THE TRANSVERSE MYELITIS ASSOCIATION NEWSLETTER

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

Volume 10 FALL 2012

IN THIS ISSUE

THE EDITOR'S COLUMN

SANDY SIEGEL

Dear Readers,

The Transverse Myelitis Association has witnessed enormous changes and accomplishments over the past six months. An important part of the process of transforming the TMA from an all-volunteer operation has been to grow a more seasoned and involved Board of Directors. I am so honored to share with you passionate leaders from our community who have joined us in this adventure. Linda Malecky, mother of a child with TM, has joined us as the Treasurer and Board Member of the TMA. Linda has an MBA with a specialization in finance. Barbara Sattler, a retired judge from Arizona, and our support group leader in Tucson, was added to our Board and offers legal counsel for the TMA. Bruce Downey brings a wealth of knowledge to our Board with a background in law and many years of experience in the pharmaceutical industry and the business world. Drs. Ben Greenberg, Carlos Pardo and Doug Kerr will be serving on the Board, bringing their many years of expertise in medicine and their unique experiences in our community. We held our first formal Board meeting in August at Johns Hopkins University in Baltimore. During that meeting, Chitra Krishnan was also voted onto the Board of Directors. Jim, Debbie and I will remain officers and members of the Board of Directors. We are very excited about the addition of such a dedicated group of accomplished individuals. We have also begun a new and wonderful relationship with a Health and Economics specialist from Amsterdam, Roberta Pesce. You can learn more about all of them on our new website (http://www.myelitis.org/about/officers-and-staff). With change and new arrivals, often we must say goodbye to a few of our friends. After serving for many years as the treasurer of our organization, Paula Peltier has stepped down to begin a new chapter in her life in California. Hannah Harter has also moved on to another position.

As we grow the organization, we need your support and are looking for volunteers and interns. If we are going to succeed in our mission, we are going to need to more directly engage our members. You have the skills, expertise, and experience that we need. Please get involved.

The TMA has a new web site that will make it easier for you to find the information you need. Our website also includes a new feature, which was developed through our partnership with Traitwise. This tool is an interactive questionnaire that provides instant feedback to the participant by communicating how your responses compare to other people who have answered the same questions. You will learn a great deal through your participation, and you can make an enormous difference in how well clinicians and researchers understand your disorder. It is critically

important that all of our members visit the new website, fill out the membership form (even if you are currently a member), and make a commitment to become a regular participant in this survey process. Through this information, we can facilitate new research and clinical trials by making the TMA a more effective partner in recruiting for these studies. It is also important for everyone to update your contact information in the membership form as many of you have changed this information since you first became a member of the TMA.

As you may have noticed, this newsletter is a bit different from the journal. To be in more constant communication, we will be publishing newsletters in the spring, summer and fall of every year and we will publish our journal in the winter. We will continue to provide the same content as we have in the past, including updates on research, information about our centers of excellence, educational opportunities, as well as information about our organization and our community. We are going to be sending more information to our community via emails, so it is very important that you keep your contact information current. We are also going to be sending more timely information to you, more frequently, through emails, blogs, and on our web site. We are suspending the distribution of the membership directory, as the cost of this publication has become prohibitive, and the information is too sensitive to send or make available electronically. We are going to be depending on our support group leaders to help people who want to connect with others from their communities or to find others with their disorder. We will also be relying on social media, such as our Facebook communities, to help us in this capacity.

This fall newsletter contains a wonderful article about the paralympians who are participating in London from our community. They remind everyone in the most profound ways that getting one of these disorders is not the end of life, but the beginning of a new way of life that can be filled with dreams, positive aspirations, opportunities and achievement.

Please take care of yourselves and each other,
Sandy
ssiegel@myelitis.org

WE HAVE A NEW WEBSITE!

We have launched a **new website**! The redesigned site will make it easier for you to find all the latest news about the TMA, clinical trials and studies, information about the disorders, and much more. Check it out on http://www.myelitis.org**!**

Please sign up again if you are already a member 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!

UPCOMING STUDY FOR IDIOPATHIC TM PATIENTS

Maureen A. Mealy, RN, BSN, MSCN and Michael Levy, MD, PhD

The current standard of care for people with a history of idiopathic transverse myelitis is supportive and aims to manage and alleviate symptoms of the disorder. There are no therapies to treat the demyelination or loss of myelin (the insulating material on nerve fibers); rather clinical care is focused on helping to live with the consequences.

The Johns Hopkins Transverse Myelitis Center in Baltimore will begin recruiting this fall or winter for a clinical trial to assess the response of idiopathic TM patients to a drug called Dalfampridine, a sustained-release potassium channel blocker that has been shown to be effective in improving gait and other neurologic functions in multiple sclerosis. This drug has the potential to improve gait and neurologic function in patients with transverse myelitis as this rare disorder shares a similar pathogenic process with multiple sclerosis.

Recently, Biogen-Idec and Acorda have teamed up in the development of a sustained-release formulation of fampridine, called dalfampridine, which maintains stable plasma concentrations of the drug and avoids toxic doses that can lead to seizures. The FDA approved dalfampridine for use in multiple sclerosis in 2009 based on the key study that evaluated the improvement in gait in the responder cohort of patients rather than the entire study population. This method of analysis focused on those who reported some benefit from dalfampridine in an initial 4-week trial period and re-assigned those who did not see benefit to the non-responder group. In contrast to MS, which affects the entire central nervous system, TM affects only the spinal cord, largely spares the brain, and is not associated with an increased risk of seizures. In addition to being a potentially safer cohort of patients for dalfampridine, TM is a more homogenous disease model in which to test dalfampridine's mechanism of action.

The study requires weekly visits to the site over a 6-month period to test walking speeds and other outcome measures. Only adult patients with a diagnosis of idiopathic TM are eligible for recruitment. Please contact Maureen Mealy at HopkinsTMCenter@jhmi.edu if you are interested in learning more about the study.

TM AWARENESS DAY IN THE STATE OF GEORGIA

A Senate Resolution, co-sponsored by Senators James, Davenport, Davis, Seay and Fort declared February 15, 2012 in Georgia - TM Awareness Day. The force behind this effort, Kim Harrison, was diagnosed with Transverse Myelitis (TM) in October 2004 at the age of 45. Kim, a resident of Atlanta, is active in a support group in her community. She also participates in the Shepard Center's Therapeutic Recreation Program. Kim's work has helped to raise awareness of the rare neuro-immunologic disorders throughout the state of Georgia. We are deeply grateful for her efforts.

AN UPDATE ON TMA-SUPPORTED RESEARCH

In 2011, Dr. Adam Kaplin at Johns Hopkins University was awarded a grant to evaluate the therapeutic potential of carbenoxolone (CBX) for the treatment of Transverse Myelitis. Patients with transverse myelitis (TM) and multiple sclerosis (MS) are commonly affected by cognitive impairment, but no treatments exist to target this aspect of the disease. CBX is a drug approved to treat peptic ulcers in the United Kingdom. In some early studies conducted in Dr. Kaplin's laboratory, mice were immunized to induce experimental autoimmune encephalomyelitis (EAE), an animal model of MS, and administered daily intraperitoneal injections of CBX or control from the time of disease induction. Animals treated with CBX experienced delayed onset and decreased severity of EAE compared to control animals. The results of this animal model study support the use of CBX as an orally available potential therapeutic treatment to reduce motor impairment in patients with MS and TM.

A second potential therapeutic agent was also studied in the laboratory. Data collected from relapsing-remitting MS patients at Johns Hopkins Hospital demonstrated a relationship between performance on a battery of cognitive tests and the level of a specific peptide, N-acetyl aspartyl glutamate (NAAG), in the hippocampus, a region of the brain well-known for its role in learning and memory functions. More specifically, patients who did better on the cognitive tests had higher hippocampal NAAG levels. It was hypothesized that pharmacological upregulation of NAAG would be an effective method of reversing cognitive impairment in patients with MS and TM. Using an animal model (experimental autoimmune encephalomyelitis, EAE) and tests of learning and memory, cognitive performance was measured following treatment with the drug 2-PMPA, a drug previously demonstrated to elevate NAAG levels. Two independent experiments confirmed that 2-PMPA-treated mice had improved cognitive performance compared to controls. Brain analysis revealed a significant increase in NAAG levels of 2-PMPA-treated mice. In summary, these animal model data support inhibition of GCPII for the treatment of cognitive impairment in MS and TM. These early results in animal models of the disease are currently being repeated and verified following which human studies have to be designed for testing.

Dr. Daniel Becker, Kennedy Krieger Institute in Baltimore was also awarded a grant in 2012 for his study to evaluate change in function (spasticity, strength, and sensation) and change in cerebrospinal fluid (CSF) inflammatory milieu in individuals with inflammatory myelopathies in response to functional electrical stimulation (FES) cycling therapy to identify the optimum dose to elicit neurological repair. Since the award of the grant, institutional review board approval has been obtained for the proposed clinical trial and to-date, 9 patients have been enrolled in the study, eight of whom have completed the study. There were 4 patients with a history of TM, 3 patients with MS and 1 patient with NMO. There was one screening failure. There were no adverse clinical events noted to-date. The total number of subjects proposed in the study is 16.

The study is enrolling people with transverse myelitis, neuromyelitis optica, and multiple sclerosis. The study involves coming to Kennedy Krieger Institute in Baltimore for a total of 3 weeks. Participants will use the FES bike either once, three times, or five times per week. At the beginning and at the end of the study, participants will undergo a detailed clinical exam in addition to blood draw and spinal tap. If you are interested in participating, please contact Shannon Inches at inches@kennedykrieger.org. This data will be crucial for the design of phase 2/3 clinical trials evaluating the efficacy of FES in patients with inflammatory myelopathies.

DR. ALLEN DESENA: FIRST JAMES T. LUBIN FELLOW

It is a great honor for the TMA to announce Dr. Allen DeSena at the University of Texas Southwestern in Dallas is the first recipient of the two-year James T. Lubin Clinician-Scientist Fellowship Award. Mentored by Dr. Benjamin Greenberg, Director of the TM and NMO Centers at UTSW, Dr. DeSena will be focusing on pediatric TM, NMO, and ADEM.

Dr. Allen DeSena attended medical school at Loyola-Stritch School of Medicine in Maywood, Illinois, located in the greater Chicago area. From there, he went on to complete a residency in general pediatrics in New Orleans at the Tulane-Ochsner pediatric program, and he earned his board certification in general pediatrics in 2009. Following his general pediatrics training, he moved to Dallas where he completed a residency in pediatric neurology at UT-Southwestern Medical Center in conjunction with Children's Medical Center-Dallas and Parkland Memorial Hospital. During that time, his interest in transverse myelitis and other neuro-immunologic disorders blossomed, and he pursued further training in those areas. In 2012, he was awarded the first James T. Lubin fellowship to pursue a clinical and research career specializing in rare neuro-immunologic disorders – ADEM, TM, NMO and ON. He is the first pediatric neurology fellow to study the rare spectrum of neuro-immunological disorders, with a particular focus on Transverse Myelitis.

During his two-year fellowship, Dr. DeSena will be leading an acute treatment clinical study in transverse myelitis to compare the effectiveness of plasma exchange (PLEX) and intravenous immunoglobulin (IVIG) as treatments to stop the inflammatory attack in transverse myelitis. Dr. DeSena's research also focuses on identifying and developing robust outcome measures to assess the effectiveness of therapies and return to function. Through the efforts of Peter Jacobson and the generous support of our members,

DR. ALLEN DESENA

we are able to fund the first year of Dr. DeSena's fellowship. As we continue to raise the funds for the second year of Fellowship training, we need your help! If you have a child with ADEM, NMO, ON or TM, supporting the training of Dr. DeSena is a very direct investment in your child's future medical care. We urge you to get involved in this critically important effort!

We are so incredibly proud to announce Allen as our first James T. Lubin Fellow. Many families have had an opportunity to meet Dr. DeSena at our last two family camps. He has already become a very important member of our community. To us, there are few goals more important than increasing the numbers of medical professionals and researchers who care for people with these disorders and are interested in studying these disorder to better understand them and to ultimately find a cure.

Please support the James T. Lubin Fellowship Fund. It is a wonderful way for all of us to ensure the best possible medical care for ourselves and our loved ones. To make an appointment with the Children's Pediatric Demyelinating Disease Clinic, contact Audrey Ayres, RN at (214) 645-7998.

2012 LONDON PARALYMPICS

The Paralympic Games began on August 29th 2012 in the beautiful and multicultural city of London. The ten-day event was the perfect occasion to demonstrate to the world how capable, courageous and persevering people are regardless of their physical and intellectual challenges. We were so impressed and proud of the number of competing athletes with a rare neuroimmunologic disorder.

British competitor, Dave Bracher (44), was diagnosed with both Guillain–Barré Syndrome and Acute Disseminated Encephalomyelitis three years ago, leaving him paraplegic after a lengthy recovery. Last year, Dave completed his dream of finishing a marathon in a standard wheelchair and he was a proud torchbearer for this year's Paralympics. Cassie Mitchell (31), a research engineer, elite athlete, and mentor was diagnosed with Neuromyelitis Optica at the age of 18, leaving her quadriplegic and with visual impairments. In 2006, a recurrence of NMO forced Cassie to leave basketball weeks after becoming an alternate on the USA's wheelchair basketball team. She competed in the Paralympics for Wheelchair Track and Paracycling.

Michael Smith (20) suddenly lost his eyesight at the age of 18 and was diagnosed with Optic Neuritis. He is now fully dedicated to soccer and has gained a place on Great Britain's national team. At 14 months, Natasha Baker (22) contracted Transverse Myelitis. Very early in her life, she became fascinated with horses. Her physiotherapist soon noticed her passion and provided her parents with details of the local Riding for the Disabled Association (RDA). She competed in the Paralympics and has won two gold medals riding her horse, Cabral.

Sarah Castle (28) has been in a wheelchair since she was 11 due to Transverse Myelitis. She first started off as a swimmer and when she experienced a shoulder injury, she decided to join the Paralympic Basketball team and won gold at Beijing. She competed in the US basketball team during this year's Paralympic Games. In 2006, Victoria Arlen fell into a vegetative state for over two years after being diagnosed with Transverse Myelitis. She is now ranked among the world's top Paralympics swimmers. Victoria's excellent performance resulted in her breaking the International Paralympic Committee world record in her event. Amanda McGrory (26) was diagnosed with Transverse Myelitis as a child and started her Paralympic journey in 2003, when she first traveled to Australia as a member of the US Jr. Team. In 2008, she won her first gold medal in the Women's 5000m at the Paralympic Games in Beijing and competed at this year's Paralympic Games. She finished fourth in the women's marathon.

Most of the athletes who competed at these games got their disorder when they were children, teens, or very young adults. For a person with a physical disability, there are many avenues for pursuing goals and ambitions. Losing the ability to walk or even to use one's arms doesn't foreclose all of the opportunities one has to use one's mind or heart to reach one's goals. What is so remarkable about the athletes that compete at this highest level is that they do so in the realm of their greatest challenge. In the face of their physical disability, they develop their physical skills to the highest imaginable level. And there have been other great athletes from our community who have also excelled – Eve Hampton, Dana Mathewson and Anjali Forber-Pratt. For these incredible athletes, they just don't excel with their bodies; they also excel with their minds. They are excellent students and they are successful in their careers.

Their athletic, academic and career achievements are reflections of great character. They are dedicated, disciplined, highly motivated, creative, intelligent people. I have had a front row seat to observe all of what they have to overcome in order to compete and to succeed in all facets of their lives. They experience the same symptoms that everyone else does with these difficult disorders. In addition to paralysis or significant motor weakness, they also experience fatigue, depression, spasticity, and nerve pain. They have significant challenges to overcome to attain their goals.

It was great to see so many individuals with the rare neuro-immunologic disorders represented at this year's Paralympics and to witness the passion with which they compete. They show the world that they're capable of reaching their dreams, no matter what obstacles they have to face - even the London transport system couldn't stop them! They represent their countries, and their community at these games; they also represent every individual who has heard the words, "you can't or you won't." These athletes exemplify in the most profound way that there is life and there are great achievements possible after ADEM, NMO, ON and TM!

FIRST BERLIN MYELITIS SYMPOSIUM

On September 24, 2011 Prof. Dr. Friedemann Paul from the NeuroCure Clinical Research Center in Berlin opened the first Berlin Myelitis Symposium, which included an open informative discussion session between the researchers and the 33 individuals diagnosed with these rare neuro-immunologic disorders and their families. Other distinguished speakers included Dr. Klemens Ruprecht, Department of Neurology of Charité Medical School, and Dr. Corinna Trebst from the Medical University of Hannover who covered all of the rare neuro-immunologic disorders and MS. The speakers pointed out the importance of co-operation between the individuals affected by these disorders and their doctors, and emphasized that those living with an unconfirmed diagnosis reach out to specialized clinics and research centers for confirmation. It was an open and honest conversation between the attendees where honesty was asked of the physicians by the patients and their families. The first Berlin Myelitis Symposium was a great success. The dialogue that was made possible through this educational program is critically important for both the patient community and for the clinicians and researchers.

BLUE ANGEL COOKIES: IN MEMORY OF MY MOM

Rosanne (Catania) McCarthy

In December 2004, my mom, Antonina Catania, was diagnosed with Transverse Myelitis. At the time, I was working at a cookie company decorating sugar cookies. I loved my job, but in order to take care of my mom, I had to quit. My dad, sister, and I had been taking care of my mom for the past seven and a half years. Two years ago I started my own cookie business from my home. My mom was so happy for me. Every day I would tell her about the theme of the cookies I was making. I made cookies for wedding showers, baby showers, holidays, birthdays, and more. Various organizations would also ask me to donate cookies to their cause. My mom passed away this past June at the age of 75, after battling TM for all those years. She was such a trooper. Every day she had a smile on her face and she never asked, "Why me?" She always talked about walking again: she never gave up hope! I'll remember her spirit and she'll be my inspiration for the rest of my life.

To give back to the Transverse Myelitis Association, I designed a blue angel cookie in her memory. The cookies are the same blue color as our wristbands and are meant to increase awareness of our organization and this horrible disease. I am asking for a $1.00 donation for each cookie sale in my community, and 100% of the proceeds will go to this very worthwhile cause. I am grateful to Sandy and the staff at the TMA for being there for my parents, and for all that you do. Keep the hope! I'll be selling my cookies locally and at various vendor shows. Please visit my Facebook page to see all of my cookies by searching "Cookie Glitz" or follow this web address: http://www.to.ly/fLGu. Don't forget to "like" it!

Thank you for taking the time to read my story, and a BIG thank you to everyone who has an opportunity to support the TMA through the purchase of my TM Blue Angel cookies.

"WE WALK FOR COLLEEN" FUNDRAISER

Mandy Edwards & Colleen Spaeth

Colleen contracted Transverse Myelitis in 2007, which completely changed her entire life plan. Her daughter, Mandy, started a wonderful initiative to support the TMA and her mother's condition. Below you can find the story of how the First TM Walk was born in their own words!

Coming up with the idea of a fundraiser to raise awareness about TM came after thinking about what I could possibly do to help the most important person in the world to me. Knowing the right things to say and do for someone, especially your mother is difficult.

The TM walk brought together all of us who love my mother and have seen her struggle and overcome obstacles over the years. The goal was to raise money, but to also raise awareness and hope. The most beautiful outcome of the event was that several people with TM were able to come to the walk and meet someone else with TM for the very first time. One of these people told me that she no longer feels alone - That's powerful stuff.

Planning this fundraiser only took a couple of months. We urge you to join this type of effort. These are some best practices that we want to share with our fellow TMA members from our experience:

- Choose a location and get permission from the local government recreation department to use the space
- Set a date and make sure that no other organization is hosting a similar event on the same day
- Obtain insurance for the walk or run, which you can acquire by getting in touch with your local insurance agent
- Set up a fundraising website in coordination with the TMA
- Create a communications and media plan, which includes making informational packets, sending out mass emails, setting up a Facebook event page, ordering custom t-shirts and contacting a photographer to capture the experience. Again, all of these efforts should be coordinated with the TMA.
- Have a registration tent set up on the day of the walk in order to track and obtain contact information for the participants. And be sure to send thank you notes to all of the people involved in the effort and who participated in the effort.

The morning of the walk arrived, a damp chilly March morning as we set up the church borrowed canopy, laid out our donated, "We Walk for Colleen & TM" t-shirts, M&Ms that said Thank You on them, blue balloons, name tags... you get the picture.

Approximately 150 brave folks turned up with their smiles and support for a worthy cause. The experience was one that our family and friends will never forget, and confirmed for us that a little elbow grease and a lot

of energy and love for a cause bigger than ourselves, and outside our comfort zones, can accomplish more than you can imagine.

What started as a seed of an idea turned out to be an amazing day, thanks to the help and participation of many people. The Walk that began as a little idea resulted in cash donations in excess of $11,000! Imagine what our Association could do if each of its members conducted a walk or some other form of fundraiser to support our efforts!

To view a very inspirational video of the 1st Annual South Jersey Transverse Myelitis Walk, go to http://www.vimeo.com/40105783.

TMA FAMILY CAMP AT THE CCK

In August, 27 families from across the country and Canada convened at a beautiful camp in Scottsville, Kentucky for the TMA Family camp. It was a magical time for the children and all of the families to spend time together at a truly wonderful camp with incredible staff and volunteers. The parents participated in an educational program with Drs. Doug Kerr, Adam Kaplin, Daniel Becker, Allen DeSena, Donna Graves, Lana Harder, Kristen Rahn and Janet Dean. To learn more about camp this year, please see the story and blog on our website by going to http://www.myelitis.org/tma-blog/messy-games.

We are already looking forward to camp next summer at CCK, which will take place from July 24th to July 28th, 2013. If you have a child with ADEM, NMO, ON or TM and they are between the ages of 5 and 17, please apply to camp! Please email us (info@myelitis.org) if your child does not fall between these ages and you would like to apply to camp.

Please look for the application on the CCK web site http://www.thecenterforcourageouskids.org. Please apply early as we anticipate an overwhelming response. You do not want to miss this experience!

TMA KIDS!

Life after diagnosis dramatically changes not only for those with a rare neuro-immunologic disorder but also for their families in a profound way. Parents and families of children living with a rare illness bring remarkable passion; creativity, drive and resilience to finding the best care for their children and become effective advocates not just for their children but also for other families and form a strong network. In August this year at The Center for Courageous Kids, a group of parents began the process of joining their efforts and their energies to work collectively to meet these same critical goals.

The TMA Kids Group was formed by parents who believe that by working together, they can make a difference for their own child and for all of the children in our community who have these disorders. They are focusing their efforts on supporting the Jim Lubin Fellowship Program in order to grow the number of clinicians and researchers who are focused on these disorders, to support the Family Camp program, and to help with other programs and activities that directly impact families and these children.

If you have a child with ADEM, NMO, ON or TM, we urge you to get involved. If you are interested, please send an email to info@myelitis.org and let us know that you would like to join TMA Kids. You can find additional information about TMA Kids at http://www.myelitis.org/get-involved/tma-kids.

INTERESTED IN VOLUNTEERING OR AN INTERNSHIP?

We are looking for volunteers and interns to help support the work of the TMA. If you have expertise in fundraising, event planning, database management, marketing and communications, administrative management, human resources management and non-profit compliance and regulations, please contact us at info@myelitis.org.

For more details on the intern job descriptions, please visit us at http://www.myelitis.org/get-involved. Please get involved and support us as we advance our goals!

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ANNOUNCEMENTS

Family Camp: July 24-28, 2013, submit your application online as soon as possible on http://www.thecenterforcourageouskids.org/camperapp.html

New Website! The TMA has recently launched a new website, please visit it on http://www.myelitis.org

Membership Form: Fill out the form on http://www.myelitis.org/join. Please help us keep your information current and help clinicians and researchers better understand these disorders.

DONATE

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