test (mandatory test for all women aged 18-55 to be done at first screening visit).
- Known allergy to dalfampridine or any other formulation of 4-aminopyridine.
- Patients unable to walk.
- Patients with history of severe alcohol or drug abuse, severe psychiatric illness like severe depression, poor motivational capacity, or severe language disturbances, particularly of receptive nature or with serious cognitive deficits (defined as equivalent to a mini-mental state exam score of 23 or less).
- Patients with severe uncontrolled medical problems (e.g. hypertension, cardiovascular disease, severe rheumatoid arthritis, active joint deformity of arthritic origin, active cancer or renal disease, any kind of end-stage pulmonary or cardiovascular disease, claudication, uncontrolled epilepsy or others).

Contact Information

If you are interested in participating, please contact the Johns Hopkins University at the contact below.

Maureen Mealy, RN | Email: hopkinstmcenter@jhmi.edu

Please refer to this study by its www.clinicaltrials.gov identifier: NCT01446575

For more information, please visit the NIH www.clinicaltrials.gov site here

2013 Rare Neuro-immunologic Disorders Symposium Coming Up!

The University of Texas at Southwestern (UTSW), the Transverse Myelitis Association (TMA) and the Johns Hopkins University Project RESTORE (JHU) are hosting the 2013 Rare Neuro-immunologic Disorders Symposium in Dallas.

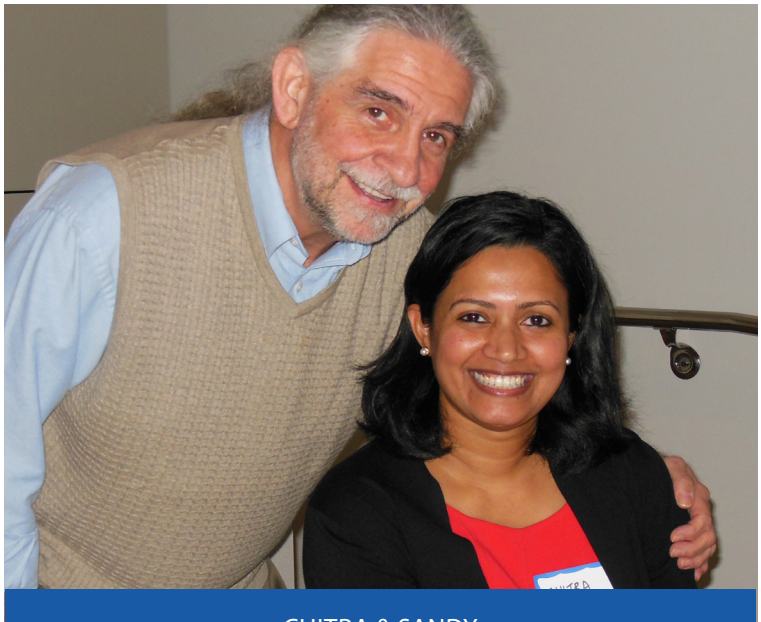
The Symposium will be held on Friday, October 25 and Saturday, October 26, 2013 in Dallas. If you live outside of Dallas, you should plan on arriving Thursday evening, as the program and research will begin early on Friday morning.

The Embassy Suites Hotel in Dallas -Market Center, is offering our participants discounted room rates of $99 + tax for Standard King or Double Rooms. Please contact Kodee Walker, Sales Coordinator at phone 214-962-1625 Or by email kodee.waler@hilton.com to make your reservations. The rate availability is subject to room availability. Reserve your room early!

Details regarding the specific agenda and the application process to enroll in the study will be provided on the TMA web site as soon as we have these plans completed.

We are looking forward to seeing you in Dallas in October 2013.

The 2013 NMO and TM Research Symposium sponsored by UT Southwestern Department of Neurology and the Office of Continuing Medical Education was held on January 11, 2013. Chitra and Sandy attended at the invitation of Dr. Ben Greenberg. It was a very productive weekend where we discussed the upcoming Rare Neuro-immunologic Disorders Symposium, spent quality time with Drs. Allen DeSena, Donna Graves, Lana Harder and with the research and clinical team dedicated to our community- Audrey Ayers, Martha Mann, Sam Hughes and Morgan McCreary and learned about the innovative research projects currently underway at UTSW. Notes and presentations from the half-day symposium are available on the TMA Blog - https://myelitis.org/resources/tma-blog/notes-from-the-research-symposium-at-ut-southwestern.



CHITRA & SANDY

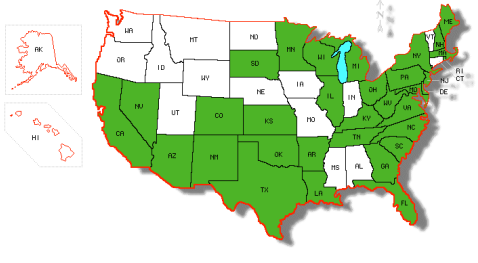
An Update from THE JOHNS HOPKINS TM CENTER

The JHTMC was established in 1999 as the first clinical center of excellence in the world to facilitate the diagnosis and treatment of patients with transverse myelitis (TM). The JHTMC is part of the Division of Neuroimmunology and Neuro-infectious Disorder in the Department of Neurology. Offering state of the art clinical care remains a primary focus of the JHTMC. Our 14th year has proven to be just as busy as ever, and we are proud to report that the Center is thriving! We have continued to focus on the multi-disciplinary approach in the management of patients with TM, including neuro-radiology, neurosurgery, rehabilitation, neuro-ophthalmology, and urology. JHTMC patients are evaluated by physical and occupational therapists from the International Center for Spinal Cord Injury at the Kennedy Krieger Institute, free of charge.

Being one of two centers in the US focused on rare neuro-immunologic diseases, facilitating a rapid patient referral process remains a focus. All patient records are reviewed and assessed to identify acute and urgent patient referrals by Maureen Mealy, RN, BSN, Program Manager at the JHTMC. The review of records allows us to better assess the needs of our patients prior to their visits, so that a more comprehensive visit can be arranged. In 2012, over 230 patient referrals were reviewed and 215 new patients were seen by the neuro-immunologists at the Center from 39 different states across the country and internationally from Bermuda, Jordan, Saudi Arabia, United Kingdom, and the Virgin Islands. In addition to the neurological assessment, based on need, patients are also referred to different specialists who focus on neuropsychiatry, spine neurosurgery, neuro-ophthalmology, neuro-rehabilitation, interventional neuroradiology and neuro-urology among others.

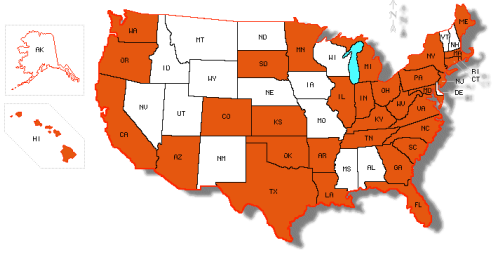
A major emphasis continues to be placed on access to patients and urgent physician consultations for those who are unable to travel to the JHTMC. This service is separate from the Remote Second Opinion Program to provide expert advice on various issues, including acute therapeutic management, diagnostic work-up, chronic treatment of diseases associated with TM, symptom management, and rehabilitation strategies. Such consultations are offered either via telephone or by e-mail communication. This free service was offered to 120 patients and physicians from 32 states across the country and internationally from Australia, Canada, China, Colombia, France, India, Lithuania, Mexico, Philippines, Puerto Rico, and the UK.

JHTMC New Patients 2012



JOHNS HOPKINS
TRANSVERSE MYELITIS
CENTER

JHTMC Consultations 2012



RESEARCH UPDATE

Several clinical and basic science research studies are underway at the JHTMC and are summarized below.

- The JHTMC will be at the American Academy of Neurology meeting in San Diego in March 2013. We will be sharing a report characterizing the clinical and neuroimaging features of patients with sarcoidosis-associated myelopathy; and also report on a set of clinical criteria that can distinguish inflammatory and vascular myelopathies.

- As already shared on the TMA website, recruitment has begun on a new clinicial study led by Dr. Michael Levy studying the safety and efficacy of dalfampridine in TM. More details on this and other studies including the FES study with Dr. Daniel Becker and the ACP repository can be found on http://myelitis.org/research/clinical-studies-trials.

- Another clinical study currently enrolling patients is in the setting of NMO to evaluate the tolerability/safety and preliminary efficacy of the medication CINRYZE® (C1 esterase inhibitor [human]). Three daily infusions of CINRYZE® are added to standard-of-care high dose steroids and two additional doses of CINRYZE® are added to plasma exchange (if necessary) to those patients presenting with TM or optic neuritis in the context of NMO. The primary outcomes are safety, tolerability and clinical changes in neurological measures -the Expanded Disability Severity Scale and Low Contrast Visual Acuity.

- As part of the National Consortium for NMO Research, we are working on investigating biomarkers in NMO through blood and cerebrospinal fluid analysis.

- Many patients experience pain as a symptom of NMO and recent studies have begun to analyze the types of pain and the best treatments for pain in NMO patients. We have launched an observational study to develop an algorithm that will help physicians classify the type of pain NMO patients experience into distinct categories that are treated differently. The second goal we hope to accomplish is assessing which medications work best for different types of pain in NMO patients. This will be done by a longitudinal observational study of NMO patients treated for pain in the Johns Hopkins NMO Clinic.

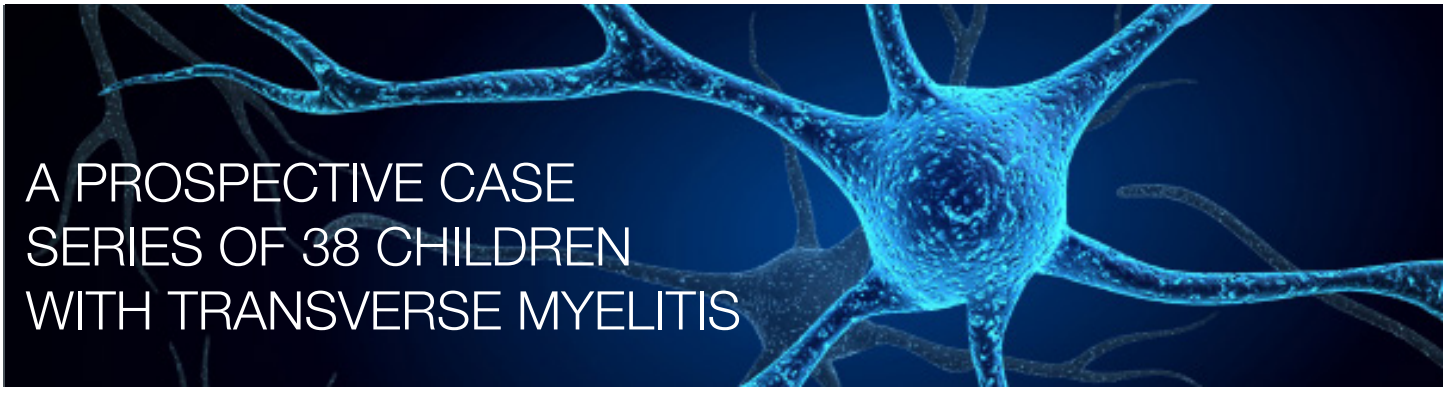
- Studies of retinal pathology and potential involvement of the optic nerve have been performed in patients with TM and NMO. Drs. Peter Calabresi, Scott Newsome and other members of the JHTMC have been using new techniques such as Optical Coherence Tomography (OCT) testing on studies of patients with neuromyelitis optica in an effort to better understand visual disability by measuring the nerve fiber thickness in the eye. The study compares the retina and optic nerve pathology in NMO, TM, and other neuroimmunological disorders related to multiple sclerosis. We hope that the scan of the nerve layer thickness in the eye will help us better understand damage caused over time in patients with neuromyelitis optica.

- Other studies of cerebrospinal fluid and blood biomarkers are underway in the Neuroimmunopathology Laboratory. Dr. Pardo's lab is actively investigating the use of cytokine and chemokine profiling, as well as the identification of micro RNAs in these biofluids for the exploration of potential biomarkers of pathogenesis and outcome. Banking of biological fluids obtained from patients with TM and other neuroimmunological disorders is actively pursued at the TM and MS Centers and serves the purpose of biomarker identification.

- Neuropathological studies are currently carried out for the characterization of the molecular and cellular neuroanatomy and neuropathology of the normal and inflamed human spinal cord. These studies will help to understand the pathophysiology of TM and other neuroinflammatory disorders such as MS and NMO.

From the desk of Dr. Carlos Pardo and Maureen Mealy | http://www.hopkinsmedicine.org/jhtmc
T: 410-502-7099| Fax 410-502-6736 | E-mail: hopkinsTMcenter@jhmi.edu

The Transverse Myelitis Association has awarded the JHTMC a one-year grant of $60,000 to support the position of the Clinical Program Manager. The goal of this grant is to facilitate research and clinical care for patients with TM, NMO, ADEM and ON.



A PROSPECTIVE CASE SERIES OF 38 CHILDREN WITH TRANSVERSE MYELITIS

A summary of the findings from a peer reviewed publication

Title: The Demographic, Clinical, and Magnetic Resonance Imaging (MRI) Features of Transverse Myelitis in Children

Authors: Terrence Thomas, MD, Helen M. Branson, MD, Leonard H. Verhey, BSc, Manohar Shroff, MD, Derek Stephens, MSc, Sandra Magalhaes, MSc, and Brenda Banwell, MD

Published: Journal of Child Neurology, 2012, 27(1) 11-21

Last year, Thomas et al published a prospective case series in the Journal of Child Neurology where the authors followed 38 children and adolescents with acute transverse myelitis from January 1999 - December 2006 at The Hospital for Sick Children (SickKids) in Toronto, Canada. All diagnoses were made on established criteria. Representing one of the larger pediatric prospective case series, demographic, clinical and radiological data was collected and patients were followed for an average of 3.2+ 2.0 years (range, 0.1–7.3 years) from transverse myelitis onset to data collection. One patient died due to complications. The average age at acute attack was 11 years. The youngest child was 6 months of age and the oldest was 17 years. There were twice as many females in the study cohort. 66% of the new patients had an acute onset of the disease in the winter months. Although 28% of the children had motor deficits at onset, at their worst 76% of the children had some motor loss either with or without sensory and autonomic dysfunction. About 67% had complete loss of bladder function at their worst deficit. Thirty children experienced pain during the illness and 74% had fever, trauma or a combination of some antecedent event 4 weeks prior to the onset of symptoms. Trauma included back or leg pain after a fall, gym or some sports activity. None of the 31 children with available vaccination records received vaccination within 30 days of transverse myelitis illness.

About 58% of the patients had longitudinally extensive transverse myelitis (lesions greater than or equal to 3 spinal segments in length) and eight children had spinal lesions that spanned the whole cord. Brain MRIs were obtained on 33 children and lesions were seen in 20 of them.

All patients received IV steroids and based on the individual needs and severity of the acute inflammation, additional treatments were given which included oral prednisone, intravenous immunoglobulin, cyclophosphamide and plasma exchange in a combination that was individualized based on the response to therapy.

The physicians at SickKids found quick recovery in about 63% of the children who were walking independently within two weeks of acute inflammation. This outcome was independent of the acute severity and the time to maximum deficit of illness. 16% remained wheelchair dependent and 22% had bladder dysfunction. Although gender of the child had no relation to the motor or bladder outcome, young age at onset seemed to predict a worse bladder outcome. Five of the children who were initially diagnosed with transverse myelitis were diagnosed with multiple sclerosis over time, four of whom had clinically silent brain lesions at acute onset and oligoclonal bands in the spinal fluid.

An interesting observation from the study was that longitudinally extensive lesions are not only found in transverse myelitis, but in about 10% of the children with multiple sclerosis and those diagnosed with MS were not wheelchair dependent and did not have severe bladder dysfunction. This suggests that idiopathic transverse myelitis may be a fundamentally different pathological process from MS, with a greater likelihood of tissue necrosis and axonal destruction. Biomarkers specific for tissue necrosis might serve as valuable indices of prognosis.

Although half of the children had some antecedent seasonal illness (onset in colder months), no specific pathogen was identified. In the 9 children who reported minor trauma in the week preceding onset of symptoms, MRI in 4 of them revealed displacement of

the posterior spinal ligament but showed an inflammatory cord lesion and was not a vascular event. One theory the authors offer is a spinal cord contusion due to transient trauma from a forcefully herniated intervertebral disc and resultant cord edema (swelling) could cause the injury although this is not proven.

This cohort was compared with the 47 patients with childhood-onset transverse myelitis (including 7 who were evaluated as adults) published by Dr. Pidcock at the Johns Hopkins Transverse Myelitis Center. There were a few key differences in the two studies About 28% of the children from the Hopkins cohort that reported vaccination within one month of onset, while none in the SickKids series reported vaccinations. This is perhaps explained by the fact that 38% of the children in the Hopkins cohort were younger than 3 years of age, a time of frequent vaccinations, as compared to only 5% in the current study. Further, the residual deficits were higher in the Hopkins group (40% were non-ambulatory, and 50% had chronic bladder dysfunction) than in this study.

Transverse myelitis is an acute debilitating illness in at least 20% of affected children. In monophasic idiopathic transverse myelitis, longitudinally extensive lesions often predict poor outcomes for motor or bladder function. While more research studies are needed to understand the immune-mediated damage of the spinal cord, more effective therapies are needed for children at highest risk for poor recovery.

AN UPDATE ON THE ANNUAL FAMILY CAMP

We are so excited to share that more than 35 families have applied to camp at The Center for Courageous Kids in Scottsville, KY this summer from July 24 (Wednesday) through July 28 (Sunday), including from South Africa and the United Kingdom! It is our goal to include 5-7 young adults who have been diagnosed with one of the rare neuro-immunologic disorders as camp counselors this year! This is a unique opportunity for both the young adults and the children to interact with each other, learn from each other and truly have an impact on their quality of life not just today but in the future as well.

We are looking forward to welcoming and accommodating 40 families and campers this year. If we have more than 40 families apply to camp, the families will be placed on a waiting list in the order applications are received.

We are so pleased to share that the TMA has received two substantial grants that will help us bring families to camp this year. We received a $10,000 grant from the Christopher and Dana Reeve Foundation and a $5,000 grant from The Roles Family Foundation. The grant from the Roles Family Foundation is specifically designated to help families with travel grants to camp. We are so grateful for this support. We are also so appreciative of the people in our community who are raising funds to support our family camp. Through this generosity, the TMA will be offering the opportunity for travel grants to families who need this support in order to be able to attend camp. We anticipate that we will be having families come to camp from around the world. We will contact the families who have applied to camp to provide instructions and the process for how to apply for these travel grants.

You can learn more about CCK by visiting their web site and by reading the stories and blogs about camp on the TMA web site. The applications are available on the CCK website at: http://www.thecenterforcourageouskids.org/camperapp.html

AN UPDATE FROM SCOTLAND

The TM Scotland Support Group was established in 2003 with 7 members attending that first meeting. We are extremely grateful for all the support we have received from the TMA since startup. Today we have over 80 members in Scotland and meet quarterly in the Southern General Hospital in Glasgow. We also have satellite meetings in other cities by member request e.g. Perth. This year we went to Aberdeen as we have several members in the North East area who for travel distance reasons cannot come to our Glasgow meetings.

On Saturday 2nd March 2013 we held a meeting at Kippie Lodge in Aberdeen. Caren Bower brought along Hattie, George and Tabitha. Lynn and Jack Winton came with Katie, Penny and Emily. Margaret and Sandy Smith travelled from the east coast, Maggie and David Bowie from Clackmannanshire, Jane Batho from Perthshire and I from South Ayrshire.

Lynn arranged the venue and, as we had six children attending, the facilities were excellent for them. We all chatted over a lovely lunch and the children, when not amongst us, had a great time in the play areas, golf driving range and enjoyed the play materials that Lynn brought along. We had a lovely time together discussing numerous issues including mobility, equipment, medication, bladder and bowel, education and accessibility.

George and Penny drew a lovely picture of some of us and signed it so I have it displayed in my home and who knows - they may become future artists! They are both adorable children and have come through so much having to deal with their TM. Penny will be attending the Kids Camp at the Center for Courageous Kids this year, so many of you will have the pleasure of meeting her and her family. We all had a brilliant time together and now able to put more faces to names when in conversation. It was a privilege to be with such lovely people and with six polite and well-mannered children who got on so well together and supported each other in the activities.

We hope to have another meeting in the North East again when other members may be able to join us.
More information of our group and meetings can be found on www.myelitis.org/scotland. Also, if anyone is visiting Scotland from overseas, we would be delighted to have you join us and get in touch.

Best wishes,
Margaret Shearer Founder/Leader of Group

PODCAST RECORDING – TECHNICAL GLITCH

On February 7th, 2013, The Transverse Myelitis Association and the Rare Genomics Institute streamed the "Ask the Experts " Podcast Series, featuring Drs. Benjamin Greenberg and Allen DeSena from the University of Texas Southwestern in Dallas.

Our apologies that despite our best intention to have a recording of the podcast for our members who were not able to attend, there was a technical error in the recording and we are not able to provide a recording of the live podcast. However, we will be re-recording the session with the same questions and answers and make it available soon on our website. We hope that those who were able to join us live found the podcast useful. We are working on replicating the podcast sessions so we can offer a few more Q & A and learning opportunities for our members. Thank you for your continued support.

THE TMA ANNUAL WALK-RUN-N-ROLL AWARENESS CAMPAIGN

April 13
New Jersey - Cooper River Park
PENNSAUKEN

April 13
Pennsylvania - Museum Bldg
SOUTH PARK TOWNSHIP

April 27
Georgia - Hunter Park
DOUGLASVILLE

The Transverse Myelitis Association is launching a nationwide campaign to increase awareness and funds for research and programs that the TMA offers, such as our James T. Lubin Fellowship and our education programs.

The first Annual South Jersey Walk, organized by Colleen Spaeth and her daughter Mandy Edwards in 2012, sparked the idea for our campaign. The walk proved to be a huge success and they raised about $11,000.

Colleen and Mandy have shared their experience and a guide for doing a TMA Walk in an article that appeared in The TMA 2012 Fall Newsletter, which created a huge momentum for walks in many different states.

Our volunteer leaders are actively planning the event in Florida, Georgia, Illinois, Maryland, New Jersey, Pennsylvania, and Washington. If you live in one of these states, please watch our web site and future publications announcing the details of these events. We urge everyone to get involved.

This is our first effort at an organized national fundraising event. It is vital for all of our members to get involved in all communities and cities to raise awareness for this important cause. We hope to make this a signature event for the TMA!

We look forward to keeping you posted on our website, http://www.myelitis.org/walk, with latest updates on the Walk-Run-Roll Campaign and city-specific information on the different walks!

May 11
Florida Walk - Riverfront Park
COCOA

ORGANIZE A WALK IN YOUR CITY

We are looking for more leaders to help us organize more walks across the country.

If you would like to join this campaign to help the TMA raise awareness and funds for research, please contact us at info@myelitis.org. We look forward to making a difference with you!

UNDERSTANDING PAIN IN TRANSVERSE MYELITIS

Q&A with Dr. Benjamin Greenberg, MD, MHS from the University of Texas at Southwestern in Dallas

Is pain a typical symptom in diseases like Transverse Myelitis (TM)?

One of the most common issues that patients afflicted with transverse myelitis experience is pain. It can come in many forms, but the most common is a burning or stabbing pain that occurs in an arm, leg or around the trunk. It is often described as a burning, aching or stabbing pain. When the pain occurs in the chest or abdomen it is often described as a squeezing sensation. Frequently the pain worsens with exertion, stress, heat or in the evening when trying to go to sleep. It is also frequently experienced in an area that had previous sensory changes. This type of pain is often not present at the onset of TM, but develops in the weeks or months after TM.

What are the different types of pain?

Medically, there are many types of pain that affect human beings. These include nociceptive pain, phantom pain and neuropathic pain. Nociceptive pain includes pain that occurs in the setting of tissue injury, such as a cut, burn or broken bone. Phantom pain occurs in the setting of a lost limb and is a perceived pain when the brain no longer receives signals from a limb. Neuropathic pain occurs when there is damage to a part of the nervous system and after that event normal sensation is replaced with uncomfortable sensations.

Why is neuropathic pain experienced in neuro-immunologic conditions?

As you might expect, neuropathic pain has a different cause, biology and treatment than nociceptive pain. When you place your hand on a hot stove, it hurts. It is supposed to hurt. A signal moves from your hand to your brain and is interpreted as pain. The wound is painful even during the healing stages. This process is there to protect animals from tissue injury. We are supposed to learn that placing hands on hot stoves is dangerous! The medications used to treat this pain include opiates (e.g. narcotics) because the brain's pain centers express large numbers of opiate receptors. When opiate medications bind to these receptors it dampens down the perceived pain. As the medication wears off, the pain returns. In reality, the pain signals are always there – transmitted from the wound to the brain, but are ignored by the brain when opiates are present.

Neuropathic pain is different. Very different! While a person's foot may burn at night, there is no flame near the skin! So why does the brain perceive pain? The answer has to do with the pain pathways to the brain and pain centers in the brain. When sensation fibers in the spinal cord are damaged by transverse myelitis there is often a loss of normal sensory input to the brain. As a result, the sensation networks in the spinal cord and sensory centers in the

brain are left with incomplete input of signals. The brain is used to receiving billions of signals every second from our bodies. Temperature, vibration, pressure, movement, light touch and pain inputs bombard our brain constantly. Every square inch of skin includes thousands of nerve endings responsible for a multitude of signal types. If the pathways responsible for vibration are damaged in the spinal cord, then the brain receives an incomplete "sensory picture" about what is happening to the feet. The spinal cord is left to manage incomplete sensory inputs. As a result of these changes the spinal cord can lead to amplification of some sensations (in an unpleasant fashion) and the brain can "fill in the gap" of missing sensation with unpleasant sensations (burning, squeezing, stabbing pains).

Why does neuropathic pain get worse at night?

Many patients indicate that their pain is worse in the evening when trying to go to sleep. You may wonder why this occurs! If the theory of neuropathic pain is correct, specifically, that the brain "fills in gaps" you might expect for distraction to lessen this phenomena. Thus, while at work or busy, people may not experience the pain, but when less distracted, their brain may be free to 'make things up'! Just as a person tries to relax, their brain kicks into gear and the pain intensifies. Neuropathic pain is not supposed to be there – no damage to the affected area exists. As such, the treatment for this type of pain would be expected to be different than the treatment for nociceptive pain (broken bones, wounds, etc.).

What are common treatments for neuropathic pain?

Treatment of neuropathic pain usually does not involve opiates. Often patients with neuropathic pain will indicate that the use of opiates 'took the edge off', but did not rid them of pain. As such, we usually use antidepressant or antiepileptic medications to treat neuropathic pain. Are patients depressed or seizing? NO! These classes of medications act on cells in the brain and spinal cord to dampen down the 'made up' signals that are interpreted as pain and as such are perfect for neuropathic pain. Examples include amitriptyline, pregabilin, gabapentin and carbamezapine. There are many other options that have been used in patients. Beyond medication, many patients will find benefit from topical anesthetics to reduce all sensory signaling, acupuncture and/or avoidance of pain triggers. A careful discussion with your physician is needed to discuss your pain, what it feels like, what triggers it, what has helped in the past and what medications might be indicated. Pain needs to be aggressively treated as it can worsen mood and energy levels. Often multiple agents need to be attempted so that an appropriate one can be found.

This article was originally published on the TMA Blog. Please visit http://myelitis.org/category/resources/tma-blog for all the latest blog posts. To subscribe to the TMA Blog email list go to http://eepurl.com/xuoGr.

IN THEIR OWN WORDS ARTICLES

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

FACEBOOK

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

POSTAL GLITCHES IMPACT THE TMA IN 2012

We want to make our members and supporters aware that for a few months in 2012, we experienced some delivery issues with our postal mail.

It is unclear at this time if this is the result of post office negligence or improper activity by a person or persons. This problem was discovered early January 2013. We were contacted by members who advised us that their check donations by mail were not cashed.

The TMA investigated and learned that the United States Postal Service was delivering a portion of our mail to the wrong address due to an unauthorized change of address form. We immediately filed an incident report with the Postal Service. The problem has since been rectified and a formal investigation initiated to determine the cause. We have also notified law enforcement due to the uncertain nature of the incident.

The TMA acknowledges all donations with a thank you letter hand signed by the Secretary of the Board, Deborah Capen. These letters are usually sent within a week of our receiving the donation.

If you or your friends and family members mailed a donation to The Transverse Myelitis Association between September and December of 2012 and did NOT receive an acknowledgement from us, or if the donation check has not cleared your bank account, or if you have any concern at all about a donation made in that time frame please contact Sandy Siegel at (614) 766-1806 or info@myelitis.org.

We apologize for any inconvenience and thank you so much for your continued support.

WE DON'T WANT TO LOSE YOU

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes either by going online to http://tinyurl.com/bswg6yp or via email at info@myelitis.org.

For those that wish to receive our communications by postal mail: the Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates. We save a considerable amount of money by doing our mailings this way. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you, after your grace period, and this class of mail is not returned to the sender. The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

RENEW YOUR TMA MEMBERSHIP

The membership of The Transverse Myelitis Association includes persons with rare neuro-immunologic disorders of the central nervous system, their family members and caregivers and the medical professionals who treat people with these disorders. The Transverse Myelitis Association was established in 1994 as an organization dedicated to advocacy for those who have these disorders.

Please sign up and update your membership information by completing our newly designed member survey made possible by a partnership with TraitWise on http://www.myelitis.org/join.

We look forward to sharing the latest information on research and education opportunities and keeping in touch!

THANK YOU FOR SUPPORTING THE TMA

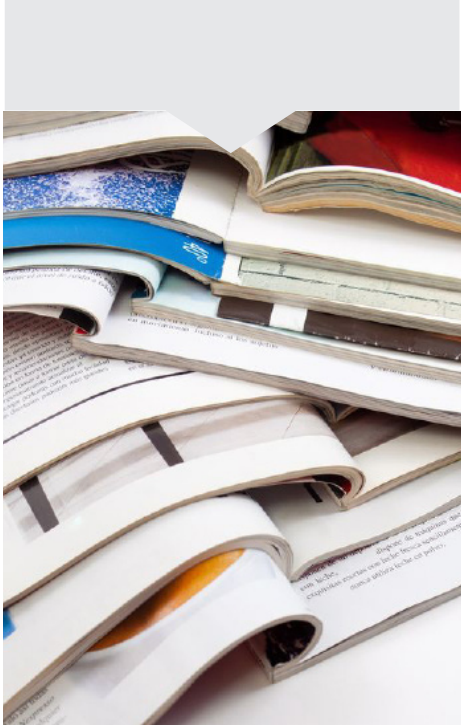
We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through your generosity that we are able to offer programs and services to more than 9000 members worldwide.

We are able to fund education symposia and programs, maintain an international support network, fund and support clinical care and research, offer an annual summer camp for children and their families, and the James T. Lubin Fellowship to advance specialist training.

TMA BLOG POSTS

The TMA Blog offers a great platform to keep you informed on all the latest news in the field of rare neuro-immunologic disorders, share the latest research and announcements on TMA specific programs and gives readers a first hand look into our members' personal experiences.

If you want to receive the latest blog posts in your inbox, please subscribe by going to http://eepurl.com/xuoGr.



THE TMA iS NOW PART OF DISEASE INFOSEARCH!

The Transverse Myelitis Association is now part of Disease InfoSearch – the largest online directory of disease advocacy organizations with information on over 13,000 conditions! Please check out our listing and explore all of the other exciting features available at www.diseaseinfosearch.org.

DiseaseInfoSearch offers disease descriptions and links to information on symptoms, diagnosis, and treatment, links to cutting edge scientific literature on PubMed and IRB approved clinical research opportunities through www.clinicaltrials.gov and other trial directories.

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ANNOUNCEMENTS

Regional Transverse Myelitis Clinical Care Symposium Focusing On YOU: June 15, 2013 at Johns Hopkins Transverse Myelitis Center, Baltimore, MD. Send an email to hopkinsTMcenter@jhmi.edu to reserve your space. For more details visit http://myelitis.org/education/symposia

2013 Rare Neuro-Immunologic Disorders Symposium: Oct 25-26, 2013, please make your hotel reservations early. Details inside.

DONATE

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