The Transverse Myelitis Association Newsletter

The organization advocating for children and adults with acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis

Volume 9 Issue 2 Summer 2010

The 2010 Rare Neuroimmunologic Disorders Symposium Friday, September 24 – Sunday, September 26, 2010 Hosted by The University of Texas Southwestern

The 2010 Rare Neuroimmunologic Disorders Symposium is being hosted in Dallas, Texas for the first time. Over the last 10 years, symposia have been held in Baltimore, Albuquerque, Los Angeles and Seattle, bringing together patients, families, clinicians and scientists with interests in rare immune mediated disorders that affect the nervous system. The 2010 symposium will include two concurrent sessions, with the ability of participants to move between them as desired. The clinical session will feature talks geared towards patients, families and practitioners who are seeking out a greater understanding of disease biology, current treatment options and a preview of cutting edge research. The basic science session will feature talks and discussions that will explore complex topics in novel ways with a goal of stimulating cross fertilization of ideas between different scientists.

The symposium will start Friday, September 24th in the morning and will be hosted at the Galleria Westin Hotel in Dallas, Texas. The last session is scheduled for midday on Sunday September 26th with the program closing at 12:30. There is a dinner planned for Saturday, September 25th with a keynote speech delivered by Dr. Lawrence Steinman from Stanford University. The clinical sessions will include talks on various neuroimmunologic disorders, including transverse myelitis, neuromyelitis optica, acute disseminated encephalomyelitis and pediatric multiple sclerosis. There will be presentations on disease management, symptom management, rehabilitation and research programs. There will be opportunities to question presenters, work in small groups, take part in moderated discussions, and connect with patients, families, clinicians and research scientists.

You will need to make a reservation with the hotel and also register for the symposium and pay a registration fee.

The Westin Galleria Dallas
13340 Dallas Parkway
Dallas, TX 75240
Phone: (972) 934-9494

The hotel rate is **$**159 per night. You must identify yourself as a participant in the "Rare Neuroimmunologic Disorders Symposium" to receive the group rate. The room block is available for the dates, September 20-28, 2010; you are eligible for this rate between those dates. The group rate is only available until August 30, 2010 and there are a limited number of rooms, so the rate is subject to availability. In other words, if you are planning to attend the symposium, please make your hotel reservation as soon as possible.

Online hotel reservations can be made at:

http://tinyurl.com/rnds2010hotel

To make the reservations by phone, please call (972) 934-9494.

The symposium registrations are being administered through the University of Texas Southwestern Office of Continuing Medical Education. The registration fees are as follows:

Physicians:	$425.00
Resident/Fellows/ Allied Prof:	$300.00
Patients/Families:	$225.00
Graduate Students:	$150.00

Registration can be completed by visiting:

www.utsouthwestern.edu/RNID2010

You can fly into either Dallas Love Field or DFW (Dallas-Fort Worth). There isn't a free shuttle service between the airport and hotel. You will either need to take a taxi or you can make a reservation with the Super Shuttle Service by calling: (800)258-3826 or online at: **www.supershuttle.com**. Once you get to the Westin Galleria Dallas, you should have little reason for ground transportation. There are many restaurants near the hotel and most of your meals will be provided at the symposium in the hotel.

The symposium program agenda will be posted on the registration web site. We are in the process of finalizing the program and presenters. If you have never been to a symposium, we strongly encourage you to attend. We are certain that you will leave Dallas as a more effective advocate for your medical care. In addition to the great

educational opportunity, you will meet many other people who understand your experience in a way that no one else does. People who meet at our symposia have developed lifelong friendships. If you have been to our symposia in the past, then you understand why you need to try to make it back.

Please check the main page of The Transverse Myelitis Association web site, as we will post updated information as it becomes available. We are looking forward to seeing you in Dallas this fall!

Dare to Get Out of the Chair!

Cody Unser invites you to participate in a ***Discover Scuba Event*** for "Symposium Participants" on ***Friday Evening, September 24, 2010, at the Westin Galleria.***

Enroll today! Space is limited and only offered to participants of the 2010 Rare Neuroimmunologic Symposium hosted by the University of Texas Southwestern.

Don't miss your chance to try Adaptive Scuba with Cody's Dive Team, ***Operation Deep Down***, who have trained students from Riley Children's Hospital, VA Hospitals, Paralyzed Veterans of America, NM Association of Blind Students, and many more! Now it's your turn to join this elite group of Adaptive Scuba Divers and Cody is thrilled.

Students will ***Discover Scuba in a team of two***…so you can try scuba with a "dive buddy" who can be a family member, friend, caregiver, or you can choose to dive with one of our many volunteers!

Who: Registrants of the 2010 Rare Neuroimmunologic Symposium

What: Discover Scuba Event – Adaptive Scuba for the Disabled

When: Friday Evening, September 24, 2010

Where: The Westin Galleria Pool

How: Enroll today at **www.codysfirststep.org**

Click "Contact" on the left menu bar and fill out the form. Ensure your message says… "I am enrolling in Discover Scuba Event at the 2010 Rare Neuroimmunologic Symposium."

Those of you who choose the dry-side of our event are welcome to watch and see how Adaptive Scuba changes lives one dive at a time!

Sponsored by The Cody Unser First Step Foundation

Experimental Surgery Performed to Repair Nerve Function of 6 Year Old with TM

Daniel Becker, M.D. [1], Allan J. Belzberg, M.D.[2] and Sandy Siegel

[1]The International Center for Spinal Cord Injury, Kennedy Krieger Institute and the Transverse Myelitis Center, Department of Neurology, [2]Department of Neurosurgery, Johns Hopkins University School of Medicine.

This story was first reported by the ABC News Medical Unit (Courtney Hutchison) on Monday, March 29, 2010; "Experimental Procedure 'Rewires' 6-Year-Old's Nervous System: Surgery May Restore Movement to Child's Paralyzed Arm."

A six-year old with transverse myelitis from Pennsylvania underwent an experimental surgical procedure to rewire the nerves in his right arm. The boy had strep throat in September 2009 which was subsequently followed by an inflammatory attack in his spinal cord. During the attack, he lost function in both arms; his left leg and he lost the ability to breathe on his own. He received a transverse myelitis diagnosis.

Over the next six months, he regained function in his neck, his left side and he regained some use of his right hand. His right arm, however, was not regaining function. In transverse myelitis, about a third of patients will regain most of their neurological function, a third will have moderate disability and the remaining third will have significant permanent disability. This 6 year old boy had severe weakness on his left side, breathing difficulties and paralysis of his right arm and shoulder after six months. After six months, his chances of regaining significant right arm function in the near future were poor. After administration of acute therapies, such as intravenous steroids, IVIG or plasma exchange, the only treatment available is aggressive physical and occupational therapy (i.e., activity based restorative therapies) to try to increase the function of the remaining intact nervous system.

After 6 months, his parents, in consultation with the physicians at Johns Hopkins and the Kennedy Krieger Institute, decided to proceed with an experimental surgery. The purpose of the surgery was to allow the boy to bend his arm using a new rewired nerve which was taken from his leg. In the five hour surgery which took place in March 2010, nerve tissue was taken from his leg and was used as a graft to reroute a nerve in his shoulder to control his right arm. This was only the third time that a nerve transfer operation has been used to treat a patient with TM; the previous two cases also having been performed at Johns Hopkins. The surgeon was Dr. Allan Belzberg, Associate Professor of Neurosurgery, Johns Hopkins University School of Medicine. The surgery went very well, but it is too early to tell if the goal has been achieved. It will take months for the boy to recover.

The idea for this procedure came about two years ago at Kennedy Krieger Institute and Johns Hopkins Hospital. A TM neurologist was sitting at lunch discussing a challenging case. The neurosurgeon at the table suggested the child be treated like traumatic injured children he sees. The chance lunch encounter lead to the novel approach to TM. The concept consists of using a nerve that is healthy and working under voluntary control and reroute it into muscles that have lost their voluntary motor control because of injury. A large number of children with transverse myelitis are cared for at the International Center for Spinal Cord Injury, Kennedy Krieger Institute (KKI) through its association with the TM Center at Johns Hopkins. Dr. Becker serves as both the Director of the Pediatric Spinal Cord Injury Unit at KKI and as a physician at the TM Center at Johns Hopkins Hospital.

Over the past few years, we have encountered a number of children who suffered from idiopathic TM who presented with arm and leg weakness. These children then recovered almost completely normal function with the exception of one arm, or in one particular case, one leg. The arm that did not regain function remained extremely weak proximally while recovering hand function. While it was great for these children to have recovered so much function overall, they were left with one basically nonfunctional extremity; and which caused them a great deal of difficulty in their day to day lives.

At KKI, we have the tremendous benefit of working with the Brachial Plexus Clinic. This clinic is comprised of a neurosurgeon, Dr. Belzberg, an orthopedic surgeon, a plastic surgeon, and several other rehabilitation experts. Traditionally, the clinic has provided care to children with brachial plexus injuries that are usually caused by birth trauma or other traumatic injuries, such as car accidents or falls. The brachial plexus is a network of nerves that conducts signals from the spine to the shoulder, arm, and hand. Brachial plexus injuries are caused by damage to those nerves.

The nerve graft should allow the boy to bend his arm when his brain sends the message to 'shrug my shoulder.' His arm will not return to totally normal function but he should be able to bend his arm. His movements should improve and become more natural in time with practice; he will have to relearn to use his arm. He may lose some strength in his right shoulder where nerves were rerouted and he may have a numb patch on his left foot where sensory nerve fibers were taken from his left leg for the graft. The surgical procedure did have risks. It was technically a very challenging operation. There are unique differences between people's nervous systems and there is a risk of damage to nerves that are functioning properly or the blood vessels that are connected to those nerves and are vital to their survival.

It will take a very long time for the nerves to regenerate. Nerve growth takes place at about one inch per month, so it will be about six to eight months before we begin to observe any changes. We will also use very aggressive physical and occupational therapy to strengthen his arm and help with coordination. It helps a lot that the boy is so young. The nervous system is very plastic; it learns quickly. The younger a person is, the easier the learning will be. We will have to train a muscle that functioned in one way (in a leg) to now function in another (his arm).

We do not know yet how successful this overall approach will be. There is also a very significant question about the perfect timing for scheduling a surgery of this type. On the one hand, we want to give the patient sufficient time to see what the natural/spontaneous recovery will be. On the other hand, the surgeons prefer to do nerve transplants earlier on because they feel that they will be more successful. If a long time has passed by since the injury, other surgical approaches remain viable options, such as transferring muscles and tendons rather than nerves.

The Transverse Myelitis Association is proud to be a source of information about Transverse Myelitis and the other neuroimmunologic disorders. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician. The Transverse Myelitis Association does not endorse medications, treatments, products, services or manufacturers. Such names appear in this publication solely because they are considered valuable information. The Transverse Myelitis Association assumes no liability whatsoever for the contents or use of any medications, treatments, products or services mentioned.

Optical coherence tomography helps differentiate neuromyelitis optica and MS optic neuropathies

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ABSTRACT

Objective: To evaluate the retinal nerve fiber layer (RNFL) thickness and macular volume in neuromyelitis optica (NMO) spectrum patients using optical coherence tomography (OCT).

Background: OCT can quantify damage to retinal ganglion cell axons and can identify abnormalities in multiple sclerosis and optic neuritis (ON) eyes. OCT may also be useful in the evaluation of patients with NMO.

Methods: OCT and visual function testing were performed in 26 NMO spectrum patients with a history of ON, 17 patients with isolated longitudinally extensive transverse myelitis (LETM) without ON, 378 patients with relapsing-remitting multiple sclerosis (RRMS), and 77 healthy controls at 2 centers.

Results: Substantial RNFL thinning was seen in NMO ON eyes (63.6 μm) relative to both RRMS ON eyes (88.3 μm, $p < 0.0001$) and control eyes (102.4 μm, $p < 0.0001$). A first episode of ON was estimated to cause 24 μm more loss of RNFL thickness in NMO than RRMS. Similar results were seen for macular volume. ON also was associated with more severe visual impairment in NMO spectrum patients than in RRMS patients. Eyes in the LETM group and unaffected NMO eyes were not significantly different from controls, though conclusions about these subgroups were limited by small sample sizes.

Conclusions: Optical coherence tomography (OCT) shows more severe retinal damage after optic neuritis (ON) episodes in neuromyelitis optica (NMO) than in relapsing-remitting multiple sclerosis. Identification of substantial retinal nerve fiber layer loss (>15 μm) after ON in a non-multiple sclerosis patient should prompt consideration of an NMO spectrum condition. OCT may be a useful tool for the evaluation of patients with NMO. ***Neurology*® 2009;73:302-308**

GLOSSARY

CI = confidence interval; **ETDRS** = Early Treatment Diabetic Retinopathy Study; **IgG** = immunoglobulin G; **LETM** = longitudinally extensive transverse myelitis; **MS** = multiple sclerosis; **NMO** = neuromyelitis optica; **OCT** = optical coherence tomography; **ON** = optic neuritis; **RNFL** = retinal nerve fiber layer; **RRMS** = relapsing-remitting multiple sclerosis.

Neuromyelitis optica (NMO; Devic disease) is an autoimmune disease that predominantly affects the spinal cord and optic nerves. Patients with NMO often experience recurrent episodes of optic neuritis (ON) that can cause severe visual impairment. Previously thought to be a rare subtype of multiple sclerosis (MS), the identification of the NMO-immunoglobulin G (IgG) autoantibody has provided strong evidence that NMO is a distinct disorder.[1]

Optical coherence tomography (OCT) has been used to measure the thickness of the retinal nerve fiber layer (RNFL) and the macular volume in patients with MS and other conditions. The RNFL consists of retinal ganglion cell axons that coalesce to form the optic nerve. The macular volume is determined by the number of retinal ganglion cell bodies, photoreceptors, and other cell types. Previous studies found a significant decrease in the mean RNFL thickness and macular volume in MS eyes with and without a history of ON.[2-7] Moreover, abnormalities

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were identified in all MS subtypes,[6] and RNFL thinning was found to correlate with brain atrophy in MS.[8]

We used OCT to evaluate the retinas of patients with NMO, patients with longitudinally extensive transverse myelitis (LETM) without a history of ON, patients with relapsing–remitting MS (RRMS), and healthy controls. The goals of this study were 1) to compare the effect of optic neuritis on RNFL thickness, macular volume, and visual function in patients with NMO and RRMS; 2) to determine whether LETM patients without a history of ON have subclinical changes on OCT; and 3) to identify OCT findings that suggest a diagnosis of NMO.

METHODS **Patients.** Subjects were recruited from The Johns Hopkins Multiple Sclerosis and Transverse Myelitis Centers and the University of Texas Southwestern Multiple Sclerosis Center. Subjects were divided into 4 groups. Group 1 was patients diagnosed with an NMO spectrum disorder who had a history of optic neuritis. This group included 26 patients, of whom 19 (73%) had "definite NMO" as defined by the 2006 criteria of Wingerchuk et al.[9] "Definite NMO" is defined by these criteria as a history of ON, history of acute myelitis, and 2 of 3 supportive criteria: 1) a contiguous spinal cord MRI lesion extending over at least 3 vertebral segments, 2) a brain MRI that does not meet criteria for MS, and 3) NMO-IgG seropositivity.[9] Four patients in group 1 (15%) had ON and were NMO-IgG positive without a history of myelitis, and 3 (12%) were considered by an experienced clinician to have NMO but did not meet the above criteria because their myelitis was less than 3 vertebral segments. When analyzed separately, results for the subset meeting criteria for "definite NMO" did not differ from the other patients in this group, so these patients were analyzed together. Group 2 included patients with isolated LETM, defined as myelitis spanning 3 or more vertebral segments without evidence of MS and without a history of ON. Group 3 was patients with RRMS based on McDonald criteria.[10] Group 4 was healthy controls. All patients undergoing evaluation for a possible NMO spectrum disorder during the time period of the study were asked to participate. The RRMS cohort was an unselected convenience sample of patients with MS evaluated in the Johns Hopkins Multiple Sclerosis Center. Healthy controls were recruited from patient's families and volunteers. Informed consent was obtained from all participants, and the study was approved by the local institutional review boards. Patients were excluded from analysis if they had a history of glaucoma, diabetes, or retinal disease, which might otherwise affect OCT measurements. Scans performed in the 3-month period after acute ON were excluded from analysis to minimize the effect of optic disk swelling on OCT measurements. Data on number of ON episodes was available for a subset of patients (the Hopkins cohort).

Optical coherence tomography. The OCT scanning protocol has been described previously in detail.[6] Retinal imaging was performed using a Stratus OCT-3 device with OCT 4.0 software (Carl Zeiss, Meditec, Dublin, CA). RNFL scans were obtained with the "Fast RNFL Thickness" protocol, and macular volume was determined using the "Fast Macular Thickness" scan. Only scans with signal strength of 7 or above (maximum 10), indicating a high-quality scan, were considered acceptable for analysis. OCT scanning failed in 8 eyes (both eyes in 3 patients and one eye in 2 patients) in the NMO group because of blindness. Imaging quality was ensured by validation of optic disk centering by the technician. Macular volume results were available for a subset of patients (80%) because this testing was added to the protocol after the initiation of the study.

Visual function testing. Visual function testing was performed using retroilluminated eye charts. Both full-contrast Early Treatment Diabetic Retinopathy Study (ETDRS) charts and low-contrast (1.25% contrast) Sloan letter charts were used. Testing was performed monocularly, and subjects were asked to use their habitual distance glasses or contact lenses. Standard testing protocols were used. Charts were scored letter-by-letter, so that the number of letters identified correctly (maximum 70) constituted the summary measure. Snellen equivalents were also determined for descriptive purposes based on full-contrast visual acuity (ETDRS chart) scores.

Statistical analysis. Nonparametric statistical methods were used because of the small sample sizes. The Wilcoxon rank sum test was used for pairwise analyses. To maintain independence of all observations, a single eye was analyzed from each patient. In analyses of ON eyes, the ON eye was chosen. In subjects where both eyes had the same history of optic neuritis, the right eye was randomly chosen for use. There was no difference in the results when the left eye was used. Multivariate linear regression models were created to control for disease duration and age. A regression with a linear spline was used to model RNFL thickness as a function of number of ON episodes. Statistical significance was defined as $p < 0.05$. All analyses were performed using STATA 10.0 (StataCorp, College Station, TX).

RESULTS Patient characteristics are described in table 1. Twenty-six patients were included in the group of NMO spectrum patients with a history of ON. Seventeen patients were identified with isolated LETM. The frequency of NMO-IgG positivity was 60% in the NMO spectrum with ON group and 24% in the LETM group. These groups were compared with 378 patients with RRMS and 77 healthy controls. There was a history of ON in 41% of the RRMS group and none of the LETM or control subjects.

Optic neuritis eyes. The RNFL thickness for each group is shown in table 1 and figure 1. ON eyes in the NMO spectrum group had a mean RNFL thickness of 63.6 μm compared with 102.4 μm in controls ($p < 0.0001$). This represents a 38% absolute difference in the RNFL thickness between NMO ON eyes and controls. In NMO spectrum patients, the RNFL was also considerably thinner in ON eyes than in non-ON eyes (63.6 vs 97.9 μm, $p = 0.002$). The difference in RNFL thickness between ON and non-ON eyes is much greater in NMO spectrum patients than in RRMS (34.3 μm in NMO vs 9.6 μm in RRMS). Data for macular volume measurements are shown in table 1 and figure 2. ON eyes in the NMO spectrum group also

Table 1 Demographic data, retinal nerve fiber layer thickness, and macular volumes

Diagnosis	No. of patients	Age, mean (SD), y	NMO-IgG positive, %	History of ON, %	ON status	No. of eyes analyzed	RNFL thickness, μm			Macular volume, mm³		
							Mean (SD)	Median (range)	p Value vs controls	Mean (SD)	Median (range)	p Value vs controls
NMO spectrum with ON	26	41 (13)	60	100	ON eyes	22	63.6 (20.3)	57.4 (31.0–99.4)	<0.0001	5.83 (0.75)	5.68 (4.32–7.12)	<0.0001
					Non-ON eyes	8	97.9 (18.3)	96.0 (73.4–121.9)	0.5	6.63 (0.54)	6.75 (5.81–7.20)	0.5
LETM	17	45 (14)	24	0	Non-ON eyes	17	96.3 (14.3)	98.9 (50.0–112.8)	0.2	6.69 (0.39)	6.65 (6.05–7.41)	0.2
RRMS	378	39 (10)	—	41	ON eyes	157	88.3 (16.5)	87.4 (44.4–129.5)	<0.0001	6.38 (0.49)	6.35 (5.05–7.69)	<0.0001
					Non-ON eyes	338	97.4 (13.9)	99.1 (44.4–144.7)	0.01	6.63 (0.47)	6.65 (5.06–8.14)	0.009
Controls	77	38 (12)	—	0	Non-ON eyes	77	102.4 (11.0)	102.2 (80.8–128.1)	—	6.83 (0.34)	6.81 (6.12–7.57)	—

RNFL = retinal nerve fiber layer; NMO = neuromyelitis optica; IgG = immunoglobulin G; ON = optic neuritis; LETM = longitudinally extensive transverse myelitis; RRMS = relapsing-remitting multiple sclerosis.

had a lower mean macular volume compared with controls (5.83 vs 6.83 mm^3, $p < 0.0001$).

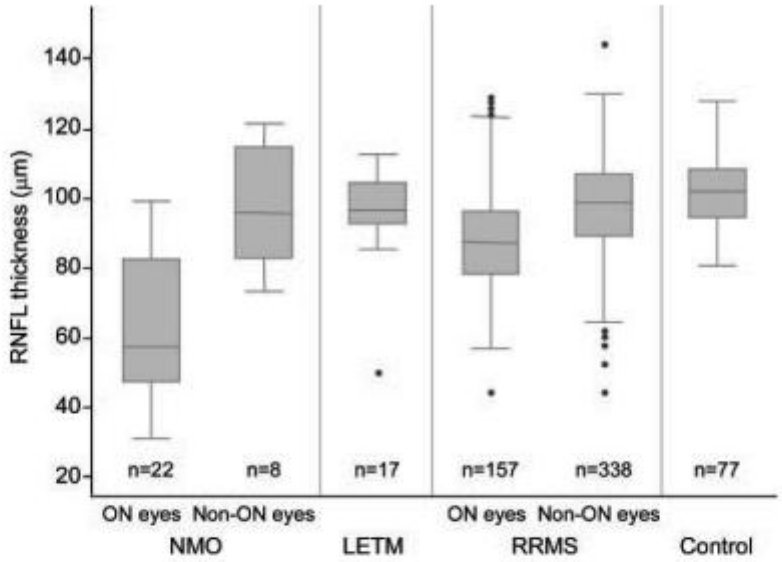
To compare the effect of ON in patients with NMO and RRMS, the mean RNFL thickness and macular volume of ON eyes were compared. The RNFL was thinner in NMO ON eyes than RRMS ON eyes (mean 63.6 vs 88.3 μm, $p < 0.0001$). Macular volume was also lower in the NMO group relative to RRMS (5.83 vs 6.38 mm^3, $p = 0.001$). This difference could result from either a greater severity or a greater number of ON episodes in patients with NMO compared with patients with RRMS. Because NMO ON eyes did have a greater number of ON events than RRMS eyes, an additional comparison was performed in the subset of eyes that experienced only 1 episode of ON. Using a multivariate linear regression analysis to control for age and disease duration, a single episode of ON was estimated to cause 24 μm more RNFL loss in NMO than in RRMS ($p < 0.001$). Thus, ON episodes are associated with greater retinal damage in NMO than in RRMS. In patients with a history of unilateral ON, the proportion of patients with a difference in RNFL thickness between the ON and non-ON eye of >15 μm was 75% in patients with NMO and 24% in patients with RRMS.

An analysis of the effect of the number of ON episodes on RNFL thickness found that the first episode of ON caused greater thinning of the RNFL than subsequent episodes in both NMO and RRMS. Using a multivariate linear regression model, a single episode of ON was estimated to cause a 31-μm decrease in RNFL thickness in patients with NMO (95% confidence interval [CI] 21–42 μm, $p < 0.001$) and a decrease of 10 μm in RRMS (95% CI 6–13 μm, $p < 0.001$). Subsequent episodes of ON in the same eye were estimated to each cause an additional loss of 10 μm of RNFL thickness in NMO ($p = 0.026$) and a nonsignificant change in the RRMS group. When stratified by NMO-IgG status, no difference was seen in RNFL thickness between the antibody-positive and antibody-negative NMO groups ($p = 0.94$).

Non–optic neuritis eyes. In eyes without a history of ON, the RNFL was mildly thinner in all groups relative to controls. This difference was only significant for RRMS eyes (97.4 μm for RRMS, 97.9 μm for NMO, 96.3 μm for LETM vs 102.4 μm for controls; table 1). The number of non-ON eyes was much larger in the RRMS group (n = 338), than the NMO (n = 8) and LETM (n = 17) groups. Consequently, the lack of statistical significance in the NMO and LETM groups may be due to small sample sizes. Similar results were seen for macular volume (table 1).

Visual function testing. Visual acuity was tested with both standard and low-contrast eye charts. The OCT

Figure 1 **Box plots of retinal nerve fiber layer thickness by disease type and optic neuritis status**

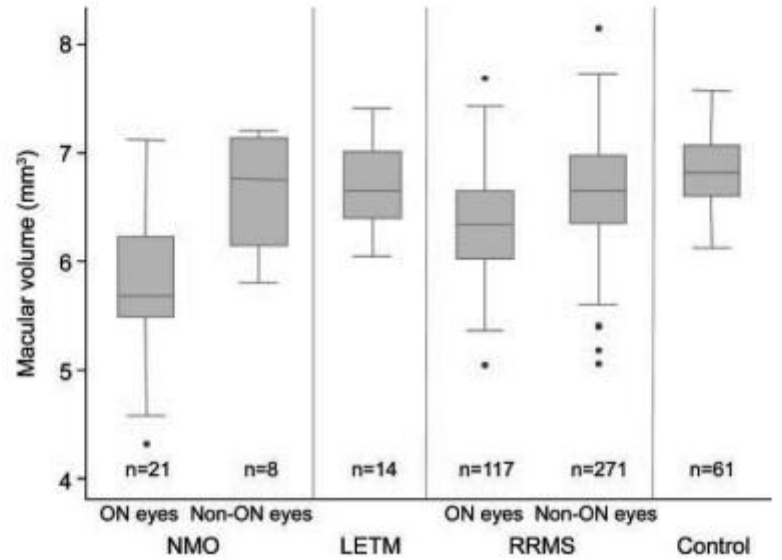


RNFL = retinal nerve fiber layer; ON = optic neuritis; NMO = neuromyelitis optica; LETM = longitudinally extensive transverse myelitis; RRMS = relapsing–remitting multiple sclerosis.

findings correlated well with the results of visual function testing. Visual acuity was worst in ON eyes of NMO spectrum patients. Using full-contrast charts, the mean number of correct letters in this group was 27 out of a possible 70, compared with 54 in RRMS ON eyes and 59 in control eyes (p = 0.001 vs RRMS, p = 0.001 vs controls; table 2). This corresponds to a visual acuity of 20/60 for the NMO ON eyes, 20/20 for the RRMS ON eyes, and 20/16 for controls. The relationship between RNFL thickness and visual acuity in NMO ON eyes is shown in figure 3. Graphically, it appears that on a standard vision chart there is a threshold RNFL thickness of approximately 60 μm, below which visual acuity becomes very poor.

Performance on low-contrast eye charts followed the same pattern (mean: 4 correct letters for NMO ON eyes, 6.5 letters for RRMS ON eyes, and 16 letters for control eyes). On low-contrast charts, the NMO ON eyes differed from controls ($p \leq 0.0001$) but not from

Figure 2 **Box plots of macular volume by disease type and optic neuritis status**



ON = optic neuritis; NMO = neuromyelitis optica; LETM = longitudinally extensive transverse myelitis; RRMS = relapsing-remitting multiple sclerosis.

Table 2 Visual function testing results

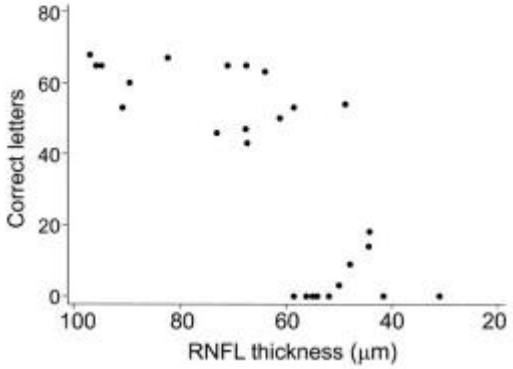
Group	100% Contrast chart			1.25% Contrast chart		
	Mean no. of correct letters (SD)	Median no. of correct letters (range)	p Value vs controls	Mean no. of correct letters (SD)	Median no. of correct letters (range)	p Value vs controls
NMO spectrum and LETM						
ON eyes	27 (29)	14 (0–68)		4 (9)	0 (0–27)	<0.0001
Non-ON eyes	59 (10)	61 (27–69)	0.26	18 (11)	18 (0–36)	0.5
RRMS						
ON eyes	54 (15)	57 (0–70)	0.003	6.5 (8)	2 (0–32)	<0.0001
Non-ON eyes	59 (8)	60 (12–70)	0.23	13 (10)	13 (0–36)	0.98
Controls	59 (5)	60 (42–69)	—	16 (8)	15 (0–35)	—

Each chart contains 70 letters.
NMO = neuromyelitis optica; LETM = longitudinally extensive transverse myelitis; ON = optic neuritis; RRMS = relapsing-remitting multiple sclerosis.

RRMS ON eyes ($p = 0.11$). Non-ON eyes in the NMO spectrum and LETM groups were combined for analysis and compared with non-ON eyes in RRMS and controls. Using both standard and low-contrast eye charts, there were no significant differences among these groups in the number of correct letters identified.

DISCUSSION Patients with NMO often have severe episodes of ON which can, in some cases, lead to blindness. In MS, ON is also common; however, the attacks tend to be less severe and have a better prognosis. This study used OCT to show that the RNFL is significantly thinner in NMO eyes that have experienced ON than both control eyes and MS ON eyes. The severe thinning of the RNFL is presumably due to degeneration of the retinal ganglion cell axons. Macular volume, which in part reflects the number of retinal ganglion cell bodies, is also significantly decreased in NMO ON eyes. Furthermore, visual acuity testing is grossly abnormal in NMO ON eyes when compared with control and RRMS ON eyes. Together, these data suggest that ON is a more destructive process with greater potential for causing visual disability in NMO than in MS. We also found that the first episode of ON seems to cause the greatest amount of RNFL thinning in patients with NMO and RRMS, with a lesser degree of thinning occurring in subsequent episodes of ON. One possible explanation for this is that after an episode of ON, axons may make up a smaller percentage of the RNFL, such that subsequent ON episodes cause a smaller amount of RNFL change.

Figure 3 Number of correct letters on a standard ETDRS letter chart in NMO spectrum eyes with a history of optic neuritis as a function of RNFL thickness



ETDRS = Early Treatment Diabetic Retinopathy Study; NMO = neuromyelitis optica; RNFL = retinal nerve fiber layer.

In NMO spectrum eyes without a history of ON, we found that the mean RNFL thickness and macular volume were slightly lower than controls, but the difference was not significant. The sample sizes in these groups were small, so the possibility remains that there is a true small difference in OCT values for this group relative to controls, If a true difference does exist, one could speculate either that ON causes a small degree of retinal damage to the contralateral eye or that the retinal abnormalities were due to an ON-independent process. A larger cohort would be needed to evaluate this.

Our results concur with French[11] and Caribbean[12] studies of OCT in NMO spectrum patients. They found significant thinning of the RNFL in patients with NMO, although they did not stratify eyes by history of ON. In agreement with our results, a small group of NMO-IgG–positive LETM patients were analyzed in the French study and no OCT abnormalities were found. They identified a strong correlation between RNFL thickness and Expanded Disability Status Score in patients with NMO.

There are several potential limitations to our study. First, blindness due to severe episodes of ON prevented successful OCT scanning in 8 eyes in the NMO group. It is likely that these eyes had the most dramatic changes in retinal architecture. Consequently, the true average OCT values in NMO ON eyes may be even more severe than what was estimated in our cohort. Second, because of relatively small sample sizes it is not possible to rule out small differences between groups that otherwise seem similar. Third, it is possible that our population of patients with NMO is more severely affected than the general NMO population because all subjects were recruited from academic referral centers. However, most patients with this uncommon condition are referred to academic centers, and all patients being evaluated for an NMO spectrum condition at the study sites were asked to participate in the study to minimize selection bias.

The identification of the NMO-IgG antibody has greatly advanced our understanding of NMO and related conditions. The antibody has a 54% to 71% sensitivity and >90% specificity for NMO.[13-15] NMO-IgG is also positive in 25% of recurrent ON patients without MS and 38% to 80% of patients with isolated LETM.[16-17] Evidence is mounting that NMO is a distinct condition, rather than simply a rare subtype of MS. In support of that idea, we found a greater degree of retinal damage after ON in NMO than in MS. Our study did not have sufficient power to definitively determine whether unaffected NMO eyes are abnormal, but retinal damage in NMO seems to be predominantly or exclusively the result of destructive ON episodes. This differs somewhat from MS, where OCT can detect retinal abnormalities even in patients with no history of ON (such as patients with primary progressive MS).[6] These results are consistent with the observation that patients with NMO rarely convert to a secondary progressive course and that disability in NMO primarily results from relapses,[18] whereas in MS, disability can result either from inflammatory relapses or slowly progressive axonal degeneration.[19]

In some circumstances, OCT may be a useful adjunct for differentiating ON due to NMO from ON due to MS or isolated ON. In a patient with ON and a brain MRI not suggestive of MS, clinical characteristics such as a bilateral presentation, recurrent ON, or poor visual recovery may suggest a diagnosis of NMO. In addition, more severe thinning of the RNFL in a patient with history of ON should prompt consideration of NMO. We found that in patients with prior unilateral ON, a >15-μm difference in RNFL thickness between the two eyes was more likely to occur in NMO (75%) than in RRMS (24%). Consequently, in patients who do not meet diagnostic criteria for MS, NMO-IgG testing should be considered when there is a history of ON that was bilateral, was recurrent, resulted in poor visual recovery, or left them with a >15-μm difference in RNFL thickness between the eyes when measured >3 months after the event. Earlier diagnosis of NMO has the potential to decrease future disability through earlier initiation of systemic immunomodulatory treatment.

AUTHOR CONTRIBUTIONS

Statistical analysis was performed by J.N. Ratchford.

DISCLOSURE

J.N.R. has served as a consultant for Teva Neuroscience and receives research support from the Partners Multiple Sclerosis Center in the form of a Clinical Fellowship Award. M.E.Q., A.C., and T.F. report no disclosures. E.F. serves as a consultant for and on the speakers' bureaus of Biogen-Idec, Teva Neuroscience, and Athena Diagnostics. L.J.B. has served on a scientific advisory board for Biogen-Idec, has served as a consultant for Biogen-Idec, and receives research support from the NIH/National Eye Institute (grant K24 018136) and the National Multiple Sclerosis Society (grants RG 3208-A-1, RG 3428-A/2, TR 3760-A-3). P.A.C. has served as a consultant for EMD Serono, Teva Neuroscience, Novartis, Biogen-Idec, Amplimmune, Vertex, Eisai, and Diogenix, and receives research support from EMD Serono, Teva Neuroscience, Biogen-Idec, and the National Multiple Sclerosis Society. D.A.K. has received research support from Nerveda in the form of a sponsored research agreement, and serves as a consultant for and holds stock options in Nerveda, for which he is a founding member.

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The Use of Mycophenolate Mofetil for Treatment of Neuromyelitis Optica

This summary was prepared by Hanni Siegel from the originally published article, "Treatment of Neuromyelitis Optica with Mycophenolate Mofetil: Retrospective Analysis of 24 Patients," Anu Jacob, MD, MRCP, DM; Marcelo Matiello, MD; Brian G. Weinshenker, MD; Dean M. Wingerchuk, MD; Claudia Lucchinetti, MD; Elizabeth Shuster, MD; Jonathan Carter, MD; B. Mark Keegan, MD; Orhun H. Kantarci, MD; Sean J. Pittock, MD. Archives of Neurology, 2009; Vol. 66 (No. 9), pp. 1128-1133[1].

Neuromyelitis Optica (NMO) is a rare, usually relapsing, inflammatory demyelinating disorder in which the optic nerve and the spinal cord are the targets of the immune system[2]. With each relapse, there is an accumulation of disability, and within five years of the initial attack, half of the individuals diagnosed with NMO require the use of a wheelchair and just over half have become functionally blind[2]. Neuromyelitis Optica-IgG (NMO-IgG) is an autoantibody specific for astrocyte water channel aquaporin 4[3,4], and its presence in patient serum serves as a biomarker that reliably identifies relapsing NMO or NMO spectrum disorders (NMO-IgG seropositive patients with optic neuritis, and NMO-IgG seropositive patients with longitudinally extensive transverse myelitis) [5]and is predictive of relapse[6,7]. Given that accumulation of disability is associated with relapse, one of the goals of treatment should be prevention of continued attacks. Current strategies employ the use of immunosuppressive drugs[8] such as azathioprine[9], corticosteroids[10], mitoxantrone[11], and rituximab[12,13]. Small case series of the use of these immunosuppressive treatments have provided evidence of their efficacy, but no randomized controlled trials have been conducted in patients with NMO, given the rarity of this disease.

The study summarized here examined the experiences of 24 patients with NMO (n=15) or an NMO spectrum disorder (NMO-IgG seropositive optic neuritis, n=1; NMO-IgG seropositive longitudinally extensive transverse myelitis, n=8) who received mycophenolate mofetil for the treatment of NMO. The median dose was 2000mg/day (range, 750-3000mg/day). Mycophenolate mofetil (Cellcept, F. Hoffman-La Roche, Basel, Switzerland) inhibits the proliferation of T and B Cells as well as the production of antibody[14]. Currently, it is widely used in cardiac and renal transplantation, and its use in the treatment of various autoimmune conditions is growing. Mycophenolate mofetil is a promising treatment option, as there appears to be fewer adverse effects, and it can be administered orally. These 24 patients were being treated at one of three of the following Mayo Clinic sites: Rochester, MN; Scottsdale, AZ; and Jacksonville, FL.

Patient gender was female in 79% of the cases, and the median age was 56 years, ranging from 34 to 77 years. The median time from initial diagnosis to initial treatment with mycophenolate mofetil was 4.2 years (range, 0.1 – 39 years). Mycophenolate mofetil was the first therapy tried for 7 of the patients. Among the other 17 patients, adverse effects of medication (n=7), continued relapses (n=8), and contraindication of azathioprine (n=2) were the reasons for switching to mycophenolate mofetil. The drugs used prior to treatment with mycophenolate mofetil were azathioprine (n= 12), interferons (n= 9), prednisone (n= 7), mitoxantrone (n= 2), IV-immunoglobulins (n= 2), glatiramer acetate (n= 4), cyclophosphamide (n= 3), methotrexate (n= 2), and IV-methylprednisone (n= 1). Additionally, 9 of the patients were undergoing additional therapies while being treated with mycophenolate mofetil.

These treatments were prednisone (n=5), methylprednisone (pulsed IV, n=2; IV, n=1; orally, n=1) and IV-Immunoglobulin (n=1). The median duration of treatment with mycophenolate mofetil was 27.4 months (range 1-89 months). The post treatment period for which follow-up information was available through telephone contact ranged from 18 to 89 months (median= 27 months). During the follow-up time, 5 of the patients stopped treatment for various reasons, including death (n=1), relapses (n=2), adverse effects (n=1), and one patient chose to switch to rituximab. For the individual clinical profiles of the patients included in the study, please refer to the original study, specifically the Clinical Characteristics of Patients Treated with Mycophenolate Mofetil Table, p. 1130.

The relapse rate was significantly decreased from a median of 1.28 relapses per year (range 0.23 – 11.78) to a median of 0.9 relapses per year (range 0 – 1.56) following treatment with mycophenolate mofetil. 79% of the patients saw a decrease in their annualized relapse rate. The decrease in relapse rate remained significant even after excluding the patients undergoing treatment with mycophenolate mofetil for less than 6 months, the patients undergoing concomitant immunotherapies, and the one patient who died. The median Expanded Disability Status Scale (EDSS) score also decreased (demonstrating physical improvement) from the time of commencement of treatment with mycophenolate mofetil (6, range, 0-8) to the time of last follow up (5.5, range, 0-10), however this decrease did not reach statistical significance. When looking on a more individualized level, the EDSS score improved for 7 patients (median reduction = 1 point, range 0.5-2.5), stabilized for 15 patients, and worsened for 2 of the patients.

There were several adverse events that occurred during the treatment and follow-up periods that must be acknowledged. One patient, who continued to relapse approximately every 6 months during treatment with mycophenolate mofetil, died 54 months following initiation of treatment of complications most likely associated with the continued attacks and consequent disability. The following adverse effects were reported by one patient each: headache, constipation, easy bruising, anxiety, hair loss, diarrhea and abdominal pain. One patient discontinued therapy due to low white blood cell counts.

This case series demonstrated an association between reduction in rate of relapse and either reduction or stabilization of disability scores and treatment with mycophenolate mofetil. There are several factors that limit the conclusions that can be drawn from the data. Potentially confounding factors include the presence of concomitant therapies in 38% of the patients, as well as possible residual effects of medications used prior to treatment with mycophenolate mofetil. It is possible that the reduction in relapse rate observed could be attributed to regression toward the mean (i.e., if relapses were frequent for an individual in the last few years by the law of averages it can only get better now!). Also, while the case series illustrates promise for the efficacy of mycophenolate mofetil in the treatment of NMO and NMO spectrum disorders, there are some safety concerns regarding the use of this drug. There are toxicity concerns, and while no cases of progressive multifocal leukoencephalopathy have been reported in patients undergoing mycophenolate mofetil *monotherapy*, cases have been reported in transplant (kidney, heart, and lung) recipients and in systemic lupus erythematosus when mycophenolate mofetil was used in conjunction with or following other immunosuppressive treatments. To give an idea of frequency, in a study examining 32,757 kidney transplant recipients, 9 cases were identified. This is a very small percentage, but worth noting.

The most common treatment of NMO is either prednisone alone or prednisone combined with azathioprine. This is based on a case series of 7 patients who showed significant improvement in EDSS scores and absence of relapse[9]. Mitoxantrone is another treatment option. Improvement was seen in a case series of 5 patients, however there was not a complete absence of relapse and cardiotoxicity is a concern with this medication, limiting the amount of time a patient can take this medication. Rituximab is another immunosuppressive medication used to treat NMO, and in a case series of 25 patients treated with rituximab, a decrease in rates of relapse, as well as improvement or stabilization in disability scores in 80% of patients was observed. However, use of rituximab may be associated with infection risk (20% of patients experienced infection that may have been due to the immunosuppressive effects of the drug) and 28% of the patients experienced adverse effects related to intravenous infusion.

While the conclusions that can be drawn from this small retrospective study are limited, they still offer insight for clinicians trying to make informed treatment decisions. This study provides evidence that it is possible that the use of mycophenolate mofetil reduces the frequency of inflammatory attacks and could result in stabilization of disability. The treatment options discussed above have also been found to be associated with a reduction in relapse rates and disability scores. Because controlled clinical trials have not been performed, definitive conclusions regarding the superiority of one treatment over another cannot be drawn. Therefore, clinicians must consider potential for adverse effects, treatment cost, and need for immediate

immunosupression when choosing the most appropriate treatment for individuals with NMO or NMO spectrum disorders.

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The Accelerated Cure Project is dedicated to determining the causes and accelerating research into finding the cures for NMO, MS, TM, ADEM, and ON. One of ACP's primary initiatives is the building of a repository of blood samples and data from people with these disorders. There are currently 2,101 subjects enrolled in the repository. Samples are distributed to researchers studying the causes of these diseases, thereby accelerating research. The repository provides a common population of samples useful for a wide variety of studies that enables results from different research perspectives to be easily combined and correlated. The repository contains various types of samples and data that can support scientists working in many fields, such as genetics, nutrition, virology, and more. Researchers gaining access to the repository must return their results to the database to be shared with other researchers; this allows for cross-correlation of their results with all other studies performed using the same samples.

While samples continue to come into the repository through increased enrollment, they also continue to be distributed in support of research into the causes of MS, TM, NMO, ADEM, and ON. You can learn more about the research being supported by the Accelerated Cure Project repository samples and data by visiting: ***www.acceleratedcure.org/repository/research.php***

In addition to expanding the breadth of the repository through greater collection site access, ACP is also expanding the depth of it through the collection of updated data and samples from already enrolled participants. One of the particularly valuable aspects of the ACP repository is that it is a longitudinal study, meaning that participants are asked to return over the course of their lifetime for follow-up visits. These visits allow for the collection of updated health information, replenishment of blood samples, and provide the opportunity to ask new questions on topics that were not addressed during the first visit. Having participants return for follow-up visits means that ACP can provide valuable samples and data to researchers in support of the study of disease course, the impact of

medications on progression, among other critical areas.

If you are a repository participant with a demyelinating disease and you enrolled more than a year ago into the repository, you may be getting a phone call or postcard soon asking you to return and continue your involvement. Your continued involvement enhances the value of the repository and accelerates research into the causes of ADEM, MS, NMO, ON and TM.

ACP, in partnership with the Guthy-Jackson Charitable Foundation, is seeking to enroll people with NMO into our repository. If you have been diagnosed with NMO and have not already enrolled in the ACP repository, we welcome your participation. Participation consists of a blood draw and an interview. This is not a treatment study. There are no drugs involved. If you do not live in close proximity to a collection site, funds may be available to offset travel expenses. Additionally, if you are unable to travel to one of ACP's collection sites, a nurse may be available to travel to your home or office to conduct the study visit on location. If you have been diagnosed with NMO, have not previously participated in the ACP repository, and have an interest in learning more, please contact the repository director as soon as possible for more information.

We also continue to enroll new subjects at all of our collection sites. To learn more about participating in the repository, contact the study coordinator at the site of interest; call ACP's repository director, Sara Loud, at (781) 487-0032, or visit the repository section of the ACP website at ***www.acceleratedcure.org/repository.***

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October 8-10, 2010
Weekend Retreat for Older Teens and Young Adults at Victory Junction

The Victory Junction Gang Camp in Randleman, North Carolina has generously invited older teens and young adults from The Transverse Myelitis Association to attend a retreat weekend. The retreat weekend will take place on October 8-10, 2010 for those with TM, ADEM, NMO, and ON between the ages of sixteen and twenty-five and their caregivers, parents, spouses or companions. If you are slightly younger than 16 or older than 25, please apply and decisions will be made on a case-by-case basis.

As our members come to camp from across the country and around the world, and as travel is very difficult for many of you, Victory Junction has graciously offered to allow people to arrive at camp early on Thursday, October 7th. It is very important to understand that the formal camp will not begin until Friday afternoon, October 8th and that no program activities will be available until that time. Arriving early will allow you time to recover from the travel. It will also be a time to visit with others who come to camp early. The TMA officers will arrive early and we will request that some of the physicians arrive early, as well.

There is no cost to attend this weekend of fun and friendships; however, you will need to provide your own transportation. The Piedmont Triad Airport (GSO) in Greensboro, North Carolina is approximately 20 miles away and airport pick-ups are available, also free of charge. Transportation arrangements need to be coordinated with Victory Junction.

VJGC will begin accepting the Retreat Weekend Applications on July 1, 2010. You will not be able to access the web-based application until July 1st. Please do not wait until the last minute to submit your application, as we believe that there will be an excellent response from our community and spaces are limited. This is an experience you are not going to want to miss! The deadline for completion of all elements of the Retreat Weekend application (application, medical form, and immunization records) is September 8, 2010.

The application process is described and the applications are available from the following link on the Victory Junction web site:

http://www.victoryjunction.org/parents/camper-application.php

There is a medical section of the application that will need to be filled out by your doctor. Please send in your portion of the application as soon as you have it completed. Do not wait for the physician section; that portion can be sent in later.

Your point of contact at Victory Junction regarding the application process and the TMA Retreat Weekend is Chris Foster. Chris can be reached at: (336)495-2019; his email address is **chris.foster@victoryjunction.org**.

We have invited physicians and medical specialists who are focused on the rare neuroimmunologic disorders to attend this retreat weekend. They will be there to participate in the activities and to answer your questions. We will provide an education workshop during camp that will focus on research and short and long-term treatment and symptom management practices. While the emphasis is going to be on a weekend of fun and relaxation, you will have the opportunity to spend time with the physicians who have the best understanding of these complex disorders. The response we have received from our physician community has been outstanding. We are anticipating that the following people are going to be able to attend: Dr. Daniel Becker, Dr. Julius Birnbaum, Janet Dean, RN, Dr. Benjamin Greenberg, Dr. Adam Kaplin, Dr. Douglas Kerr, Dr. Michael Levy, Dr. Carlos Pardo, and Dr. Frank Pidcock.

We are also anticipating that Cody Unser will be attending the retreat weekend at Victory Junction. Cody has expressed an interest in being at camp and we are hopeful that her schedule will allow her to attend.

If you are an adult with TM, ADEM, NMO or ON and are interested in being a volunteer for this retreat weekend, please fill out and submit a volunteer application as soon as possible. Claire Rutan is Victory Junction's Volunteer Director, and may be reached at (336) 495-2016 or **crutan@victoryjunction.org**, should you have questions about volunteering.

http://www.victoryjunction.org/volunteers/apply.php

The weekend will provide a chance for you to meet with others who understand your experiences better than anyone. Having the opportunity to share your experiences with each other will be enriching and empowering. We know that you will come away from this retreat with lifelong friendships.

Please visit the web site to learn more about Victory Junction: **www.victoryjunction.org**

Pauline, Kazu and I look forward to seeing all of you in October!

KAKKIS EVERYLIFE FOUNDATION

CURETHEPROCESS™
ACCELERATING BIOTECH INNOVATION FOR RARE DISEASES

The Transverse Myelitis Association has become a partner organization of the Kakkis Everylife Foundation and has endorsed the CURETHEPROCESS campaign for rare disease treatment development. The campaign strives to inspire science-driven public policy to increase the predictability of the regulatory process for rare disease treatments. The goal is to give even the most rare diseases access to the accelerated approval process and fulfill more completely the original intentions of the Orphan Drug Act.

The TMA has endorsed these efforts to: **Establish a new Office of Drug Evaluation for Genetic and Biochemical Diseases,** consolidating expertise to ensure safe, effective and timely patient access to needed treatment.

Create a new standard for the surrogate and biomarker endpoints used for rare disorders, to allow treatments for these diseases to have full access to the accelerated approval pathway.

Devise new clinical study design paradigms for rare diseases that properly account for clinical heterogeneity and disease complexity to properly capture treatment effects.

The following is a message from the Chairman of the Kakkis Everylife Foundation:

When your child gets sick, you hope there will be a treatment available for them. For many patients with rare disorders, those treatments don't exist. This situation is made even more tragic when the science exists to develop a treatment, but the cost and complexities of development have slowed or even stopped progress. Despite the advances made in the last 10 years for some rare diseases, there are hundreds of others where the science exists for a treatment, but the next step of development will not happen.

I created the Kakkis EveryLife Foundation to CURETHEPROCESS and focus on fixing the problems associated with developing treatments for rare disorders. Our goal is to improve the regulatory environment surrounding the approval of effective treatments. We plan to effect change in regulation of rare disease treatments by insightful scientific analysis and dialogue, grass roots support and political sponsorship, complementing but not competing, with the role of patient societies and research foundations.

We believe: No disease is too rare to deserve treatment. We already have the science we need to treat more rare disease patients. We need an improved process with new study designs and disease measures to accelerate the development of new treatments. We need the right people in both industry and FDA to make these changes effective. All new drugs for rare disease should be safe.

The Kakkis EveryLife Foundation will be focused primarily on analyzing the problems and providing solutions that can accelerate the development process for rare disease treatments. We know it will be hard and complex, but the science is here and we have many patients depending on us, to CureTheProcess and treat them.

Working together we will achieve the needed regulatory changes at the FDA to increase the predictability of the regulatory process and encourage biotech innovation for rare biochemical and genetic disorders. With your support we can give even the rarest diseases access to the accelerated approval process and put orphan treatments on the fast track.

Thank you for your support,

Emil D. Kakkis, M.D. Ph.D.
President, Kakkis EveryLife Foundation
77 Digital Drive, Suite 210
Novato, CA 94949
(415)884-0223
www.curetheprocess.org

Patient Advocate Foundation (PAF)

Members of The Transverse Myelitis Association with ADEM, NMO and TM may be eligible for benefits from the Patient Advocate Foundtion (PAF) Co Pay Relief program. It is critically important to keep in mind that the benefit for the TMA members only applies to those of you who are receiving medication for the treatment of pain. The benefit, if you are eligible, would apply to your pain medications only. TMA members may also be eligible for the mediation and arbitration services offered by PAF.

The PAF Mission: to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

www.patientadvocate.org

Co Pay Relief: Patient Advocate Foundation (PAF) Co-Pay Relief Program (CPR) currently provides direct financial support to insured patients, including Medicare Part D beneficiaries, who must financially and medically qualify to access pharmaceutical co-payment assistance. The program offers personal service to all patients through the use of call counselors; personally guiding patients through the enrollment process.

Are You Eligible? The Patient Advocate Foundation (PAF) Co-Pay Relief Program (CPR) currently assists insured patients who are financially and medically qualified and are being treated for breast, lung, lymphoma and cutaneous t-cell lymphoma, prostate, kidney, colon, pancreatic, head/neck cancers, malignant brain tumor, sarcoma, diabetes, multiple myeloma, myelodysplastic syndrome (and other preleukemia diseases), osteoporosis, **pain**, hepatitis C, rheumatoid arthritis, selected autoimmune disorders and CIA/CIN.

For Patients We are pleased to now offer a dedicated, secured web based application for patients to enroll electronically for the Co-Pay Relief Program (CPR). Please be advised that only one application per patient will be accepted. The patient's social security number is required to complete the application process. The program also offers personal service to all patients through the use of call counselors who personally guide patients through the enrollment process. You may reach the CPR team by calling 1-866-512-3861.

The hours of operation for CoPay Relief are 8:30 AM - 5 PM Monday - Thursday and 8:30 AM - 4 PM on Fridays.

The electronic enrollment may be accessed from the following web address:

www.copays.org

I hope this information will be helpful to your members.

Patient Advocate Foundation
421 Butler Farm Road
Hampton, Virginia 23666
(800)532-5274
www.patientadvocate.org

2010 WORLD STEM CELL SUMMIT

Detroit Marriott Renaissance Center | Detroit, Michigan USA | October 4-6, 2010

Free public day: October 3, 2010
Detroit Science Center

The Transverse Myelitis Association is honored to be an endorsing organization for the GPI 2010 World Stem Cell Summit.

The World Stem Cell Summit unites the stem cell universe of researchers, regenerative medicine industry leaders, funders, medical philanthropies, policy-makers, advocates, educators and regulators to chart the future of regenerative medicine. The 2010 World Stem Cell Summit will happen on October 4-6, 2010 at the Renaissance Center in Detroit, Michigan. The University of Michigan, Michigan State and Wayne State are the educational partners, alongside the Michigan Economic Development Corporation. GPI anticipates upwards of 1500 stakeholders from pharma, biotech, academic/research, government, policy, ethics, law, finance, advocacy and more will attend.

The 2010 World Stem Cell Summit program is designed to cover the field's most pressing topics including: progressive research strategies, translational and preclinical findings, cross disciplinary initiatives, drug discovery, funding opportunities (federal, public and private), commercialization plans, technology transfer platforms, venture capital insight, market trends, regulatory issues, ethical and societal implications, philanthropic opportunities, medical tourism challenges, cell banking projects, intellectual property landscapes, insurance questions, international perspectives, clinical use and the pressing advocacy agenda.

The World Stem Cell Summit serves to unify, educate and empower an ever growing network of stem cell sciences and regenerative medicine stakeholders committed to the advancement of cures.

The program agenda for the summit is posted on the following web page: **http://www.worldstemcellsummit.com/summit-agenda**

The Genetics Policy Institute (www.genpol.org) is a nonprofit focused on the global advancement of stem cells sciences and the field of regenerative medicine. GPI is the producer of the annual World Stem Cell Summit.

WebMD Health Exchange

http://exchanges.webmd.com/transverse-myelitis-association

WebMD has introduced a way to assist you in making better health decisions. The WebMD Health Exchange is a place where you can get support and information for health issues from experts and other members who are dealing with ADEM, NMO, ON and TM via discussions, tips and resources sharing.

The TMA Member Exchange connects to WebMD's resources and is also linked to information from our web site. The Exchange is searchable not only on WebMD, but on the Web, making it easier for users to find the TMA.

Another great feature of the Exchange is that we can include our support groups; each support group can create their own local or regional Exchange and each of these groups will be indexed in the WebMD searchable Exchange directory. By creating local Exchanges, it would make it easier for our members to find local resources. If you are interested in creating a local Exchange for your state or country support group, please get in touch with Jim and he can help you get started.

21st Anniversary!
The James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders

Jim posted the following message on the transverse myelitis internet club:

Today, May 17th, makes 21 years since I became a ventilator dependent quadriplegic due to acute transverse myelitis. I was 21 when it happened so it has now been half my life. I woke up that morning with a sore shoulder. Thinking I just slept in a wrong position, I went to work. After about 30 minutes, the pain in my shoulder increased and I started feeling dizzy. I tried to stand up, but could not. Someone helped me lay down. In a short amount of time, I remember a paramedic asking me my age. I tried to answer, but could not talk. I found out I had stopped breathing. The next memory I have is waking up in the hospital unable to move or speak.

Transverse Myelitis is an inflammatory attack in the spinal cord. It is an auto immune disorder where a person's own immune system mistakenly attacks and destroys myelin, the insulating material that surrounds nerves. There is no known cause or cure. It can happen to anyone at any age.

In 2008, the Transverse Myelitis Association established the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders. The purpose of the Fellowship is to encourage the development of medical specializations in TM, ADEM and NMO through a year of study under a leading TM, ADEM or NMO specialist. If you think this is a worthy cause and would like to make a tax deductible donation to support it, you can do so using this link: http://www.myelitis.org/fellowship-donation

Jim has devoted the past twenty years of his life to helping others. To honor Jim's devotion to our community and to recognize his incredible contributions to people with the neuroimmunologic disorders and their families, The Transverse Myelitis Association has established the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders. There is no greater need in our community than the provision of medical care by neurologists who have experience and expertise in these rare disorders. There is also a critical need to foster the development of scientists who are interested in these disorders. What better way to recognize and honor Jim than to establish a fellowship that will ultimately provide the best clinical care to the people Jim has devoted his life to helping and find the causes and cures for TM, NMO, ON and ADEM.

We are going to need your help to raise this money, and this help is going to need to be offered on a continuing basis in order to make this fellowship program a reality. The TMA is committed to an aggressive fundraising effort to create and maintain this fellowship program. More than any other program we have initiated, the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders represents the most significant investment in all of our futures.

The purpose of the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders is to encourage the development of medical specializations in TM, ADEM and NMO through a year of study under a leading TM, ADEM or NMO specialist. The fellowship is focused on the provision of exceptional clinical care and/or research into these rare neuroimmunologic disorders. Award of the Fellowship will be based on the expectation that the recipient will continue to specialize in ADEM, NMO and/or TM. If the fellowship includes a clinical and basic science research project, the fellowship term may be up to two full academic years.

The fellow will be required to work with a mentor (a TM, NMO and/or ADEM specialist). The mentor must be a faculty member with demonstrated clinical specialization and practice in at least one of the disorders. Preference will be given to medical centers of excellence in the disorders. If the fellowship includes a research program, the mentor must also be a scientist with research experience and publications in these rare disorders.

In order to award one fellowship each year, the TMA will need to raise $100,000. The number of fellowships we can offer will only be limited by the resources we are able to devote to this important program. Most of the people that I speak with for the first time are seeking a TM specialist or a NMO specialist or an ADEM specialist. If you have one of these disorders or if you are a family member or friend of a person with one of these disorders, an investment in this fellowship program will bring you very direct and profound benefits.

We urge you to get involved in this fundraising effort. I know that over the years many people have been inspired by Jim. Please join us in honoring Jim by helping to get this important program started. I can think of no greater legacy for Jim than to have highly motivated, brilliant and skilled physicians enter the discipline of neuroimmunology to provide clinical care to the people Jim has cared for so deeply for the past twenty years. Please make a donation to the TMA for the purpose of funding the James Timothy Lubin Fellowship and then please make your contributions a regular part of your generous giving. If you have been considering starting a fundraising program with your friends and family, this fellowship would be an excellent focus of your efforts. What more pressing or critical issue do you have in your own life or in your child's life than to assure that you or they have the best medical care available and that there are researchers who are interested in understanding TM, NMO, ADEM and ON.

Kristen Armer

Kristen Renee Armer, of Van Buren, Arkansas died Saturday, October 24, 2009 in Arkansas Children's Hospital from pneumonia. Kristen came into my life through a telephone call I received from her grandmother, Donna Hibbs, shortly after she was diagnosed with transverse myelitis. She got TM when she was just an infant.

Kristen was 12 years old and a 7th grade student at Cedarville Middle

School. Kristen was an inspiration and a joy to her family. Kristen also left an indelible impression on her classmates and in her community. She was a member of First Assembly of God in Van Buren, a member of Partners in Christ, the 2009 Cedarville Junior High Football Homecoming Princess, awarded the Pirate Spirit Achievement Award, two-time Gold medalist for Arkansas Special Olympics 100 meter motorized wheelchair race and a former Cedarville Little League Football cheerleader.

Our memories of Kristen should serve as a blessing for her family and for all of us.

Children's Database

The Transverse Myelitis Association has initiated an important project to collect information for a pediatric/young adult TM (recurrent TM)/NMO/ADEM/ON data base. The information we are collecting will be used for the following purposes:

1. To develop a contact list that will be used by the TMA to notify and recruit families and older teens and young adults for the family camps and the older teen/young adult retreat opportunities, such as those that are held at Victory Junction Gang Camp;

2. To develop a contact list to recruit for pediatric studies and clinical trials related to TM/NMO/ADEM/ON; and

3. To develop a directory that can be used by TM/NMO/ADEM/ON families to share information and support between families in similar situations.

This project is being directed by Linda Malecky. Linda's daughter contracted TM at the age of two in 1999.

If you have a child (25 years old or younger) with one of the rare neuroimmunologic disorders, we are requesting that you send us the following information:

- Parents' names
- Postal address
- Parent's phone
- Parent's email
- Name of child with TM/NMO/ADEM/ON
- Diagnosis (TM, NMO, ADEM, ON, recurrent TM)
- Child's birth year
- Year child contracted TM/NMO/ADEM/ON
- Age at onset
- Child's phone and email
- Birth year of brothers and sisters Medical facility where child's care given

The TMA is very aware of and sensitive about the short and long-term privacy concerns surrounding the information that we are requesting from you about you and your children, especially as it relates to a directory. We propose the following to address these concerns:

1. The information provided will not be incorporated in the TMA website in any way;

2. Your family will only be included in the directory at your request;

3. The directory will be published and mailed **only** to members who agree to be included in the directory;

4. Only the following information from the data base will be included in the directory:

- Parent's names
- State/Country where living
- Child's diagnosis
- Age (birth year) of child with TM/NMO/ADEM/ON
- Parent's email
- Parent's phone

The TMA believes that it is extremely important for families (including the children with TM/NMO/ADEM/ON) to be able to find other families and children for information and peer support, which is why we are collecting information for a directory. However, even with the limited information and distribution we are proposing for the directory, we realize that you or your children, now or in the future, may be concerned about being identified as someone with TM/NMO/ADEM/ON. We will only include those families who specifically indicate that they want to be included in a directory. **Please provide the data base information regardless of whether you want to be included in the directory or not.** This will ensure that you are contacted when camp or retreat opportunities arise or if there are studies or trials available that may help your child.

If you have ideas about additional information that we should be collecting for the database and/or including in the directory, please let us know.

If you would like to participate, please send your information to Linda Malecky via email: **LAMALECKY@VERIZON.NET**. If you do not have internet access, you can send Linda the information via the postal service: 107 Tweed Way, Harleysville, PA, 19438.

When you send us your information, please make it clear as to whether you would like to have your information listed in the pediatric TMA directory.

If you have any questions or concerns about the project, feel free to call Linda (215-855-3488) or myself (614-766-1806).

We believe that this project will help us better serve the families in our community by making you aware of important opportunities and by facilitating a support network for our families. We are grateful to Linda for her willingness to make this critically important project possible.

Caring for Children and Teens with Acute Disseminated Encephalomyelitis, Multiple Sclerosis, Neuromyelitis Optica, Optic Neuritis and Transverse Myelitis

In 2006, the National MS Society established a nationwide network of six Pediatric MS Centers of Excellence to provide diagnosis, comprehensive evaluation and care to children and teens under the age of 18 who have ADEM, MS, NMO, ON and TM. The centers were selected on the basis of having multidisciplinary teams of adult and child specialists; ties to an adult MS center; staff to evaluate and address school and other psycho-social issues; support for families; and the ability to work collaboratively with other institutions in the network. Approximately 60% of the children who are cared for at the pediatric MS centers have ADEM, NMO, ON or TM.

The centers are working together to:

Improve evaluation and managementstrategies to enhance diagnosis and care of children with MS and other related disorders;

Develop resources for families, health care professionals and the public;

Collect data that will enable large scale research initiatives.

Each Center Offers:

The latest in comprehensive care and treatment for children with these central nervous system demyelinating disorders, as well as the information and support their families need.

Evaluation and diagnosis involving both pediatric and adult neurologists.

A team of professionals that offers:

Nursing services

Cognitive and psychological evaluation

Rehabilitation assessment (physical, occupational, speech and language)

Vision care

Neuroimaging (MRI)

Individual case management and social services to ensure proper care and support

Information and resources for patients and families

School support

Families now have National MS Society-supported resources for evaluation, diagnosis, medical care and support. Children with symptoms suggestive of any CNS demyelinating disorder will be evaluated at one of the centers. A priority of this network is to provide comprehensive care to children with central nervous system demyelinating conditions, regardless of ability to pay. Financial assistance is also available for travel and accommodations according to need.

For information on the Pediatric MS Centers of Excellence or for programs and services available to your child and family call: 1-866-KIDS W MS (866-543-7967) or email: childhoodms@nmss.org.

Additional information can be found at: www.nationalMSsociety.org/pediatricms

The Centers:

Center for Pediatric-Onset Demyelinating Disease at the Children's Hospital of Alabama, University of Alabama at Birmingham
CHB 314K
1600 7th Ave South
Birmingham, AL 35233
Center director: Jayne Ness, MD, PhD
Contact person: Sarah M. Dowdy, MPH
Phone: (205) 996-7633
Web: www.uab.edu/cpodd/

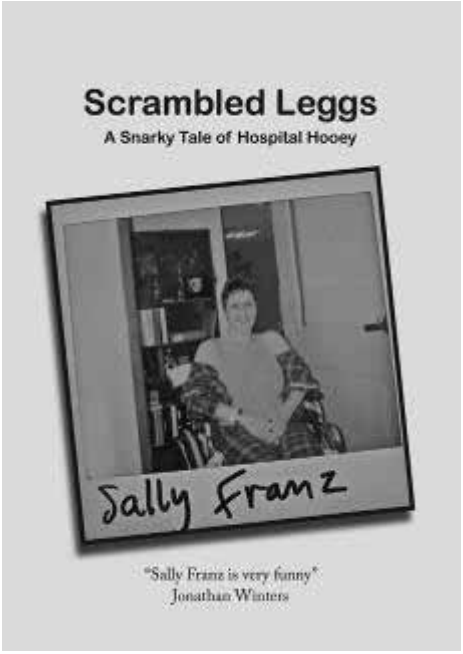
UCSF Regional Pediatric MS Center University of California, San Francisco
350 Parnassus Avenue, Suite 908
San Francisco, CA 94117
Project director: Emmanuelle Waubant, MD, PhD
Contact person: Janace Hart
Phone: (415) 353-3939
Web: www.ucsfhealth.org/pedsms

Partners Pediatric MS Center at the Massachusetts General Hospital for Children
Yawkey Center for Outpatient Care, Suite 6B
55 Fruit St.
Massachusetts General Hospital
Boston, MA 02114
Center director: Tanuja Chitnis, MD
Contact person: Rose Fratarcangeli
Phone: (617) 726-2664
Web: partnersmscenter.org/pediatric

Mayo Clinic Pediatric MS Center Rochester, MN
200 1st St. SW
Rochester, MN 55905
Center directors: Nancy L. Kuntz, MD & Moses Rodriguez, MD
Contacts: Paula Freitag, MSW
Phone: (507) 538-2555 or (507) 284-2111
Web: www.mayoclinic.org/pediatric-center

Pediatric MS Center of the Jacobs Neurological Institute
State University of New York, Buffalo
219 Bryan St.
Buffalo, NY 14222
Center director: Bianca Weinstock-Guttman, MD
Contact person: Mary Karpinksi, MSW
Phone: (877) 878-7367
Email: PedMS@thejni.org
Web: www.pedms.com/

National Pediatric MS Center at Stony Brook University Hospital
Department of Neurology, HSC-T12-020
Stony Brook University
Stony Brook, NY 11784-8121
Center director: Lauren Krupp, MD
Contact person: Maria Milazzo, MS,CPNP
Phone: (631) 444-7802
Email: info@pediatricmscenter.org
Web: www.pediatricmscenter.org/



Sally Franz got transverse myelitis while she was chaperoning a ski trip with a church youth group. Her experience in the emergency room was of the unfortunate and not uncommon variety. Unfortunately for Sally, much of her experience in the hospital and throughout her rehabilitation was more than difficult. She was paralyzed from the waist down and suffered from severe nerve pain. She also suffered from the other typical symptoms of TM, including bowel and bladder dysfunction and spasticity. The physical challenges would have been enough to try a person's emotional and psychological reserves; the nature of the treatment that Sally received from the physicians and hospital staff only compounded her difficulties. In describing and explaining the experience, Sally characterizes the many frightening and frustrating episodes with the doctors, nurses, therapists and staff with great humor and very sharp sarcasm. This perspective on her situation came very naturally to Sally, as she is a former stand-up comic and an award winning humor writer; she describes the world as she sees the world.

As full disclosure in discussing Sally's book, when faced with life's obstacles, I'm the first to be laughing, even when there is almost nothing to laugh at or even smile about. I've always found that my laughter is a good first defense against anxiety and fear; it always beats the heck out of screaming and crying in sheer terror. And I consider myself something of a connoisseur of humor. I'm pretty sure my people invented sarcasm and humor sometime between the invention of circumcision and the hora. Humor is a wonderful way to engage in social commentary, while minimizing the risk that the czar's army will burn down the village as a reaction to one's insightful and brilliant observations. Hummmm … is he a revolutionary, a union organizer or the court jester?

If you had a marvelous experience in the emergency room and you only find humor in Tom and Jerry cartoons, Sally's characterizations of her experience might come across as a bit harsh. If, however, your sense of humor is well developed and you are able to relate to her experiences surrounding the confusion and delay of her diagnosis and treatment, you are going to find her descriptions to be wonderfully clever, insightful and very funny. In addition to the trials surrounding diagnosis and treatment, Sally does a meticulous job of describing the difficulties she experienced in having the nurses, doctors and medical staff pay any attention to her words or her needs or to her, in general. Sally devotes a chapter of her book to a description of the symptoms from TM; you will so appreciate her depiction of these incredibly difficult symptoms.

Life doesn't make an appointment with a person to fit in a transverse myelitis attack; it happens when it happens. Such was the case for Sally. While she was going through the experience of getting, rehabbing from and adjusting to transverse myelitis, she found herself in financial ruin, she was losing her home, her mother passed away, she was diagnosed with cancer, a close friend died, and her husband was being unfaithful and she ended her marriage. It is a very good thing that Sally has a sense of humor.

Humor and sarcasm are the tools Sally uses to construct a very honest and frightening characterization of her experience with getting TM, going through the rehabilitation process, and adjusting to the long-term consequences of permanent damage to the spinal cord … and all of what that means for a person and their family. Her candor in describing her experience is both courageous and incredibly generous. She opens up and lays it all out there about everything. Her willingness to share the details about the whole experience can only help people who are going through or have gone through the same experiences. What is truly interesting about Sally and her approach to telling her story is that all of this honesty, candor, humor and sarcasm are wrapped in an envelope of great spirituality and faith.

Scrambled Leggs is a funny, quick read. For people who have TM or ADEM or NMO, you will relate to many of Sally's experiences and ap-

preciate her willingness to share these with you in a very personal way. Sally's work is also an important message, albeit packaged in a very lighthearted approach, that it is impossible to treat a person without listening to what they have to say. The effective provision of health care requires that the patient and their family be informed participants in the decision-making process.

I encourage you to read Scrambled Leggs because I believe that you will appreciate and enjoy Sally's book. Sally is donating 10% of the proceeds from your purchase to The Transverse Myelitis Association, if buy it before August 8th. Thank you, Sally.

www.ScrambledLeggs.net
Sallyfranz.com
FaceBook/Twitter: Sallyfranz
FB Fan Page: Sally Franz Uncorked
Also: Google Sally Franz

Cody Unser and Allen Rucker in New Mobility Magazine

Cody

Transverse Myelitis awareness got a very big boost in the March 2010 issue of New Mobility Magazine. There is a very dramatic and beautiful photograph of Cody on the cover and a fantastic article about Cody and her wonderful efforts in promoting scuba diving as a quality of life endeavor for people with paralysis and related disabilities. The article chronicles Cody's experience with getting TM and then establishing the Cody Unser Firststep Foundation. Cody speaks candidly about her challenges with TM, being paralyzed, and how she intends to change the quality of life for people stricken with paralysis and spinal cord injuries. She discusses how she decided to create the 'Operation Deep Down' Dive Team and the CUFSF partnership with PVA.

Cody received her open water scuba certification in 2000. She loved the sport so much that she wanted to share it with others. In 2002, Cody's Great Scuba Adventure was created and provided Open Water Adaptive Scuba training and a trip to the Caribbean for 11 Adaptive Divers. Two of the divers on that great adventure were Pauline Siegel and Paula Lazzeri. Then in 2005, Cody's Great Scuba Adventure II collaborated with partners to enhance the lives of 40 individuals--20 paralyzed and physically challenged people and their 20 able-bodied partners-- and they dove Cozumel.

Cody believes in using her voice for a 'bigger mission.' Like others, she knows that living with a disability can make leading a meaningful life more challenging, but she uses Adaptive Scuba Diving as one of her vehicles in finding fulfillment.

The TMA is very proud of our partnership with Cody and Shelley and the Firststep Foundation. And all of us in the TMA community want to offer the most heartfelt ***MAZEL TOV*** to Cody for her acceptance into The George Washington University Medical Center's School of Public Health and Health Services Master of Public Health - Health Policy Program. Way to go, Cody!

Allen

In the same March 2010 Issue of New Mobility Magazine, Allen Rucker has a wonderful article entitled, "The Myth of Walking" (p. 23). The 1971 vintage photograph of Allen on page 36 should provide sufficient motivation to pick up this issue of the magazine. Allen offers a very interesting, funny and poignant perspective on walking or not walking. Allen is a regular contributor to New Mobility Magazine. His insights about life after paralysis are always filled with sensitivity, intelligence, thoughtfulness, realism, and a very very healthy dose of great humor.

We are so thankful for Allen and Cody's wonderful work in raising awareness about transverse myelitis. We are also very grateful to New Mobility Magazine for their continued attention to transverse myelitis and the people in our community. Jim Lubin was the New Mobility Person of the Year in 1999!

We've made our website talk! ReadSpeaker Added to www.myelitis.org

ReadSpeaker is an innovative program that transforms text into speech. We added ReadSpeaker to our website to facilitate access to information for people who have visual impairment from Optic Neuritis, Neuromyelitis Optica or Multiple Sclerosis. Also, for thousands of people who visit our web site seeking information and support,

English is not their first language. Listening to the text could make it easier for people to understand this critically important information.

It is very easy to use; no plug-ins or downloads are required. To activate speech on a web page, all you have to do is look for the "SayIt" icon on the page and click it.

All of the text from the article will be read to you and the speech quality is excellent.

The Transverse Myelitis Association

The membership of The Transverse Myelitis Association includes persons with the rare neuroimmunologic 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.

The TMA was incorporated on November 25, 1996 in the state of Washington and became a 501(c)(3) organization on December 9, 1996. The TMA has more than 7,900 members from every state in the United States and from more than 80 countries around the world. There are no membership fees. The TMA is registered with the California Department of Justice, the Maryland Secretary of State, the Ohio Attorney General's Office, and the Washington Secretary of State.

The TMA has a large number of support groups across the United States and around the world. Some of our international support organizations have been formally recognized by their governments, including the United Kingdom, Germany, Ghana, Australia and Canada.

The TMA has been registered with the National Organization of Rare Disorders since 1994. The TMA is a member of or has a partnership with the following organizations: Cody Unser Firststep Foundation, the Johns Hopkins TM and NMO Centers and Project RESTORE, the University of Texas Southwestern TM and NMO Centers, the Accelerated Cure Project, Victory Junction Gang Camp, Spinal Injuries Association – Australia, Christopher and Dana Reeve Foundation, National Family Caregivers Association, American Autoimmune Related Diseases Association, Genetic Alliance, Kakkis Everylife Foundation, and the Guthy -Jackson Foundation.

Paralysis Resource Center Blog Squad

The Christopher and Dana Reeve Foundation established a Blog Squad to address a wide variety of topics of interest to the paralysis community. Transverse myelitis is very well represented in this conversation. Two of the people participating in the Paralysis Resource Center Blog Squad have transverse myelitis.

Kristi Allen was diagnosed with Lupus when she was just 10 years old and then was paralyzed from transverse myelitis when she was 15. Kristi is 29 years old and she lives in Sioux Falls, South Dakota.

Allen Rucker is a writer and lives with his wife, Ann Marie, in Los Angeles. Allen got TM as an adult and wrote about his experience in the wonderful book, "The Best Seat in the House: How I Woke Up One Tuesday and Was Paralyzed for Life" (Harper-Collins 2007). Allen is a contributing editor to New Mobility and chairman of the WGA Writers with Disabilities Committee. Allen is very active in The Transverse Myelitis Association. Through his many public speaking opportunities, Allen does a great job of raising awareness about TM. Allen is also a regular contributor to the TMA publications.

Learning about TM and the Other Neuroimmunologic Disorders: Bibliography and Videos on www.myelitis.org

For those of you trying to learn about Transverse Myelitis, Chitra Krishnan has compiled an excellent bibliography about TM. Chitra serves on the TMA Medical Advisory Board. You can find the bibliography by typing this address into your web browser: ***http://www.myelitis.org/Bibliography.htm***

Jim has created links from the articles in the bibliography to Medline; so when you click on the article citation, you can easily get to a copy of the article to read. Additionally, when you are in Medline, you can link to other recently published articles by clicking on the authors' hotlinks.

Another tremendous resource about TM and the other neuroimmunologic disorders is the streaming video that Jim has posted on the web site. The presentations from the 2008 (Seattle), 2006, 2004 and 2001 Symposia, from the Southwest Symposium (sponsored by the Cody Unser First Step Foundation), and from the 2002 children's workshop are available under the link 'Symposia Information' or by typing http://www.myelitis.org/events.htm

into your web browser. Jim has the presentations organized as they appeared in each of these symposia program agendas. You can also find PDF files of most of the handouts and PowerPoint presentations. The video presentations are also available by going through the Streaming Video Presentations link from our main web page or by typing http://www.myelitis.org/multimedia.htm into your web browser.

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 to me via email at ssiegel@myelitis.org; you can send changes to me by mail, or you can fill out a change of information form on the web site: http://www.myelitis.org/memberform.htm – just click on the box indicating that you are changing existing information.

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 in this fashion. 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; the materials we are mailing to a bad address just ferment on some post office floor. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

The TMA Membership Directory

In order to receive a TMA membership directory, you must be willing to have your name and contact information listed. Those who have designated that they do not want to be listed in the directory will no longer receive one. The purpose of the directory is to assist our members in finding each other in their local communities, states and countries. As our membership is small and widely scattered around the globe, the directory serves as a way to facilitate the local or regional sharing of information and support. The value of this directory is commensurate with the numbers of our members who are willing to participate in our support network.

It is the expressed policy of the TMA not to share this information for any commercial purposes. The vast majority of our members are listed in the directory. This designation was made when you first completed the membership form on www.myelitis.org or when the original email or telephone contact with the Association was made. If you are not currently listed in the directory, and would like to change your designation so that you can receive the directory, please call (614)766-1806 or send an email to ssiegel@myelitis.org requesting that your contact information be listed.

This would also be a good time to check the directory to be sure that your current information is accurate. If your phone number or email address has changed, please notify us. Your membership information will be updated. When you send us any changes, please include all of your information so your membership listing can be easily found and the changes identified.

In addition to receiving the directory, another important benefit of being listed in the directory is having access to local support groups. Over the past several years, our local support groups have been developing around the country and around the world. If you are not listed in the membership directory, we assume that you do not want to be contacted. We do not provide your information to anyone, including the support group leaders who are currently operating in and around your area, or to those who will establish groups in your area in the future.

Due to the increasing size and cost of the TMA Membership Directory, we will be printing and mailing new directories no more frequently than every two years. If you are not currently listed, please consider doing so. We appreciate the willingness of so many of you to make yourselves available to assist others in your communities, states and countries.

Contacting the TMA by Email

When writing email messages to the officers of the TMA or to support group leaders, please use TMA, Transverse Myelitis, TM, ADEM, NMO or ON in the subject header of the message. Please be sure to include a title in the subject header. The volume of emails that we receive and the way spam filters work makes it increasingly difficult to sort through emails to find legitimate messages. Also, if you would like to send an attachment, it is always a prudent approach to send an email notifying the person that you are going to follow up your message with a second email that includes the attachment; and explain the nature of the attachment. If you want to be sure that we see it, save it and open it, please include a subject header in your message and use words that will identify you as a person interested in contacting the TMA. We appreciate your help!

Inspirational Women from the TMA Community, Kolkata, India

Business Economics is a publication from Kolkata, India. The April 1-15, 2010 issue was devoted to the topic of women; their status in society, in politics and government, in education and in business and economics. The magazine addressed some incredibly important issues for Indian society. The cover story for this issue was about "Overcoming Odds" and told the story of four inspirational women. Three of the women featured in this article have transverse myelitis, Maggie Winston, Pauline Siegel and Sushma Rani. One of the women has neuromyelitis optica, Grace Mitchell. These are, indeed, very inspirational women. The author of the article is a writer and reporter for ***Business Economics***, Abhijit Ganguly. Abhijit holds a master's degree in Economics.

Abhijt got TM when he was in his early 20s and became the TMA Support Group Leader in India. Abhijit and I have become very close friends. Abhijit has become very close friends with a lot of people in our community. Abhijit has found a variety of ways to write about TM and the related disorders, and to feature stories about the people in our community. He does an amazing job of creating awareness. We are so grateful for Abhijit's efforts.

This has been a very special year for Abhijit. Our son, David and his wife, Kathryn, were invited to a wedding of a very close friend. The wedding was to be held in Surat, India in December. When David and Kat told me that they were going to India, I asked them if they would be open to meeting Abhijit and to spending a couple of days with him. They said that they would be honored to meet him. Abhijit took his first plane flight from Kolkata to Surat and he spent two days living in the same house with David and Kathryn. They did some sightseeing together and they spent two days visiting with each other. David and Kat took Abhijit for his first meal at a McDonalds! David and Kat understand my deep love, care and concern for Abhijit, and, thus, it was a very emotional visit for the three of them.

COVER STORY

For all the mothers fighting
For better days to come
And all my women, all my women
sitting here trying
To come home before the sun
And all my sisters
Coming together
Say yes I will
Yes I can

Singer Alicia Keys tried to capture the essence of every woman through her song "superwoman". There are women in this world achieving great things against all odds.

Overcoming Odds

■ *Abhijit Ganguly*

What is common between 27 year old Maggie Winston from Kenai, Alaska, Pauline Siegel from Ohio, Grace Mitchell from Pennsylvania and Sushma Rani from Ghaziabad. They all suffer from a rare neurological disorder called Transverse Myelitis (TM). They have defied their disability and have been great achievers showing a remarkably positive attitude to life.

Transverse Myelitis is a neurological disorder caused by an inflammatory process of the grey and white matter of the spinal cord, and can cause axonal demyelination. It is an auto-immune disorder very similar to multiple sclerosis. TM inflames the spinal cord, causing pain, weakness, and often paralysis. About 1,400 new cases of this disorder are diagnosed each year in the United States.

Hope these stories inspire people with disabilities to remain as active and healthy. Women have it in them to rise to the occasion.

MAGGIE WINSTON

Maggie has the most incredibly indomitable spirit- On her twin son's birthday, she was diagnosed with TM. She woke up at about 8 o'clock in the morning with a severe pain between her shoulder blades. Within four hours, she couldn't move anything below her arms. She was admitted to Providence Alaska Medical Center in Anchorage. After one week in the intensive care unit, one week in the neurological unit and a week in rehabilitation, she started getting better. Almost two months after she first felt the pain in her back, Winston was transferred to the University of Washington Medical Center, in Seattle, for six weeks of rehab. Daily treatments involved 1 1/2 hours of physical therapy followed by 1 1/2 hours of occupational therapy. Maggie became totally paralysed from neck down and ventilator dependent.

Maggie was a hairdresser. Hairdressers from A Star Reflection Salon in Kenai, have conducted fund-raisers in Winston's name.

She is no more ventilator dependent but never regained any movement in her arms. She is a college student. She is also support group leader for Alaska for the TMA.Since her attack she had to face enormous and difficult challenges. But she has faced all her challenges with a broad smile.

"My motivation is my children. I want them to know that nothing is impossible, and I can't just tell them that... I have to show them" ... said Maggie.


Maggie with her twin sons - Daemon and Dylan


Pauline with Kazu (service dog) and her husband Sandy

PAULINE SIEGEL

Pauline Siegel was experiencing flu-like symptoms for a few days. One morning she stepped out of her shower and felt severe pain. She was paralysed from the waist down within seconds. Pauline was diagnosed with TM in 1994. She was in an acute care hospital for a week after her attack. Once she received IV steroids and her doctors were comfortable that her condition had stabilised, she was transferred to a rehabilitation hospital.

Pauline was completely paralysed from the waist down. She had absolutely no bowel or bladder control. She could move nothing below her waist. She was at a rehabilitation hospital at The Ohio State University Medical Center for almost two months. She did outpatient physical therapy for over a year!

Business Economics 32 April 01-15, 2010

Abhijit has helped to reinforce something that I have been learning since becoming involved in the TMA … our shared experiences have made the world a very small place. Regardless of where you live, what language you speak, or your culture, the experiences you have had after getting ADEM, NMO, ON or TM have created an intense and lifelong connection between you and other people who have these disorders. Thank you, Abhijit, for your constant concern and advocacy for the TMA worldwide community!

SUSHMA RANI

Sushma got TM in 2006. She was on her way to school when she felt that her legs were not moving properly; later on her hands were not moving either. Eventually she lost control of all body below the neck.

Now, after 4 years she has sensation in all her body parts. She can move her right leg properly but has a little problem with the left leg. She cannot move her fingers. Presently she is doing B.Com from Delhi University, gives tuition to children during daytime. Her hobbies are painting, clay painting, mehandi designing and cooking.

Everyone's life is a unique combination of events, some of them may seem as setbacks, but these setbacks provide the uniqueness to our life, so enjoy every moment because no one's life is perfect. It's how we live it…. Every event provides lessons on how to live fully. It's you who set limits to your life. Mind has infinite potential. Let it flow…

She lost most of the muscle function down her lower back and down through the back of her legs. So, Pauline can bend over, but she can't get back up. She is able to walk with canes, and if she goes to a mall or museum or some other place that involves a lot of walking, she uses her wheelchair. Pauline has adjusted to her physical limitations and manages to lead a very good and productive life. In spite of daunting odds however she has now risen to the position of Second grade teacher.She was a kindergarten teacher when she got TM.

Pauline was placed with a service dog named Kazu from Canine Companions for Independence. Kazu is awesome; he does what Pauline tells him to do and he remains focused on Pauline in school. Kazu also picks things up off of the floor for Pauline. Kazu opens and closes the doors in the bedroom every night for her. Pauline is the perfect leader for Kazu – and it is hard to imagine a better follower than Kazu. Pauline has fought to gain more mobility, going from the wheelchair to a walker and finally to canes.

A few months after Pauline got home from the hospital, she and her husband, Sandy, became involved in establishing The Transverse Myelitis Association (TMA). Sandy is the President of TMA. The Transverse Myelitis Association is an international advocacy organisation that offers information and support to its members. The organisation has grown from 187 members in 1997 to more than 7,800 members today. The members come from more than 80 countries around the world. There is a wonderful support group of the TMA in India.

Pauline has found a way to turn a horrible tragedy in her life into a positive role for herself and for the many other people she has touched through her work for the TMA. Through her efforts people who experience this very difficult disorder know that they are not alone.

GRACE MITCHELL

Grace was diagnosed with Devic's Neuromyelitis Optica (NMO) in 2005. She had six episodes of NMO, which included three episodes of paralysis and three episodes of ON. Despite suffering from this disease, she manages to maintain her passion to reach out to fellow patients of the disease who are in need of support and comfort.

It has been her mission to collect information and the most current research updates on NMO, and she devotes her time to encourage and uplift others who are similarly diagnosed. The Discovery Channel's Discovery Health, featured Grace's story on an episode of Mystery ER.

NMO reseach has literally exploded in recent years. Thanks to the dilligence of researchers, so much more is understood about the pathology of the disease. Todays' patients are also better educated and are taking a proactive stance re: disease management.

We have great reason to hope that more viable treatment options will be discovered and that the research effort will one day lead to a cure,' said Grace.

These Are Very Special Times for Dr. Anibal Molina Lugo

On Saturday, March 27, 2010 he met Ashley Harrington!

On Thursday, June 3, 2010 he graduated from The Ohio State University Medical School!

I met Al and Ashley in the same way; I received a phone call from a family member while they were experiencing severe inflammatory attacks. In Al's case, I started communicating with his sister, Ivetteliz. In Ashley's case, I communicated regularly with her father, Jeff. Both were given a diagnosis of acute disseminated encephalomyelitis or ADEM.

Ashley had a very severe attack about three years ago. Her recovery has been very slow but steady. She has regained significant motor function and is slowly but surely regaining the ability to eat and to communicate. It isn't easy to communicate with a person who is not speaking, but this is not the case with Ashley. She has such a beautiful smile and such sparkling and knowing eyes, that she makes expression of ideas, thoughts and emotions not entirely dependent on spoken words. I write about Ashley often, because she has taken up permanent

residence in my heart and my mind. I encouraged Jeff and Mary to bring Ashley to the retreat weekend at Victory Junction. They did attend two years ago and also came to the family camp last year. It was just incredible spending time with Ashley and her family. She is such a special person. Ashley and I have been connected by the heart from the very first time we set eyes on each other. We share equal measure of smiles and tears through every visit.

Al was diagnosed with ADEM when he was 24 years old; it was March of 2003. Al was admitted to Henry Ford Health Services Center in Detroit, Michigan. Through incredibly hard work and perseverance, Al has regained significant motor function. While Al has managed to gain independence, he still has symptoms from the severe inflammatory attack he experienced in his brain and spinal cord. When I first met Al, he had recently been accepted into the doctoral program in chemistry at The Ohio State University. His academic pursuits were shelved after he was diagnosed with ADEM and began a long and difficult rehabilitation process. A few years after his ADEM attack, Al announced to me that he had applied and had been accepted to The Ohio State University Medical School. Pauline and I were so thrilled; Al was going to become a doctor and Al was going to be coming to live in Columbus. Over the past four years, we have been in touch with Al by phone and we have gotten together on a fairly regular basis to be sure Al was getting a break from his studies and getting a decent meal. Medical school has been a grueling process for Al. No one could have higher expectations nor push themselves physically and mentally as hard as Al has over the past four years. Along with Al's parents and sister, Pauline and I have been Al's cheerleaders throughout his journey through medical school.

Because the world is such a small place, Al developed a very close relationship with a Professor from the Department of Neurology at the Medical School. Her name is Dr. Joanne Lynn. Dr. Lynn also happens to serve on the TMA medical advisory board and is Pauline's neurologist. Dr. Lynn has served as a mentor for Al and has provided him with tremendous guidance during his education. Through this important relationship, and through Al's personal experiences, it is no great surprise that Al is going to specialize in Neurology.

I attended Al's graduation on June 3rd. Dr. Lynn is the Associate Dean for Student Life of The Ohio State University School of Medicine. Al asked her to perform the great honor of hooding him at the graduation ceremony. Watching Anibal Molina Lugo become Dr. Lugo by having Dr. Joanne Lynn place the hood over his head was one of the more cosmic moments I'm going to have in my life. Al is headed back to Henry Ford Health Services Center in Detroit, Michigan, and this time, not as a patient, but to begin his residency in neurology! Al can decide to specialize in whatever he wants, so long as it is neuroimmunology with a focus on acute disseminated encephalomyelitis.

Al has been talking on the phone with the Harringtons since Ashley was diagnosed with ADEM. I connect Al to families all the time. He is going to be an excellent physician. Al is an incredibly kind, sensitive and compassionate person; and it is these qualities that are going to make him an exceptional clinician. One of my goals over the past couple of years has been to arrange for Al to meet Ashley and her parents, Jeff and Mary. Finally, on March 27th, we arranged to meet the Harringtons halfway between their home in Fort Wayne, Indiana and Columbus. We picked a hotel just off of the freeway in Lima, Ohio for our meeting. Pauline, Kazu and I drove Al up to Lima and we met Ashley, Jeff and Mary at around noon on Saturday. It was an awesome six hour visit. We're all looking forward to a reunion this fall at the Victory Junction Retreat Weekend.

Over the years, Pauline and I have become very close with both of these families. I think about Al and Ashley all of the time. A day doesn't go by that I don't think about Ashley. In both Ashley's and Al's cases, their recoveries have been significantly impacted by the efforts, love and care of wonderful, supportive families. There couldn't be families on the face of the earth that could be any more devoted to their children than the Harringtons and Lugos. And Al and Ashley have been incredibly disciplined and motivated to do all of the hard work that is required of rehabilitation. I wanted for Ashley to meet Al and to share in the hope that Al represents for her future on so many different levels. As we were leaving the hotel, Al's first words to Pauline and I were that Ashley was just so filled with dignity. We all see this in Ashley. Without her speaking a word, you know you are with a very intelligent, very wise, very spiritual, very sensitive human being. Ashley is so filled with dignity and I believe in my heart of hearts that she has a bright and positive future before her. Ashley

will have her time and her opportunity to heal the world.

Al will also have his chance to heal the world. I marvel at your accomplishment and I share the great pride of your Mom, Dad and Sister. We can only imagine the journey you've been on in the past five years. We wish you the very best of luck throughout your residency. ***Mazel tov***, Al!

Help Keep Our Membership Information Accurate

By doing something as simple as keeping your information accurate in our records, you are helping to save the TMA money; funds that can be used for research or to support symposia or the TMA Kid's Camp.

In addition to asking people to take personal responsibility for keeping address, phone and email information updated and accurate, we are seeking help from our support groups in this important effort. We currently have a number of support groups who regularly contact their membership in order to confirm the accuracy of their information. For instance, the TM support groups in Canada, India, Germany, Italy, South Africa, Australia and New Zealand, Ghana, Scotland and the UK TM Society regularly check their membership information. Please consider getting involved in this important activity! If you have a flat rate long distance calling plan and internet access, you would be able to easily reach all of the members from your state or country to help verify their information. You would be helping the TMA to save valuable resources, and you would be offered the wonderful opportunity to make connections with the very special people in our community. As our international postage costs are so high, we have a critical need for this work to be done in our support groups outside of the United States.

If you are a support group leader and are involved in a mailing to your state or country members, please be sure to let us know if you are made aware of any information changes. You can send this information to Sandy Siegel at ssiegel@myelitis.org or to: 1787 Sutter Parkway, Powell, OH 43065-8806 USA.

If you are interested in helping us, please get in touch with Sandy Siegel or Debbie Capen at dcapen@myelitis.org or (951)658-2689. Even if you do not have a support group in your state or country, but would like to help us with this work, please get in touch. We would be grateful for your assistance.

Find us on Facebook

You can find The Transverse Myelitis Association on Facebook. It is a great way to support the TMA and it a wonderful way to network with people in our community. Please take the time to become a fan of the TMA and tell your friends and family about your community's page. Our page is a great way for us to raise awareness about these disorders and about your experiences.

http://www.facebook.com/myelitis

Support Groups

Alabama

My name is Anita Dudley. I was diagnosed with NMO in the spring of 2006. In September of 2005 I was paralyzed from the waist down. The doctors at the hospital where I was being treated had no idea what caused the inflammatory attack in my spinal cord. They gave me a transverse myelitis diagnosis. They did every test they could think of to find the cause and to determine the diagnosis.

In the spring of 2006 my neurologist went to a meeting and mentioned my case to the speaker. He was told that it sounded like NMO. So, the NMO-IgG antibody test was done at the Mayo Clinic and it came back positive for NMO.

It was a very scary time. I can now walk unaided, but not very far and not on uneven ground. I found help through The Transverse Myelitis Association web site. Reading about others and their experiences was such an inspiration to me. And all of the information on the website is just wonderful.

I am hoping that I can help others in our state. Please feel free to contact me. I am here for support and any information that I can give or help you find.

Sincerely,
Anita Dudley
Mobile, AL 36695
(251)607-0323
dudleygene@bellsouth.net

My name is Missy Logan and I am excited to work with Anita Dudley as co-coordinators for the Alabama Support Group! Here's my story…

January 3, 2004, I started my new dream job. I was healthy and happy, and life was good! Little did I know that one week later, I would be spending nine days on the neurology floor at the University of Alabama – Birmingham (UAB) Hospital! I was 33 years old and had never spent even one night in the hospital, let alone nine!

My diagnosis was an acute episode that started out with complete urinary retention and then a tingling / burning sensation in my legs on Wednesday, January 5. This terrifying incident took me to the emergency room twice in one day to be cathed; with the last visit sending me home with a bag catheter and a follow up appointment with an urologist. No one at either ER visit questioned me about other symptoms or issues. They thought my problem was related to a reaction to an antibiotic I was taking for an upper respiratory infection and sent me on my way!

However, within two days, the burning and tingling sensation worsened, and I began losing mobility from the waist down. This worsening resulted in a third visit to the ER. By this time, I could barely squat without assistance. I had numbness in my back and feet, I continued to have urinary retention, and I was ***scared*** to death! The doctor on-call from my doctor's office sent me for an MRI immediately to rule out MS, but his initial diagnosis based on my conditions/ symptoms was Transverse Myelitis (TM) (thank goodness for this doctor)! Following this ER visit, I was transferred to UAB where the neurologists conducted routine tests, including a spinal tap, another MRI, and other electromagnetic testing. They confirmed the diagnosis of TM and began my IV steroid treatments.

I consider myself very fortunate to have had a doctor who was educated on TM and transferred me to a teaching and research hospital where they had treated other TM patients. I also recognize that my acute episode was very minor compared to some others. I never lost complete control of my legs or other extremities, and today, while I still experience some numbness and tingling, I do have complete and full use of my legs. And, even though I do continue to intermittently cath to completely empty my bladder, I can void on my own! I am able to play tennis, exercise regularly, shop and I also gave birth to our first child February 14, 2005 – one year and one month after being released from the hospital with TM!

My neurologist and urologist, of course, do not know the cause of my attack – either the upper respiratory infection or the flu vaccination that I had received a few weeks prior to the onset of my symptoms. While I had excellent care and received a lot of information regarding my diagnosis in a timely fashion, I know others do not always have this experience, which is why I look forward to working with The Transverse Myelitis Association and helping others in Alabama!

Missy Logan
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Alaska

Maggie Kay Winston is the new support group leader in Alaska. Ordinarily, the support group leaders write these introduction articles for a new state or country support group or a new support group leader. I am making this introduction for Maggie, because she is currently recovering from

a severe pressure sore and surgery. Thank goodness, she is doing much better and is feeling good. Maggie got TM a few years ago on her twin son's first birthdays. Over a short period of time, she lost all function below her shoulders, including the ability to breath on her own. She has since been weaned from the ventilator but remains a full quad.

Pauline and I met Maggie, her brother, Huey, and her good friend, Sheena, on a small plane on our way to Victory Junction Gang Camp for our first retreat weekend. Maggie was on the third leg of flights to North Carolina and had been traveling for more than twenty-four hours to participate in camp. It was pouring rain in Charlottesville as Maggie was carried onto the plane by Huey and Sheena. Her bright turquoise hair was dripping wet and the three of them were laughing hysterically as they lowered Maggie into her seat in the bulkhead and covered her with a blanket. Pauline looked at me and pronounced, "they're coming to camp." Pauline and I were two rows behind them. I introduced Pauline and I and gave Maggie my TMA wristband. And thus began our love affair with Maggie.

Pauline and I love Maggie as a member of our family. I've told Maggie before that with as protective as I am, G-d knew what I would have done to a daughter, so he gave her to someone else. While Maggie has been spared my incredibly neurotic worrying, it is only by matter of degree. Maggie gets the periodic calls from me during which I interrogate her on various health matters, her progress in school, her diet and nutrition, and everything else under the sun. Maggie tolerates my obsessive activity because she's not in the least confused about where this worrying comes from in me. She knows how much we love her, and she knows that she's a quadriplegic living in a community of 5,000 people in a place where there's no snow on the ground for ten minutes a year.

I love the work that I do for the TMA. There is nothing more motivating and energizing for me than to provide guidance to people who are seeking information and a strategy for managing one of the most devastating experiences they are likely to have in their lives. I always hang up the phone feeling very good about how I spend my time. But there are many times when I hang up the phone and feel emotionally drained. No matter how many times I've had a conversation with a parent about an infant going through an ADEM or TM attack, I'm an emotional wreck for a while after the call. When the emotions accumulate to a certain point, I begin to seek my own support network to manage these very complicated feelings. No matter how I'm feeling, after a conversation with Maggie, I'm feeling good. Maggie is one of the most positive, well-adjusted, inspirational people I've ever met. Period. Maggie is just so comfortable in her own skin. She and Jim share this perspective and attitude about life. It remains totally remarkable to me. Both of them have recreated a great life after suffering this horrible challenge of not being able to move a muscle below their necks. A conversation with either of them almost never involves any of these physical issues. Maggie and I always talk about her boys, music, her college courses, her future goals, what kinds of things she is doing with her friends, and her current interests and hobbies. She started skiing last winter through an adaptive sports group. There are photos from these ski trips with her son's on her Facebook page.

When I need a support group, I have Maggie. Now Maggie is Alaska's support group leader. Alaska, you are so very fortunate to have her. If you live in Alaska and have TM, ADEM, NMO or ON, please get in touch with Maggie and please get involved in her group.

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Australia and New Zealand

The Spinal Injuries Association and the TMA Announce Partnership

The Spinal Injuries Association of Australia and The Transverse Myelitis Association announced an affiliate relationship to ensure that members of the TMA from Australia and New Zealand would receive education and support, as well as advocacy for research and clinical care. The announcement was made at the Spinal Injuries Association Transverse Myelitis Day in Brisbane, Queensland, Australia on May 17, 2010. In so many different ways, this event marked a very auspicious occasion for the TMA and the Spinal Injuries Association. The very first TM Day in the world was held in Australia on May 12, 1999 and was organized by Ian Hawkins. This Australian experience led the way for a number of other TM awareness days that have taken place across the United States and around the world. The announced partnership and awareness day also took place during the Spinal Injuries Association's celebration of its 50th anniversary of assisting and empowering people to live independently.

Bernice Quinn, Member Networks Coordinator, was instrumental in coordinating the TMA and Spinal Injuries Association partnership and also in the planning of the TM Awareness Day. David Riley, President of the Spinal Injuries Association addressed the participants at the TM Awareness Day Program and announced that the Spinal Injuries Association would become the affiliate of the TMA in Australia and New Zealand to provide support services and education to people with TM, NMO and ADEM. Also participating in the Awareness Program were Mark Henley, CEO of the Spinal Injuries Association and John Mayo, the Executive Manager of Community Relations of the Association.

The TM Awareness Day Program included two presentations. Sandy Siegel, President of The Transverse Myelitis Association talked about the history of the TMA, offered a status report and discussed the future of the Association. Dr. Benjamin Greenberg, the Director of the TM and NMO Centers, University of Texas Southwestern Medical Center, offered a presentation on the current state of research in these rare neuroimmunologic disorders. There was a question and answer session after each presentation which was simulcast to the audience in Australia via web cam. A lunch followed the presentations and the people who attended the program had time to visit and share in their experiences. It was a wonderful celebration of the newly formed partnership, as well as an educational and inspirational gathering for all who were able to participate.

The support group leaders in Australia are Errol White and Ian Hawkins. The support group leaders in New Zealand are Dyllice Eastwood, Jennifer Murray and Steve and Ali Alderton. These people will remain involved in the TMA community and will continue in their roles as support group leaders in Australia and New Zealand by serving as points of contact for people seeking information and support. We are so grateful for their many years of service to our community! Errol has, for more than a decade, taken on the responsibility of distributing all of the TMA publications for our members in both Australia and New Zealand. We so appreciate all that you have done, Errol, for all of these years. You are such a good man.

The TMA is honored to have such an exceptional partner organization in Australia. The Spinal Injuries Association will serve as the affiliate of the TMA for both Australia and New Zealand. They will distribute the TMA's publications to our members in Australia and New Zealand and will support our mission and goals for people who have ADEM, NMO and TM. We look forward to working with the wonderful people at the Spinal Cord Injuries Association in the years to come.

Canada

My name is Kimberley Kotar and in June of 2008 I had written an article in the TMA newsletter about starting a support group in Montreal, Quebec. Well, a lot has happened since that article was published. I managed to complete a half marathon and three marathons in the last eleven months; the last one being the Boston Marathon. While this is great in the fight against TM by raising awareness, my biggest news is that I was asked by Sandy Siegel to spearhead the establishment of the Canadian Transverse Myelitis Association; an affiliate support group of The Transverse Myelitis Association. Our organization will serve Canadian members of the TMA who have transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, and optic neuritis, their family members, as well as the medical professionals who perform research on these disorders and provide clinical care to the people from our community.

When you sign up for membership in The Transverse Myelitis Association through the TMA web site, you will automatically become a member of the TMA and the Canadian TMA. The international TMA will continue to maintain the database of members.

I am in the process of submitting the application for our not-for-profit status. Through this application, the Canadian Transverse Myelitis Association will become a self supporting entity within The Transverse Myelitis Association. We will take over the responsibility for printing and mailing new member packets, the journals, newsletters and membership directories. While many of these documents can be distributed via email, there are some people who request hard copies sent via the postal service. Also, the membership directories are sent via the postal service to limit the ability to create an electronic document from these lists, thus helping to protect the privacy of our members. This means that the Canadian TMA will have significant printing and mailing costs. Sandy, and the other officers and board of the TMA, are requesting that contributions made by our members from Canada be made directly to the Canadian Transverse Myelitis Association to cover these costs. The Canadian TMA will be establishing programs in the future, such as a fellowship fund, to provide direct services

and benefit to Canadian members.

I would also like to ask for assistance from all of our support group leaders to organize fundraising in their city or province to benefit the Canadian Transverse Myelitis Association. If support group leaders need help in the form of ideas or getting started, please feel free to contact me. We also need for more people to get involved in serving as support group leaders. We would like to have at least one support group leader from each province and it would be great if we had more than one support group leader in each province. I ENCOURAGE anyone interested to contact me about getting involved.

The current support group leaders are:

Marieke Dufresne
82 Somerville Ave,
Westmount, Qc, H3Z 1J5
Canada
(514)489-0471
marieke@myelitis.org

It might seem like a challenge to become a support group leader. We are confident you can do this and it is very rewarding to help other sufferers who have these rare neuroimmunologic disorders of the central nervous system. I want to see the Canadian TMers coming together to support their association and to help make it a success to benefit us all! This is your association, Canadians, so feel free to get involved in anyway you can. Please send me your ideas and suggestions, and please let me know how we can better serve you in the future.

I can be contacted via email at kkotar@myelitis.org.

Donations may be sent to: the Canadian Transverse Myelitis Association, 263 Malcolm Circle, Dorval, Qc. H9S 1T6. We appreciate your support!

Living with severe disabilities in Ghana

Nana Yaa Agyeman

A lot of focus has been given to the disability movement in the last few years, which culminated in the passing of Ghana's Disability Law (Act 715) in 2006.

The popular refrain now is: Disability is not inability.

Mary, a 40 year old member of Sharecare Ghana, had TM eight years ago with the delivery of her second child. She was paralyzed after her first child and recovered, and no one traced the cause of the paralysis.

Since the birth of her second child, she has been paralyzed from the waist down and has lately been having problems with her eyesight. This tells those of us in the support group that she most likely has NMO, but the doctors are yet to give her a diagnosis.

Her husband deserted her, taking her older child along when the illness started. She now lives with her daughter in what we call in Ghana, a chamber and hall; in a house let out to many different families. But the landlord wants her to move out....

Mary has no care-giver and no income. She and her daughter rely on the benevolence of friends and church members. Her eight year old daughter makes their breakfast before going to school, and lunch has to wait for her return.

This is the situation - and it is not isolated - that Sharecare Ghana wants to change. The support group cheers Mary up with periodic visits and members make donations whenever they can. This is neither sustainable, nor is it right. A society that cares about the vulnerable must have a safety net for people when they are going through such challenges.

Although there is a state funded Department of Social Welfare in Ghana, there are no community workers giving home care to those who have to rely on others for their activities of daily living. A few private care agencies have sprung up, but if like Mary, you cannot pay for their services, then for you, they do not exist.

As a stop gap measure, Sharecare and the School of Social Work in Accra, Ghana's capital city, are beginning an internship program for students to give home care to members of the group with severe disabilities as part of their curriculum. The school is run by the Department of Social Welfare, but this project is seen as independent and is being financed through our fund raising efforts.

We look forward to a time when no matter the health situation or the disability, every citizen is made to feel like a useful member of the society. With the situation as it exists now, I keep saying that for some of us, disability is inability.

Nana Yaa Agyeman is The Transverse Myelitis Association support group leader in Ghana. She established and has been the director of Sharecare Ghana since shortly after she was diagnosed with neuromyelitis optica. Nana Yaa is such an exceptional human being. Rather than being focused exclusively on her own medical issues and challenges, she has become an advocate for people who have the rare neuroimmunologic disorders in Ghana. We had the honor and privilege of meeting Nana Yaa at our symposium in Seattle in 2008. If you would like to make a donation to support Nana Yaa's work in Ghana, you can make a donation to The Transverse Myelitis Association and designate your contribution for Sharecare

Ghana. Thank you for supporting this wonderful effort to help people who so desperately need your care.

INVITATIE ASOCIATIE DE PACIENTI

FORUMUL NATIONAL AL ASOCIATIILOR DE PACIENTI
5-7 martie 2010, Bucuresti
Motto: *„Nimic pentru noi, fara noi!”*

Dan Bucataru is our support group leader in Romania. We met Dan in 2004 when he attended the Rare Neuroimmunologic Disorder Symposium in Baltimore. Shortly after the symposium, Dan became involved in the Romanian support group and began his advocacy work for people with TM, ADEM and NMO. Dan was invited to the Romanian National Forum of the Association of Patients on 5-7 March 2010, in Bucharest.

The Forum is a collaborative effort of the Chronic Coalition Organizations in Romania, established by the Romanian General Assembly in 2009, and the College of Physicians in Romania. The Chronic Coalition Organizations is the only national organization that represents the associations and federations advocating for patients across Romania. The Forum will bring together over 400 members of the federations and associations of patients to have a dialogue for an exchange of experience between associates. The forum aims to inform authorities, healthcare professionals and the whole society on the work of patient groups and to emphasize the importance of such bodies which fight for promotion and protection of patients in the Romanian health system. The Forum will address issues and patients' involvement in projects and initiatives dedicated to health, but also in health policy at the national and regional level to support the College of Physicians in Romania.

It is hoped that through this event, the patients' associations will be more effectively recognized as an important part of the Romanian health system. Another important outcome of the meeting will be the publication of the first Patient Guide, a publication for the general public which will contain medical information and other important information for patients.

Dan will be representing The Transverse Myelitis Association at the Forum and will be advocating for our members in Romania. This is a great honor for Dan and a great opportunity for our community.

The South Carolina / Georgia Transverse Myelitis Online Support Group

We started off as the CSRA Transverse Myelitis Support Group in May 2008, serving only a section of South Carolina and Georgia known as the Central Savannah River Area. Soon after we were established, the TMA began sending us the names of folks from across both states wishing to join. So this year we changed our name to better reflect our two state region.

The goals of the SC/GA TM Support Group are to provide fellowship and support through the sharing of our common experiences, to provide educational information, and to open the doors of communication between patients and our local medical communities.

If you have TM, ADEM or NMO or are the caregiver or family member of a person with one of these disorders, and you live in the state of South Carolina or Georgia, you are invited to join our online group. We are members of the International Transverse Myelitis Association. In order to set up membership in our group, please send us the following information: full name, complete postal address, phone number, and email address. Please also let us know if you are the patient, caregiver or family member.

Are you currently a member of The Transverse Myelitis Association? If not, please fill out the membership form from the TMA web site. You will automatically be enrolled, there are no membership fees and the publications are sent to members without charge. If you request to have your contact information added to the TMA directory, you will also receive a copy of the membership directory. It is useful in finding other people with TM, ADEM and NMO in your area. Being listed in the directory and receiving the directory is optional; please indicate whether you would like to participate in the directory when you sign up for membership.

As soon as I receive your contact information, I will process your request to join our online support group.

You can find our main website at http://groups.yahoo.com/group/CSRATMSupportGroup

You can also search for us on Facebook as the South Carolina/Georgia Transverse Myelitis Online Support Group. We look forward to getting to know you.

Thank you,
Vicki McKie
http://mamamckie.wordpress.com/

ADEM, NMO, ON, Recurrent TM, TM or NMO with Lupus, Sarcoidosis, Sjogren's and HIV: Finding Each Other to Share Information and Support

We are trying to assist people who have the very rare neuroimmunologic disorders find each other for the purpose of sharing information and support. We are creating the lists identified below for that purpose. If you have one of these neuroimmunologic disorders and would like to be added to the list and then receive a copy of the list, please send us your information. We only share these lists with people who are willing to be added to the lists.

- Recurrent Transverse Myelitis
- TM or NMO with HIV
- Optic Neuritis

If you are interested in being added to one of these lists and then periodically receiving a copy of the list, you can send me your contact information either by email or through the postal service. Please send me your full name, complete postal address, phone number and email address (if you have one). Be sure you clearly identify to which list you would like to be added.

Sandy Siegel
1787 Sutter Parkway
Powell OH 43065-8806
ssiegel@myelitis.org

Acute Disseminated Encephalomyelitis (ADEM)

The ADEM list is being compiled by Barbara Kreisler. If you would like to be added to the list, please send your information to bkreisler.imprint@verizon.net. An ADEM Directory will be published and mailed to everyone who is on the ADEM list.

Neuromyelitis Optica (NMO) or Devics disease

The NMO list is being compiled by Grace Mitchell. If you would like to be added to the NMO list, please send your information to gmitchell@myelitis.org. An NMO Directory will be published and mailed to everyone who is on the NMO list.

TM or NMO and the Rheumatic Disorders (SLE or Lupus, Sjogren's syndrome, Sarcoidosis)

This list is being compiled by Sharon Robinson. If you would like to be added to this list, please send your information to Rufusandchi@yahoo.com. A directory will be published and mailed to everyone who is on the list.

The TMA Equipment Exchange

Please participate in the TMA Equipment Exchange on www.myelitis.org. You will see the link to the Equipment Exchange on the column of links on the main page of the TMA web site. I have been assisting the TMA Board in developing and offering this program to all individuals affected by TM, ADEM, NMO and ON and their families. The program is intended to assist our community in exchanging surplus equipment with each other for the cost of shipping only. If you are like our family, we have several pieces of equipment that have been outgrown by our son, Jason, who has had TM since ten months of age. We have donated some of his equipment in the past to other organizations, but we are glad to now have another option to share this equipment with others affected with the neuroimmunologic disorders and their families.

We encourage all of you to begin to list your equipment as soon as possible. The more equipment that is listed, the more individuals in our community will be helped. If you have any questions as you begin to use the program, please use the help link on the equipment exchange web site.

Thank you for your support,
Darian Vietzke

TMA Equipment Exchange Instruction Sheet

The TMA equipment exchange is explicitly for exchanging free equipment except for the cost of shipping only. How the cost of shipping is divided is agreed upon by the individual(s) donating the equipment and the receiver (s). Selling of an item is explicitly disallowed.

To list an item(s) to exchange, first follow the on-line instructions to register as a new user and then use the on-line instructions on the Member Area tab to list your item(s) to exchange. Note that several fields can be completed after an item is exchanged. This information is being requested in order to gather statistics to request grant funds to assist in covering shipping costs when exchanging items in the future.

If you are looking for a particular item, follow the on-line instructions to view current ads. Once the item is found, contact the donor (lister) using the on-line instructions to discuss specifics of the item, discuss how to exchange the item if it matches what you are looking for, and how the cost of shipping is to be managed.

Any item inappropriate for exchanging will be removed by the site administrator. To report any item that is inappropriate, please send an e-mail to exchange@myelitis.org

Items exchanged via this site are not tax deductible. Any questions regarding taxes should be directed to your

tax accountant.

If you have items you wish to sell and donate a percentage to the TMA, please click on the related link on the front page to use eBay Giving Works.

If you have any comments or questions regarding the TMA Equipment Exchange, please send an e-mail to exchange@myelitis.org. Thank you.

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ADEM Support Group
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Devic's Syndrome/NMO Support Group
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Devics-Support
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gmitchell@myelitis.org

Sandy Barry
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SistaMoon Foundation
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Awareness and Fundraising

The TMA Greeting Card Program

http://www.myelitis.org/cards/

We are thrilled to introduce The TMA Greeting Card Program. The cover of each of the cards is a beautiful water color painting of landscapes or flowers. The back of the cards include the TMA logo, our web address and a description of our Association. The inside of each card is blank and perfect for offering your own sentiments. We urge you to use these wonderful paintings as your regular cards for the holiday season, for thank you and everyday notes or for any purpose.

The proceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. As the neuroimmunologic disorders are rare and our membership is small, it is extremely difficult to raise funds for our cause. We work most diligently to focus our resources on the direct services to our members. By using these beautiful greeting cards, you will be supporting the important work of the TMA and also raising awareness about acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis.

About the Card Artwork

Sandy and Margaret Smith are members of The Transverse Myelitis Association from Pittenweem, Fife, Scotland. They are active members of the Scotland Support Group led by Margaret Shearer. Sandy has TM. Margaret is an artist. Margaret has created beautiful paintings of landscapes and flowers. She has donated this artwork to the TMA and we are very pleased to be able to offer you these beautiful greeting cards.

Honor the Children in Our Community and Support the TMA

The Transverse Myelitis Association held a Children's and Family Workshop in Columbus, Ohio in July, 2002. The TMA Workshop focused on children from infancy to their early twenties and included their brothers and sisters and their parents. For most of the parents and children, the workshop represented the first time they had met another child with TM. As TM is a rare disorder, these families often feel isolated in their experiences. The workshop was an incredible opportunity for these families to make connections with others who could offer them emotional support and encouragement.

The workshop offered the children an opportunity to have a fun weekend. One of the many activities they participated in during this special weekend involved working with an art therapist from Chicago, Lori Stralow Harris. With the help of Ms. Harris, the children created beautiful paintings which were constructed into a quilt of courage and hope. The original artwork currently hangs in the Johns Hopkins Transverse Myelitis Center where it is appreciated by the hundreds of patients every year who are cared for at the Center.

We are very pleased and proud to be able to offer you the children's artwork through Café Press. The pro-

ceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. We hope you will take the opportunity to enjoy the children's work and to support the TMA.

http://www.cafepress.com/tmagifts

Help Raise Awareness with a TMA Wristband

For the past 3 years, thousands of our members have been helping to raise awareness of the TMA by wearing bright blue wristbands. They have been available on the TMA website and at our symposia for purchase. The wristbands are available in a marbled blue/grey in the adult size and solid blue in the youth size. The youth size also fits women with small wrists. These wrist bands are made with 100% synthetic silicone rubber and debossed with the abbreviations "TM-ADEM-NMO-ON" and "www.myelitis.org."

Many families have purchased these wristbands as party favors for birthday celebrations, fundraisers for raising research dollars, and to just proudly wear every day. Several people have sent us photos of themselves displaying their wristbands at known landmarks around the world. All of the money raised through the sale of the wristbands goes towards the cost of printing and mailing out the information that you receive in newsletters like this one, and for mailing out new member packets for those newly diagnosed with TM, ON, ADEM, and NMO.

The wristbands are inexpensive – only $2.00 each – and you can either order them online at our website, making your purchase with a credit card transaction, or you can mail a check to The Transverse Myelitis Association and when we receive your payment, we mail them to you.

To order online, please go to our website at: www.myelitis.org/wristbands.htm.

For check payments, please mail your payment along with your order request to:

The Transverse Myelitis Association
Paula Lazzer, Treasurer
10105 167th PL NE
Redmond, WA 98052-3125

Specify "for TMA wrist bands"

Shipping charges:
1-5 - $1.00
6-10 - $1.50
11-25 - $5.00

For quantities more than the above, please send an email. If you would like us to calculate your shipping for you, you can send an email to wristbands@myelitis.org and we will tell you how much to send. You can also call Debbie Capen at (951)658-2689 to get your total cost and more information.

Don't miss out on getting your own one-of-a-kind TMA wristband!

Heart of Hope Bracelet Benefiting the TMA

Kathie Ketels-Lichtig is a jewelry artist who combines her jewelry business with charitable giving to benefit various organizations, including the ALS Association. Kathy lost her husband, Bill, to ALS in 2005. She met Cynthia Noonan who was a volunteer with the ALS Association. Cynthia got TM in November 2007. To learn more about Cynthia:
http://noonansupport.blogspot.com

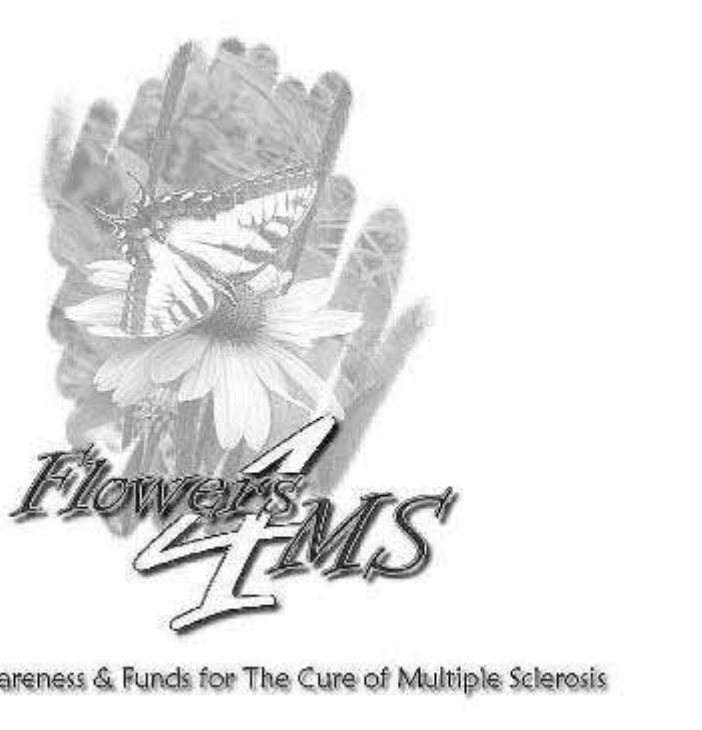
To honor Cynthia, Kathie created a special bracelet that could be sold to friends and family to help defray some of her medical expenses. True to her generous spirit, when Kathie offered her the bracelet and the proposal for help, Cynthia quickly responded, "I know people want to help and it is truly an honor to have someone create something to help with what you're going through. There are others who don't have as much as I do. So…I think we should be donating the proceeds to the TM Association."

The Heart of Hope bracelet benefiting The Transverse Myelitis Association is hand-crafted using beautiful 6mm Swarovski® crystals in shades of olive, amber, amethyst and persimmon. Each bracelet is finished with

sterling silver COURAGE and awareness ribbon charms. The fold-over, magnetic heart clasp assures a secure closure. While the magnet is not very powerful, please check with your physician if you are pregnant or have a pacemaker! The copyrighted design was inspired by Cynthia's love of fall colors and her courage and determination as she adjusts to life with TM. In Cynthia's honor, $25 of the purchase price of each piece will be donated to The Transverse Myelitis Association in your name and is tax deductible.

The bracelet can be ordered on the following website:
http://www.kathielichtigstudio.com/transvers-myelitis.html

Thank you, Kathie and Cynthia!



Flowers 4 MS

My name is Angela Sergio Cleary. I have Multiple Sclerosis and I would like to introduce you to a project I call Flowers4MS. I am originally from Italy, but I have been living in the United States for many years. I was diagnosed in October of 2006 at the age of 33 and I had my first relapse 3 days after I was told I had MS.

While learning more about the disease through the National MS Society website, I was able to find out about the work being done at Johns Hopkins to find a cure for the rare neurological diseases that affect so many of us.

After learning about the scientists that work at Johns Hopkins, like Dr. Peter Calabresi and Dr. Carlos Pardo, I was deeply touched by their commitment and compassion in dealing with these diseases. Learning about them and about their work, I felt inspired to help and to be a part of their world. While my disease has been very active, and is not quite under control, I have been able to do my best in raising funds to support their research.

I started by writing a letter to tell my story to family and friends in May of 2007. With the help of a special friend, in September 2007, I then created a project that I call Flowers4MS. In April 2008, I launched a website called ***www.Flowers4MS.com***, where I share my story and where I sell floral greeting cards. I donate 100% of the proceeds to support the scientists engaged with Project RESTORE research. Since its inception, and despite several MS relapses, I have raised over $17,000.

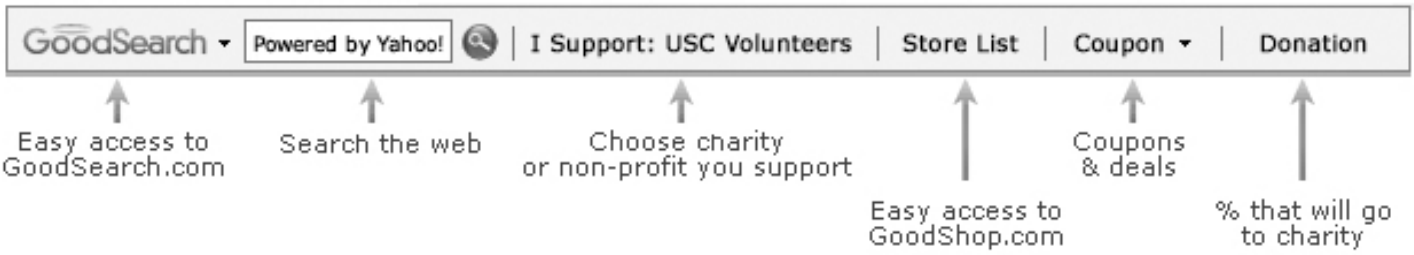
I view flowers as a symbol of hope, beauty and life and I feel they are the perfect representation of my dream, which is finding a cure for Multiple Sclerosis and for all the rare neurological diseases that are so similar to it. During my research I have been touched by the stories of those afflicted with Transverse Myelitis and I feel that if we can unite our efforts, we can really make some headway in finding cures and treatments for all of us.

I wanted to use something as beautiful and positive as flowers to overshadow the pain and suffering that these disorders can cause. Flowers bring joy and beauty in very simple, but wonderful ways and they speak to everyone's hearts through their beauty. For more information, please visit my site or email me at the address below.

You can also see my project on the Project RESTORE page of the Johns Hopkins website (***www.hopkinsneuro.org/restore/)*** and on the Johns Hopkins Multiple Sclerosis home page at ***www.hopkinsneuro.org/ms/.***

Thank you and take care,

Angela Cleary
angelusa73@aol.com
www.youtube/angelusa73



The Goodsearch Toolbar for the TMA

We have something new and exciting we'd like to share with you! It's the new Transverse Myelitis Association toolbar - once added to IE or Firefox, each time you shop at more than 1,300 stores (from Amazon to Zazzle!) a percentage of your purchase will automatically be donated to The Transverse Myelitis Association - at no cost to you (and you may even save money as the toolbar provides coupons and deals as well!). The toolbar also has a search box and each time you search the Internet, about a penny is donated to The Transverse Myelitis Association.

And please pass this along to all of your friends. The two minutes it takes to add this toolbar to your browser can make a lifetime of difference!

Get the toolbar NOW!

http://www.goodsearch.com/toolbar/transverse-myelitis-association

Helping to Fund the Work of Your TMA

The officers and board members of the TMA are volunteers; they receive no compensation of any kind for their work. There are no employees in the TMA. There are no offices; the officers work out of their homes. In order to facilitate access to support and information, the TMA does not charge membership fees. As TM, NMO, ADEM and ON are rare conditions and our membership is small, it is extremely difficult to raise funds for our cause. We work most diligently to focus our resources on the direct services to our members. We operate exclusively on the basis of the generous and voluntary support of our members. There are numerous ways for everyone to help support the TMA, even if you are not in a position to make a financial contribution. Please consider getting involved in one of our fundraising efforts.

Search the Internet and Raise Money for the TMA

You can raise money every time you search the web, at iSearchiGive.com. Make it your homepage and use it to find everything from news on the economy, to mood-lifting jokes (we recommend the latter). The Transverse Myelitis Association gets a penny (or more!) every time you search. Believe it or not, it adds up quickly and best of all, it costs you NOTHING!
> Start iGiving at:
www.iSearchiGive.com/TMA

Donate your cell phones

You can donate your cell phones to help raise funds for The Transverse Myelitis Association. Go to http://cellphones.myelitis.org

Online Shopping

There are numerous online shopping opportunities, as well as sales on eBay which can be made through the following link: http://www.myelitis.org/store.htm A percentage of the sales are donated to the TMA.

Save Gas. Save Time. Raise Money!

With over 700 stores in the iGive Mall and access to hundreds of exclusive coupons, free shipping deals, and sales, iGive is the smart way to shop. You'll find everything from daily necessities to special occasion and holiday gifts, at stores you know and love. So save a trip to the mall, and avoid the long lines. You'll never pay more when you reach a store through iGive, and up to 26% of each purchase benefits The Transverse Myelitis Association!
> Start iGiving at: **www.iGive.com/TMA**

Café Press Shop for items with The Transverse Myelitis Association logo to raise awareness and show your support!

http://www.cafepress.com/myelitis

Amazon.com You can shop at Amazon.com for Books, Music, DVDs, Videos, Toys and more.

http://www.myelitis.org/amazon

Music Downloads for any device!

Shop for your favorite song or album from our mp3 store powered by Amazon and download music that works with an ipod or any mp3 player.
http://www.myelitis.org/shopmp3

eBay

Now you can sell an item on eBay and donate from 10% to 100% of the final sale price to help support the TMA.
http://www.myelitis.org/ebay

Reading for Rachel

If you are a teacher, a student or a parent of a student and would like to establish the Reading for Rachel Program in your school, everything you will need to get the program started can be found on the Reading for Rachel web site:

http://www.readingforrachel.org.

All funds received by The Transverse Myelitis Association for the Reading for Rachel Program are used exclusively for research to better understand TM, to find treatments for the symptoms of TM, and to ultimately find a cure. If you are interested in starting the Reading for Rachel Program in your school, you can also contact Cathy Dorocak, Rachel's Mom and International Chair of the Reading for Rachel Program: cathy@readingforrachel.org (440)572-5574.

Donations by Check

We always welcome and are grateful for a donation to the TMA. You can download a donation form to include with your check from the link: www.myelitis.org/donationform.htm Please make a check or money order payable to The Transverse Myelitis Association and mail it to:

The Transverse Myelitis Association
Paula Lazzeri, Treasurer
10105 167th PL NE
Redmond, WA 98052-3125

Thank you!

Donating by credit, debit, or gift card

You can make secure donations online with Google Checkout using any credit, debit, or gift card with the following logos: Visa, MasterCard, American Express, and Discover.

Go to http://myelitis.org/donations.htm, enter the amount you want to donate; then click the blue Donate button. You will be taken to the Google Checkout page. We greatly appreciate your support!

Inkjet and Toner Recycling Program

The Transverse Myelitis Association has partnered with the Funding Factory Recycling Program to collect empty inkjet and toner cartridges. This is an important fund raising effort for the Association.
Please go to our web site at http://www.myelitis.org/recycle/. Once you register, you can order pre-paid UPS return labels that you put on any box you have. When you fill in the information, use your own name as the "Organization" name, but also, **PLEASE USE ID NUMBER 63960 AS THE BENEFICIARY.**

This ensures that the TMA will be receiving the benefits of the collected cartridges. When filling out the contact information, the form asks for a

"title". You can list "other" and put "supporter" for your title. Once the company has your information and you request shipping labels, they will ship them to you to place on the boxes. Once the boxes are filled, you can take them to any place that picks up UPS packages (such as "Mailboxes, ETC.").

We appreciate your participation in this important program!

The Transverse Myelitis Association Credit Card Program

Share your passion and donate to our cause with your everyday purchases. We've partnered with Capital One® Card Lab Connect to bring you our newest fundraising program, which helps us earn money effortlessly every day! Just carry one of our custom credit cards (it comes with a competitive rate), and 1% of purchases made with the card will be donated to The TMA. We'll also receive a $25 bonus donation when you make your first purchase. And not only will you be donating to our cause with each purchase you make, you'll be helping to spread the word when people see your unique card, which includes our name and logo, as well as Margaret Smith's artwork as backgrounds.

Apply online via a secure web page at **http://www.myelitis.org/creditcard**

We urge you to only make purchases with this credit card that you are able to pay off each month. We would love to receive the benefits from this program without your paying any interest on your purchases.

The Transverse Myelitis Association is an all-volunteer, non-profit organization. We greatly appreciate your support!

The TMA Membership Directory and Privacy on the Internet

The information we provide on our web site and in our publications to our membership is one of the most important functions of The Transverse Myelitis Association. When you share your information in an In Their Own Words Column, you change lives. I have no doubt about this, because I hear from people every day who are inspired and informed by these writings. The access our support group leaders provide to people in their communities is invaluable. To know that you are not going through this experience alone or to find support and information in your community is truly a blessing for people.

Sharing information in our publications and on our web site is a selfless, kind and generous act, and we are all grateful for your participation. It is also very important to understand and accept that once this information is posted on our web site, it is available to anyone who has a computer and internet access across the globe. This ubiquitous access is the incredible value and also the bane of the information technology age.

So, we want and need for you to be generous about sharing this information, but we also want for you to be informed and judicious about making these decisions to share information. If you do not want to be found in a web search or you do not want for your information to be identified in a web search, please do not write an article for the newsletter or journal and please do not volunteer to be a support group leader. In addition to the information in our publications, it is important to bear in mind that any postings you put on a message board or in a list-serve group can also be accessed through a web search. It is almost always the case that if you are wanting anonymity in your life, the less you put out there electronically, the better, and that includes email messages, because once you hit that send button, you have no control over what the person does with that information on the receiving end.

It is also critically important to bear in mind that The Transverse Myelitis Association does not put membership information on our web site or post it electronically anywhere. We publish the directory in paper copies and we mail these directories only to our members who are listed. We send

electronic copies of our member information to the people who do our mailings around the world, but they only receive the information for the people for whom they do the mailings. They do not receive the entire membership database. We expend a great deal of effort in protecting your information and limit to the extent possible, the electronic versions of this database.

If you want privacy, we do what we can to help you achieve that end. Please help us by making informed decisions in regards to what you submit for publication and what you post on the web site on our message boards and in the list serve groups. The TMA functions so effectively as a support network, because so many of you are willing to share and to help others. We urge you to continue to do so; we depend on your willingness to do so. But we don't want for you to participate in this sharing, if this activity is going to compromise any concerns you might have about privacy. Be smart and be realistic about how the internet works and what is private and what is public about the internet.

The TMA Newsletter and Journal Archives

The TMA announced a new publication schedule and format for our newsletters and journals. We will publish two newsletters and a more extensive journal each year. When people sign up for membership in the TMA, they receive a packet of information which contains the most recently published TMA Journal or Newsletter. We encourage people to read the previously published newsletters and journals. They are an excellent source of information about the neuroimmunologic disorders, both through articles written by medical professionals and by people with these disorders and their family members, which describe their personal experiences. Through these publications, you can also learn about research and clinical trials, the TMA, awareness and fundraising efforts, and the support groups around the country and around the world.

All of the newsletters and journals are archived on our web site; you can find them under the link 'newsletters' on the main page of our web site or you can type www.myelitis.org/newsletters/index.html into your web browser. You can view the newsletters and journals as they were published by selecting the PDF files from the column on the right, or you can view them in html format from the column on the left. The html files include an index which makes it very easy to find articles covering specific subjects. Additionally, Jim has installed a search engine for the entire TMA web site, which allows searching for specific subjects. Topics may be searched in the newsletters and journals by using the search engine.

If you have difficulty in finding information about any topic on our web site, and the search engine does not provide you with the results you were seeking, you should always feel free to contact Jim for assistance. You can send Jim a question or a request for help at jlubin@myelitis.org

Medical Advisory Board

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The Transverse Myelitis Association

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The 2010 Rare Neuroimmunologic Disorders Symposium
Friday, September 24 – Sunday, September 26, 2010
Hosted by The University of Texas Southwestern

Weekend Retreat for Older Teens and Young Adults
October 8-10, 2010
Victory Junction Gang Camp, North Carolina