

---

---

# The Transverse Myelitis Association Newsletter

---

Volume 8 Issue 2

Fall 2008

## **The James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders**

I first met Jim Lubin shortly after Pauline was diagnosed with Transverse Myelitis. I typed "transverse myelitis" into the Yahoo search engine and the link for Jim's disABILITY resources web site appeared on my screen. I followed the links to Jim's home page where Pauline and I learned about Jim's experience with Transverse Myelitis. I immediately began communicating with Jim. Pauline and I were so excited to meet another person with TM and we were thrilled to initiate a relationship with Jim. I have no idea when that day was; I don't even remember the year. But I have no doubt that if I asked Jim to send me those first email messages between us; he would have them sent to me within about ten minutes. In the grand order of things, it is so appropriate that our first meeting was on the internet. What Jim does with computers and technology is more than amazing.

At the time I met Jim, Paula and I were already working with Deanne to develop the TMA. We had absolutely no internet presence. Deanne, Paula and I were using email, but we didn't have the slightest idea how to construct a web site. Web sites and the internet were still in their infancy. After seeing Jim's disABILITY resources and his home page, I approached Jim about setting up a web site for the TMA. Jim and I were both AOL subscribers. AOL had just begun to offer members server space to create web pages. Jim established the first TMA web site on the AOL server. Jim immersed himself in developing

the content and format for our web site. Through Jim's creativity, energy, and tremendous skill, our web site has evolved into an incredible resource for our community and for medical professionals with an interest in the neuroimmunologic disorders.

After working with Jim on our web site and on numerous administrative matters for the Association, Jim became an officer and board member of the TMA. It would be impossible for me to chronicle all of the amazing contributions Jim has made to the TMA through his mastery of information technology, but I would like to share with you some examples of Jim's work. It is important to bear in mind that almost none of these efforts resulted from a request made of Jim by the other officers. Almost all of these incredibly brilliant and creative projects have developed from Jim's own interests and initiative and from his passion to help others.

Jim is responsible for collecting, organizing and presenting all of the content on our web site. We have gathered a tremendous amount of information over the years about the neuroimmunologic disorders. In addition to the medical information, if you are seeking information about social service programs or assistive technology or a myriad of other subjects, Jim has the information and links to an enormous number and variety of resources on our web site. Jim is constantly tinkering with the organization of the site to make it

easier for people to use and find information.

No one has done more than Jim to create a real sense of community among the TMA. Jim has established numerous ways for people to interact and to share information with each other. Jim has constructed all of the support group pages, he has set up and runs many different message boards and he created and maintains the transverse myelitis internet club, one of the longest running list-serves on the internet.

Jim automated our membership enrollment process on the internet. Through this automated process, Jim has been responsible for growing our membership from just under 200 members in 1997 to the more than 7,000 members we have today from more than 80 countries around the world. And Jim has played a primary role in the development of our international support groups.

One of the more interesting and critically important of Jim's initiatives has involved the translations of significant areas of our web site, as well as critical medical articles, into numerous languages. This effort has quite literally made the information on our site accessible to the largest number of people. Jim uses a volunteer web site to post requests for language translators. Each of the flags that you find on our web site denotes that a particular web page or article has been translated into that country's language. And with almost all of his work, Jim finds a way to accomplish these efforts without any cost. The translators do all of this work as volunteers. We have met the most wonderful people through Jim's translation program. Jim and I began

regular communications with our Italian translator and developed a personal relationship with Federica Boiani. Freddie lives in Rome. She was so moved by the TMA's work and our cause that she offered to initiate a support group in Italy. Not only does Freddie facilitate communications between our members in Italy, she also translates all of our new member packet materials into Italian and mails these materials to our new members. She is a remarkable human being that we found through Jim's efforts.

We wanted to find a way to create awareness of the neuroimmunologic disorders by placing our organization name and logo on items that we could sell. As the TMA does not have the resources to purchase items, and warehouse and ship them, we had to find a more creative way to accomplish this goal. Jim found and set up the TMA logo store on Café Press. Our members can purchase numerous items with the TMA logo, and for the international and state support groups who have designed their own logos, Jim has created stores for these items as well.

Jim has worked so hard to find easy and creative ways to raise funds for the Association. We recognize that many of our members struggle with financial issues; that is one of the reasons the TMA does not have membership dues. But Jim has found ways for everyone to participate in our fundraising efforts, regardless of their personal resources. From our inkjet recycling program to the cell phone recycling program, to the igive shopping mall, Jim has found so many different ways to fund the TMA's programs.

Jim is the TMA's IT Director and all of our IT staff! Jim is directly involved in the production process for the creation and dissemination of all of the TMA's publications. Jim has established and manages our numerous internet accounts and our email accounts. And Jim is constantly trouble-

shooting the many different and complicated computer issues that his technologically-challenged fellow officers create for him on a daily basis. Jim is our expert on all things technology. We don't purchase it or use it without first consulting Jim and obtaining his advice and guidance. And as with every request made of Jim, you ask for help at 11:00 AM, and you get your response at 11:15 AM. Jim is just totally amazing in all ways.

Through his work, Jim has helped to make a very grassroots organization with very limited resources look and behave like a very large, professional and well established association. If you learn about the TMA from our web site, one would not likely conclude that the international headquarters of the TMA is the Siegel family kitchen.

Jim does this work almost all day long and seven days a week. Jim is central to the TMA. Paula, Debbie and I consider Jim the heart and soul of the TMA.

Jim was so severely impacted by TM. Jim was just 21 years old when he had his attack. At the time, Jim was working for a company that manufactured high tech medical equipment that is used for cardiac catheterizations. Jim was at work when his attack began. In many ways, it is a miracle that Jim survived. His attack was not only quite severe, it occurred at the very top of his cord. Jim is full quadriplegic and ventilator dependent. In the more than 20 years since Jim's attack, he has not recovered any motor function. It was during his very long rehabilitation that Jim met an occupational therapist who introduced him to the sip and puff technology approach for using a computer. Jim learned the approach quickly and has become incredibly proficient at using it. Jim does all of this computer

work by sipping and puffing Morse code into an adaptive device. Jim can type about 17 words a minute. You don't get dissertations communicating with Jim, but you wouldn't get a dissertation from Jim if he typed 80 words a minute.

Jim came home from the hospital and his rehabilitation to an incredibly loving and supportive family. Jim's mom is Jim's primary caregiver. Jim receives the most outstanding care from Helena. She is one of the most remarkable people I have met in my life. Jim's brother, Joe, has been there for Jim in all ways through this entire experience. Jim is so blessed to have Helena and Joe. Jim's family is one of the primary reasons that for the past twenty years, while he cannot move a muscle below his neck or breathe on his own, he has incredibly good health.

Jim is not angry or bitter about his experiences. In fact, Jim is one of the most positive and hopeful people that I know. Jim loves so much about his life. Jim loves food. Jim loves to listen to music – all kinds of music. Jim loves movies. Jim has an interest in so many different things in the world around him, from world events to our space program and astronomy to his world of technology. Jim very rarely leaves his house and yet he communicates with far more people than I do. And Jim is communicating with people from across the globe. Jim has good friends from all over the world that he talks to on a daily basis. There is very little that is small or confined about the world Jim lives in.

It is impossible to know Jim and to understand what Jim has lived through for the past twenty years without reflecting on your own life, which I do often. What would I do if this happened to me? Would I be able to find a way to be so positive and hopeful? Would I find a way to continue to love life? Would I be able to find a way to have a meaningful life? Of course, I

have absolutely no idea. I have learned over the years that we don't know what we would really do in a particular situation until it actually happens to us. While I don't know what I would do, I sure hope that I would be able to find a way to emulate Jim.

Over the years, Pauline and I have become very close with Jim, Helena and Joe. We love them as members of our own family. I know that Paula and Debbie feel the same way. I have also come to know Jim very well. I have no doubt in my mind that Jim could have had a very entertaining and enjoyable life spent surrounded by his technology and doing all sorts of really geeky things all day long. There is no shortage of highly stimulating programming and software applications. There are millions of people who do spend a huge amount of their lives gaming; and now this gaming can be done over the internet. It would be very easy and very entertaining for Jim to be immersed in this entertainment. But that is not the direction Jim has taken in his journey. Jim's life is filled with helping people; all day long and in so many different ways. Jim not only fills his life working for the TMA; he also runs a support group for quadriplegics and a vent-dependent support network. And Jim is always building new web sites for other organizations. Jim's numerous accomplishments were recognized in 1999 when he was awarded the New Mobility Magazine's Person of the Year. Jim's contributions are internationally recognized.

Paula, Debbie and I regularly seek ways to recognize Jim's efforts and his impact on all of our lives. For instance, in our bylaws, the elections for the officers and board are scheduled on Jim's birthday. Blue is Jim's favorite color; it is no accident that our logo, our web site and our wristbands are blue. And we refer to this shade of blue as "Lubin blue".

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 is establishing 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.

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 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.

I am thrilled to announce that Sharon Robinson will be directing our efforts to create, develop and manage the James Timothy Lubin Fellowship Program. Sharon owns and operates an architectural firm in the Seattle area. Sharon is also our support network leader for people who have one of the rheumatic disorders as an underlying condition of one of the neuroimmunologic disorders. Sharon has Lupus and TM. We are grateful for Sharon's willingness to volunteer her time, energy and expertise to this critically important program.

We urge you to get involved in this fundraising effort. I know that over the years many people have been in-



spired 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 interesting in understanding TM, NMO, ADEM and ON.

Dr. Douglas Kerr announced the first specialization in TM in 1999. In 2006, Dr. Benjamin Greenberg joined the Johns Hopkins TM Center and became the second specialist in TM. That's two. Dr. Kerr and Dr. Greenberg are the most wonderful physicians and scientists but they would also be the first to acknowledge that there is a critical

need to grow the discipline. It is going to be our responsibility to make this happen. We have 7,000 members from around the world. It is going to be incumbent on each of us to participate in this program in some way.

If you would like additional information about the fellowship, please contact Sharon Robinson.  
[srobinson@myelitis.org](mailto:srobinson@myelitis.org)  
 (360)671-8415

The James Timothy Lubin Fellowship emanates from our admiration and respect for Jim and our gratitude for all he has accomplished for all of us. Thank you for inspiring the best from each of us, Jim. We love you.



### Victory Junction Gang Camp August 12 – 16, 2009

The Transverse Myelitis Family Camp will be held from Wednesday, August 12 to Sunday, August 16, 2009. The family camp is for children with TM, ADEM, ON and NMO, brothers and sisters and their parents. In an attempt to get as many families into camp as possible, please limit your attendance to your immediate family. Camp can accommodate 32 families. If we are willing to double up families in cabins, we might be able to accommodate more, but we will need your cooperation to make this happen, and there is a limit due to the number of people who can be accommodated in the Pit Stop (cafeteria and dance hall).

The following criteria will be used to determine acceptance into VJGC:

- Children with TM, ADEM or NMO must be between the ages of 6 and 16.
- All children must be socially competent, not exhibiting unwanted behaviors which warrant removal from a group activity or setting.
- All children must be able to communicate their needs, whether via speech, sign language, or a communication device.
- Children must have a cognitive level of 6 years or above and be able to function within a group (not require 1:1 behavioral attention).

All applications are subject to medical

© The Transverse Myelitis Association Journal and Newsletter are published by The Transverse Myelitis Association, Seattle, Washington and Powell, Ohio. Copyright 2008 by The Transverse Myelitis Association. All rights reserved. No part of this publication may be reproduced in any form or by any electronic or mechanical means without permission in writing from the publisher. We ask that other publications contact us for permission to reprint any article from The Transverse Myelitis Association Journal and Newsletter.

and behavioral review. Victory Junction also reserves the right to make selections/decisions based on other factors deemed appropriate.

The camp facilities and the recreation program are totally accessible. The directors, staff and volunteers at camp are among the most caring, loving, kind people you will encounter in your lives. If you have never been to camp, you will be transformed. If you are returning to camp, you will be transformed ... again! The camp experience is free – your meals, lodging, recreation. The only cost is your travel expenses. If you are not able to afford the travel expense, please get in touch with Sandy Siegel as quickly as possible; we don't want the cost to be the reason that you are unable to attend camp.

Dr. Peter Sim is the Medical Director of Victory Junction Gang Camp. The camp has an exceptional medical facility and there are full time and volunteer nurses working with Dr. Sim. Any specific medical issues or concerns that you have should be directed to Dr. Sim. Your children will be very well taken care of at camp; you will not find a safer or more nurturing environment. Dr. Sim is a wonderful doctor and an exceptional human being. You can reach Dr. Sim at (336)495-2015 or [psim@victoryjunction.org](mailto:psim@victoryjunction.org).

In addition to the awesome facilities and activities, members of our medical advisory board will be attending camp with their families. They will present an educational program, and you will have access to the doctors during the entire week to ask questions and to discuss any issues you might have about your children. Dr. Douglas Kerr, Dr. Adam Kaplin, and Dr. Benjamin Greenberg will definitely be attending the camp.

The camp will begin accepting applications for TM Family Camp on December 15<sup>th</sup> 2008. The deadline for

applications is March 15<sup>th</sup> 2009. Please have your application completed in its entirety and sent to camp as close after December 15<sup>th</sup> as possible. Please do not procrastinate; we don't want you to lose out on this incredible experience, and we are likely to reach our limit.

It is important that you understand the role of the TMA in the TM Family Camp. We will work hard to recruit families for the camp and to get as many people to camp as we can. We will serve as volunteers at VJGC for our week. We will be wildly waving our pom poms around at every opportunity. Victory Junction Gang Camp manages the entire application process, the camp facilities and program, the travel logistics, and everything else involved in this incredible camp experience. If you have specific questions, please get in touch with VJGC. Our camp recruiting coordinator is Chris Foster. Chris can be reached at: (336)495-2019 or [chris.foster@victoryjunction.org](mailto:chris.foster@victoryjunction.org).

If you are going to be flying into camp, please do not make your plane reservations until you have been formally accepted to camp. If you are traveling from outside of the country, please begin the process to obtain your travel VISAs immediately. Please get in touch with Chris Foster if you need a letter from VJGC in the VISA application process.

Victory Junction Gang Camp is near Greensboro, North Carolina. The closest airport to fly into is Greensboro Piedmont Triad Airport (GSO).

### **2009 Summer Application Instructions**

#### **Important Dates to remember:**

December 15, 2008 – Begin Accepting Summer Applications

March 15, 2009 – Summer Application Deadline

April 15, 2009 – Begin Sending Summer Acceptance Notification in order of our sessions

#### **Step 1: Getting the Application**

Apply online at [www.victoryjunction.org](http://www.victoryjunction.org). Click on the "How to Apply" tab for the link; Download paper application from the website: [www.victoryjunction.org](http://www.victoryjunction.org)

Request a paper application by email, phone or mail

#### **Step 2: Completing the Application** **SUMMER APPLICATION**

Camper Application (to be completed by the parent/guardian)  
Camper Medical Form (to be completed by healthcare provider)  
Immunization Records

#### **FAMILY WEEKEND APPLICATION**

Family Weekend Application (to be completed by the parent/guardian)  
Family Medical Information (one form for each family member coming to camp)  
Immunization Records (for anyone under 18 coming to camp)

Applications will **NOT** be reviewed by the Medical Team until all of these items have been received.

Because our week is a family camp, you need to fill out both the summer camper application and the family weekend application.

#### **Step 3: Sending It**

Via fax: 336-495-2045 or 336-495-2050

Via mail: Camper Admissions, Victory Junction Gang Camp, 4500 Adam's Way, Randleman, NC 27317

Via e-mail to [chris.foster@victoryjunction.org](mailto:chris.foster@victoryjunction.org)

#### **Step 4: Processing**

You will receive a postcard informing you that your complete application has

been received or if any further documentation is required. If your child is not eligible based on our criteria, you will receive a letter from a member of our Selection Criteria Team.

### Step 5: Acceptance

Acceptance notifications to be sent out starting on April 15<sup>th</sup>.

### APPLICATION DEADLINE

All summer applications, medical forms and immunization records must be completed and postmarked by March 15, 2009.

For additional information or questions, please contact a camper recruiter at [info@victoryjunction.org](mailto:info@victoryjunction.org) or 877.VJG.CAMP (877.854.2267) ext 2002/2017/2019.

### 2008 Retreat Weekend at Victory Junction Gang Camp

Paula Lazzeri

In October 2008 the TMA held their 2<sup>nd</sup> Young Adult Retreat Weekend at Victory Junction Gang Camp in North Carolina. Approximately 25 people attended who have TM, ADEM and NMO and ranging in age from 16 through their mid twenties. There were family members who also attended and they came from across the United States to participate. Some of the activities included bowling, fishing, archery, boating, horseback riding, arts and crafts, video games, and VJGC's wonderful stage night in the theater. We enjoyed some spectacular acts from singing to Halloween jokes to "Kazu, the Amazing Service Dog." For some of the campers, it was their 2<sup>nd</sup> camp experience. For many, it was their first experience at camp and the first opportunity they've had to meet someone else with their disorder. All of these people began lifelong friendships during this very special weekend.

Dr. Doug Kerr and Dr. Adam Kaplin

from the TMA Medical Advisory Board were on hand for the entire weekend to educate, answer many questions, and to have fun right along side the campers. According to Dr. Kerr, "The retreat weekend, like the two camps we did before, was amazing. VJGC provides a wonderful opportunity for individuals with TM and their families to have fun, to get to know others who have gone through similar experiences, to feel part of a caring community and to learn from us, the health care practitioners who are trying to understand TM. But it also invigorates me to be part of such a special community and to realize how important it is for us to keep working to develop better therapies in the future." Dr. Adam Kaplin adds, "These experiences, that involve the coalescing of people personally affected by TM and MS, their caregivers and care providers, are like none other.... All of the ingredients are present to create a moment that seems frozen in time that is at once unforgettable, caring and transformative.... And the lesson that there can be no rainbow without rain is as beautiful a way of characterizing the magic that is VJGC."

Thank you to Victory Junction Gang Camp, their awesome staff and incredible volunteers, Dr. Doug Kerr, Dr. Adam Kaplin, TMA officers, and the campers and families for another memorable time!

### Help Wanted: Keeping 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. The TMA uses a bulk postage rate for our mailings which results in considerable cost savings. Unfortunately,

with this method of mailing, we are not notified when an envelope is not delivered due to a bad address without incurring additional costs.

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 Germany, Italy, 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](mailto: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](mailto: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.

Reprinted with permission from *Neurology*, 2008;70:344-352. *Neurology* is a copyrighted publication of Lippincott Williams & Wilkins (LWW).

## Neuromyelitis optica-IgG in childhood inflammatory demyelinating CNS disorders

B. Banwell, MD,  
FRCPC\*  
S. Tenembaum, MD\*  
V.A. Lennon, MD,  
PhD  
E. Ursell  
J. Kennedy  
A. Bar-Or, MD  
B.G. Weinshenker,  
MD  
C.F. Lucchinetti, MD  
S.J. Pittock, MB, MD

Address correspondence and reprint requests to Dr. Sean Pittock, Department of Neurology and Laboratory Medicine and Pathology, Mayo Clinic College of Medicine, Rochester, MN 55905  
Pittock.Sean@mayo.edu

### ABSTRACT

**Objective:** To determine seroprevalence of neuromyelitis optica (NMO)-IgG in childhood CNS inflammatory demyelinating disorders.

**Methods:** We analyzed demographic, clinical, and radiologic data in a blinded fashion and assessed serum NMO-IgG status for 87 children: 41 with relapsing-remitting multiple sclerosis (RRMS), 17 with NMO, 13 with monophasic/recurrent optic neuritis (ON), 13 with transverse myelitis, of whom 10 were longitudinally extensive on MRI spine (LETM), and another 3 with LETM in the context of acute disseminated encephalomyelitis (ADEM).

**Results:** Ten of the 87 children (11%) were seropositive. Eight of 17 with NMO (47%) were seropositive (7 of 9 with relapsing NMO [78%], 1 of 8 with monophasic NMO [12.5%]). Two other children were seropositive: 1 of 5 with recurrent ON and one child with recurrent LETM. No seropositive case was identified among 41 with RRMS (14% of whom had LETM at some point in their clinical course), 8 with monophasic ON, 9 with monophasic LETM, or 3 with LETM in the context of ADEM.

**Conclusions:** The similar frequency of neuromyelitis optica (NMO)-IgG in both childhood and adult cases of NMO, and its rarity in relapsing-remitting multiple sclerosis, supports the concept that these diseases have a similar pathogenesis in childhood and adulthood. It is noteworthy that none of nine children with monophasic longitudinally extensive transverse myelitis (LETM) was NMO-IgG-seropositive. Furthermore, LETM does not appear to be as predictive of an NMO spectrum disorder in children as it is in adults. Longitudinal studies of larger pediatric LETM cohorts are required to ascertain whether the absence of NMO-IgG is a negative predictor for relapse in this childhood entity. *Neurology*® 2008;70:344-352

### GLOSSARY

**ADEM** = acute disseminated encephalomyelitis; **EDSS** = Expanded Disability Status Scale; **LETM** = longitudinally extensive transverse myelitis; **NMO** = neuromyelitis optica; **ON** = optic neuritis; **RRMS** = relapsing-remitting multiple sclerosis; **TM** = transverse myelitis.

The defining characteristic of neuromyelitis optica (NMO) is the combination of monophasic or recurrent episodes of optic neuritis and longitudinally extensive transverse myelitis (LETM), either monophasic or recurrent.<sup>1</sup> In adult patients, NMO is traditionally distinguished from multiple sclerosis (MS) by the selective involvement of optic nerves and spinal cord, a longitudinally extensive spinal cord

Editorial, page 334

e-Pub ahead of print on December 19, 2007, at [www.neurology.org](http://www.neurology.org).

\*Both authors contributed equally to the study.

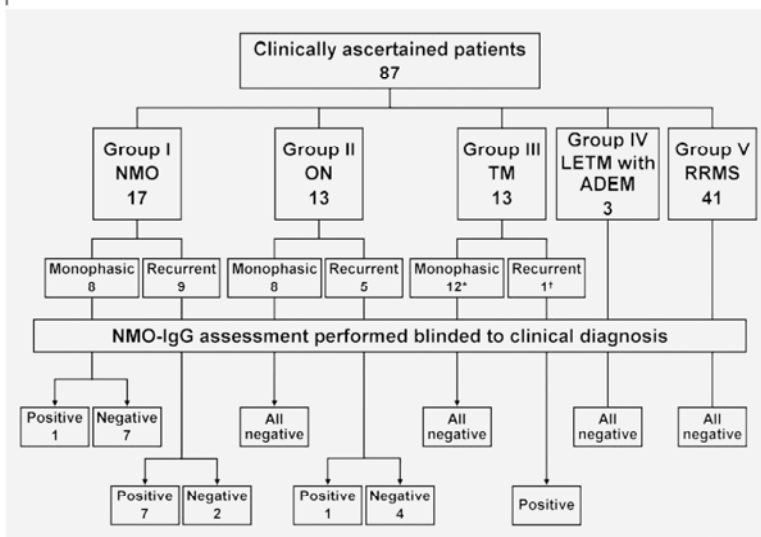
From the Division of Pediatric Neurology and the Research Institute (B.B., E.U., J.K.), The Hospital for Sick Children, University of Toronto, Canada; Department of Pediatric Neurology (S.T.), Hospital de Pediatria Dr. J.P. Garrahan, Buenos Aires, Argentina; Departments of Neurology (V.A.L., B.G.W., C.F.L., S.J.P.), Laboratory Medicine and Pathology (V.A.L., S.J.P.), and Immunology (V.A.L.), Mayo Clinic College of Medicine, Rochester, MN; and The Montreal Neurological Institute and McGill University (A.B.-O.), Montreal, Canada.

Supported in part by the Mayo Foundation, the Ralph Wilson Medical Research Foundation, The Wadsworth Foundation, and the Canadian Multiple Sclerosis Scientific Research Foundation, and the Don Paty Career Development Award from the Multiple Sclerosis Society of Canada (A. B.-O.).

**Disclosure:** The authors disclose that, in accordance with the Bayh-Dole Act of 1980 and Mayo Foundation policy, Drs. Lennon, Lucchinetti, and Weinshenker stand to receive royalties for the discovery related to AQP4 autoantigen. This intellectual property is licensed to a commercial entity for development of a simple antigen-specific assay to be made available worldwide for patient care. The test will not be exclusive to Mayo Clinic. To date the authors have received a total of <\$10,000 in royalties. Mayo Clinic offers the test as an indirect immunofluorescence assay to aid the diagnosis of NMO, but the authors do not benefit personally from the performance of the test. Dr. Weinshenker has received consulting fees from Genentech.



Figure 1 Study design for recruitment of patient groups I-V



NMO = neuromyelitis optica; RRMS = relapsing-remitting multiple sclerosis; ON = optic neuritis; TM = transverse myelitis; LETM = longitudinally extensive transverse myelitis; ADEM = acute disseminated encephalomyelitis. \*Nine of 12 patients with monophasic TM had LETM on MRI spine (one did not have neuroimaging, one had MS-like lesions, and one had a normal scan). \*Single child with recurrent LETM.

lesion, a higher relapse rate, a shorter interval between relapses, and poor recovery with early paraparesis or blindness.<sup>1</sup> The aquaporin-4-specific (AQP4) water channel autoantibody, NMO-IgG, is detected in 73% of adults with NMO and is 92% specific for NMO or a partial form of that disorder.<sup>2,3</sup> These disorders include recurrent optic neuritis (25% seropositive for NMO-IgG) or longitudinally extensive myelitis (60% of patients with active relapsing LETM seropositive, and 38% seropositivity at the first episode of LETM in patients at high risk for relapse or development of optic neuritis). Thus, in adults NMO-IgG defines a spectrum of inflammatory disorders involving the spinal cord and optic nerves that may share a common autoimmune pathogenesis.<sup>2,4</sup> Immunopathologic studies reveal loss of AQP4 immunoreactivity in CNS regions that exhibit vasocentric deposition of immunoglobulins and products of complement activation. These findings support a pathogenic role for a complement-activating, AQP4-specific autoantibody as the initiator of the NMO lesion.<sup>5,6</sup>

Published reports of NMO in children are rare. Sporadic cases of NMO-IgG sero-

positive pediatric NMO cases have been encountered,<sup>7</sup> but the frequency of this serum autoantibody in NMO and other inflammatory CNS disorders in children is unknown. The limited literature suggests that NMO may be a milder disease<sup>8</sup> in children. Thus, data from adult disease might not extend to the pediatric population. The particular challenge of distinguishing NMO in children, on clinical grounds, from isolated TM, optic neuritis, acute disseminated encephalomyelitis (ADEM), or relapsing-remitting multiple sclerosis (RRMS) prompted us to review the clinical and radiologic characteristics and NMO-IgG status in a large group of children with acquired inflammatory demyelinating disorders of the CNS.

**METHODS Patients.** Children with a diagnosis of acquired inflammatory demyelination of the CNS (onset before age 18 years) were enrolled from the Pediatric Demyelinating Disease Programs at two clinical sites (Hospital for Sick Children, Toronto, Canada, and the Hospital de Pediatria Dr. J.P. Garrahan, Buenos Aires, Argentina). Forty-seven children (54%) were enrolled from Canada and 40 children (46%) were enrolled from Argentina (figure 1). Demographic and clinical features are described in tables 1 and 2. Group I included all patients with clinical NMO from both sites. Patients with optic neuritis (Group II), TM (Group III), ADEM with LETM (Group IV), and RRMS (Group V) were selected on the basis of serum being available for testing.

Group I consisted of 17 children meeting 1999 diagnostic criteria for NMO.<sup>1</sup> Relapsing NMO was defined as recurrent episodes of optic neuritis, TM, or both occurring after sentinel episodes of optic neuritis and TM.

Group II consisted of 13 children with optic neuritis (monophasic 8, recurrent 5) defined by acute or subacute vision loss in association with one or more of the following: relative afferent pupillary defect in the affected eye in unilateral cases, visual field deficit or scotoma, impaired color vision, optic disc edema, or abnormal visual evoked potentials in the absence of clinical evidence of spinal cord disease.<sup>9</sup>

Group III consisted of 12 children with a single episode of TM, plus a single case that fulfilled published criteria for recurrent LETM.<sup>10</sup>

Group IV consisted of 3 children with LETM in the context of a clinical diagnosis of ADEM (encephalopathy with multifocal neurologic deficits) and MRI evidence of multifocal demyelination.<sup>11,12</sup>

Group V consisted of 41 children meeting diagnostic criteria for RRMS,<sup>13,14</sup> of whom 27 had relapses involving optic nerves or spinal cord.

Data acquired prospectively from each institution included age, sex, ethnicity, country of patient's and parents' birth, immigration history, country of residence, medications, number of demyelinating events, clinical characteristics of each relapse, most recent functional status (defined by



	Group I: NMO	Group II: ON	Group III: TM*	Group IV: LETM + ADEM	Group V: RRMS
No. of patients	17	13	13	3	41
F:M	3.2:1	1.2:1	2.3:1	3:0	1.6:1
Disease course					
Monophasic <sup>†</sup>	8	8	12	3	—
Relapsing	9	5	1	—	41
Country of birth (% per group)					
Albania	—	—	8	—	—
Argentina	81	23	31	100	38
Canada	19	62	62	—	46
Other	—	16	—	—	16
Ethnicity (% per group)					
White	69	54	84	67	57
Asian	—	8	8	—	10
Black	6	8	—	—	2
Hispanic	—	8	—	—	—
Mestizo	—	8	—	—	2
Middle Eastern	—	8	—	—	5
Native Canadian	—	—	—	—	2
Native Argentinean	25	8	8	33	15
Native Bolivian	—	—	—	—	2
Mixed	—	—	—	—	5
NMO-IgG-positive, n (%)					
Monophasic	1 (12.5)	—	—	—	—
Relapsing	7 (78)	1 (20)	1 (100)	—	—
CSF-oligoclonal bands, n (%)					
Positive	—	—	1 (8)	—	21 (51)
Negative	13 (76)	6 (46)	4 (31)	3 (100)	11 (27)
Not done/not available	4 (24)	7 (54)	8 (61)	—	9 (22)
Age at first clinical attack, y, median (range)	10.4 (4.4-15.2)	11.1 (4.4-17.8)	11.6 (0.5-14.9)	2.9 (0.7-8.2)	10.8 (1.9-17.2)
Age at serum sampling, y, median (range)	13.9 (6.4-17.3)	12.6 (7.4-17.9)	12.3 (1.6-16.0)	3.0 (0.7-8.2)	14.4 (2.2-19.2)
Medication at serum sampling, n (%)					
None	6 (35)	7 (54)	10 (77)	2 (67)	15 (38)
Disease-modifying agent <sup>‡</sup>	2 (12)	—	—	—	23 (56)
Steroids	7 (41)	6 (46)	3 (23)	1 (33)	1 (2)
Cyclophosphamide	2 (12)	—	—	—	—
IVIg	—	—	—	—	1 (2)
Other	—	—	—	—	1 (2)
Disease duration at last visit, y, median (range)	3.0 (0.1-10.5)	1.0 (0.4-6.4)	1.8 (0.2-3.7)	0.4 (0.2-0.4)	4.3 (0.2-11.1)
EDSS at last visit, median (range)	2.5 (0-8)	1.0 (0-4.5)	2.0 (0-9.5)	1 (0-9.5)	1.0 (0-8.5)
Mobility, n (%)					
Normal	15 (88)	13 (100)	8 (61)	2 (67)	33 (80)
Limitation but cane/aids not required	1 (6)	—	1 (8)	—	6 (15)
Wheelchair-intermittently walks short distance	—	—	—	—	1 (2)
Wheelchair-dependent	1 (6)	—	4 (31)	1 (33)	1 (2)
Vision, n (%)					
Normal	5 (29)	9 (69)	11 (85)	2 (67)	31 (76)
Decreased-no limitation in daily activities	8 (47)	3 (23)	—	—	7 (17)
Severe impairment (requires visual aids)	4 (24)	1 (8)	—	—	2 (5)
No functional vision	—	—	—	1 (33)	—
No information	—	—	2 (15)	—	1 (2)

\*Ten patients had LETM on MRI spine, one did not have neuroimaging, one had MS-like lesions, and one had a normal scan.

<sup>†</sup>Monophasic refers to the absence of recurrent ON or TM following the initial defining ON and TM events. It is possible that children currently categorized as monophasic will experience relapses in the future.

<sup>‡</sup>Disease-modifying agents include interferon- $\beta$  or glatiramer acetate.

NMO = neuromyelitis optica; ON = optic neuritis; TM = transverse myelitis; LETM = longitudinally extensive transverse myelitis; ADEM = acute disseminated encephalomyelitis; RRMS = relapsing-remitting multiple sclerosis; EDSS = Expanded Disability Status Scale.

	Monophasic	Relapsing	p Value
No. of patients	8	9	
F:M	5:3	7:2	0.490
Median onset age, y (range)	11.2 (4.4-14.5)	10.4 (6.3-15.2)	0.923
Median follow-up duration, y (range)	1.1(0.1-7.3)	4.95 (1.8-10.5)	0.016
NMO-IgG positive, n (%)	1 (12.5)	7 (78)	0.007
Median EDSS (range) at last follow-up	1.5 (0-4)	4 (0-8)	0.044*

\*Not significant after adjustment for disease duration.  
EDSS = Expanded Disability Status Scale.

questionnaire), and Expanded Disability Status Scale (EDSS)<sup>15</sup> assessed at most recent clinical examination. NMO-IgG status for each participant was determined without knowledge of the clinical diagnosis.

**Neuroimaging.** All available brain and spine MRI scans were reviewed blinded to NMO-IgG status. One or more brain scans were available for 86 of the 87 children (99%) and were obtained at a median of 1.0 month from clinical onset (range 0 to 90 months). Lesions were scored from T2-weighted MRIs for number, location (periventricular, juxtacortical brainstem, cerebellar, corpus callosal, or hypothalamic), size, and configuration. Number and location of enhancing lesions were recorded from postcontrast T1-weighted MRIs. Those with MS-like lesions were scored as satisfying or not satisfying diagnostic criteria for MS lesion dissemination in space.<sup>14</sup>

Spinal cord scans were available for 17 children with NMO (100%), 31 children with RRMS (76%), 12 children with TM (92%), and 3 children with LETM plus ADEM (100%). Only 5 children with isolated optic neuritis had spine MRI scans. Spinal cord imaging was typically performed within 1 month of onset of symptoms (median of 1.2 months, range 0 to 88.8 months). For spinal cord MRI scans, the number of lesions, lesion enhancement, and the maximal spinal segment length of each lesion were recorded. Single or

	Group I: NMO	Group II: ON	Group III: TM	Group IV: ADEM+LETM	Group V: RRMS
No. of Patients	17	12*	13	3	41
Lesions found†	9 (53)	5 (42)	6 (46)§	3 (100)	41(100)
Met McDonald criteria†	1 (6)	—	—	1 (33)¶	41 (100)
Medulla/brainstem	6 (38)	1 (8)	5 (38)	—	27 (64)
Hypothalamic	1 (6)	1 (8)	1 (7.7)	0 (0)	2 (5)
Corpus callosum¶	1 (6)	—	—	—	22 (52)

Values are n (%).

\*MR images unavailable for one child with isolated recurrent ON and for one child with TM. Outside reports indicated lack of white matter lesions.

†Lesions consistent with demyelination.

‡Lesions meeting three of the four criteria proposed by McDonald et al.<sup>14</sup> were considered positive for dissemination in space.

§Transient in one patient.

¶Details in text.

¶Intracallosal lesions only. Lesions abutting, but not encompassing, the corpus callosum were excluded.

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

multiple lesions that were small (less than three vertebral segments in length) or encompassed only a portion of the cord diameter were deemed “MS-like.” Lesions spanning three vertebral segments or more were classified as LETM. Lesion distribution in the brain and spinal cord MRIs are described in tables 3 and 4.

**Serologic testing.** Serum samples from the 87 children were analyzed for NMO-IgG blinded to clinical diagnosis in the Mayo Clinic Neuroimmunology Laboratory both by quantitative indirect immunofluorescence on a substrate of mouse cerebellum and midbrain<sup>2</sup> and by immunoprecipitation using GFP-AQP4 solubilized from stably transfected HEK 293 cells as antigen and protein G agarose as immunoprecipitant.<sup>3</sup> Immunofluorescence results were scored as positive or negative by two experienced readers; sera from 30 healthy control children (median age 5.0 years, range 2 to 17 years) also were tested and scored in blinded fashion (figure 2).

**CSF analyses.** Testing for oligoclonal IgG bands was performed in local laboratories at the time of acute presentation.

**Statistical analyses.** We compared the frequency of NMO-IgG in all groups and assessed demographic and clinical features of seropositive and seronegative patients within each diagnostic category.  $\chi^2$ , Fisher exact test, or *t* test analyses ( $\alpha = 0.05$ ) were used as appropriate.

The study was approved by the Institutional Review Boards of the Mayo Clinic, Rochester, MN; the Hospital for Sick Children, Toronto, Canada; and the Hospital de Pediatría Dr. J.P. Garrahan, Buenos Aires, Argentina.

**RESULTS** Table 1 shows demographic and clinical characteristics and NMO-IgG status for the five study groups. Figures 1 and 2 show NMO-IgG status and titers.

**Group I (NMO).** All patients fulfilled NMO diagnostic criteria.<sup>1,16</sup> Eight of 17 children (47%) were NMO-IgG positive (figure 1). Relapsing NMO was diagnosed in 9 children (annualized relapse rate 1.27, range 0.2 to 2.7). Seropositivity was more prevalent in children with relapsing NMO (7 of 9, 78%) than in children with monophasic NMO (1 of 8, 12.5%,  $p = 0.01$ ). Median NMO-IgG titers (3,840, range 960 to 61,440) were higher in children with relapsing NMO than in the single NMO-IgG seropositive child with monophasic NMO (titer 960, figure 2). Table 2 compares the clinical and demographic characteristics of relapsing and monophasic NMO. The follow-up period for children with monophasic NMO was significantly shorter than for children with relapsing NMO (median 1.1 vs 4.95 years,  $p = 0.016$ ). EDSS at last follow-up was not significantly different in monophasic, compared with relapsing, patients when adjusted for duration of follow-up. NMO-IgG status had no significant effect on EDSS.

	Group I: NMO	Group II: ON	Group III: TM	Group IV: ADEM+LETM	Group V: RRMS
No. of patients*	17	5	12	3	32
Lesions found*	17 (100)	0 (0)	11 (92)	3 (100)	22 (69)
MS-like	0 (0)	0 (0)	1 (8)	0	19 (86) <sup>†</sup>
LETM	17 (100)	0 (0)	10 (83)	3 (100)	3 (14) <sup>‡</sup>

Values are n (%).

\*Scans not performed or unavailable for 10 patients with RRMS, 8 patients with ON, and 1 patient with TM.

<sup>†</sup>Consistent with demyelination.

<sup>‡</sup>Percent of patients in whom lesions were found.

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

All but 3 of the 17 patients with NMO were enrolled from the Pediatric Demyelinating Disease Program in Buenos Aires. The paucity of clinical NMO in the Toronto group is representative of the Canadian experience (B. Banwell, unpublished observations) in which only 6 of 185 children (3.2%) enrolled to date in a prospective national incidence study presented with NMO compared to 20 children with NMO among 235 (8.5%) with CNS demyelination enrolled to date in the Argentina program.

Seropositive and seronegative patients with NMO did not differ significantly with respect to sex or ethnicity. Oligoclonal bands were not detected in any of the 12 children for whom CSF results were available. Seven of the eight seropositive children were receiving immunosuppressant therapy at the time of serum acquisition (four prednisone, one glatiramer acetate, and two monthly IV cyclophosphamide pulse therapy, table 1). Four of the nine seronegative patients (seven monophasic, two relapsing) were receiving immunosuppressant therapy at the time of serum acquisition (three prednisone and one interferon-β 1a for relapsing NMO).

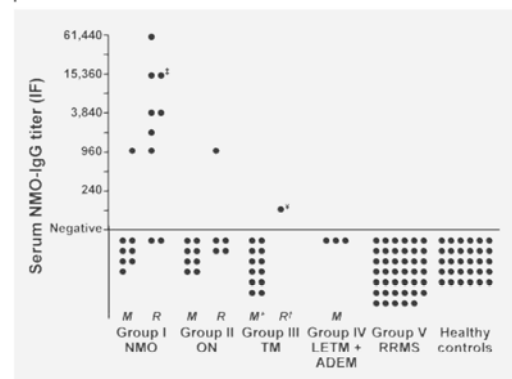
Nine patients (53%) had MRI brain abnormalities (table 3). Six patients (three seropositive) had T2 signal abnormality extending from the cervical cord into the lower brainstem (figure 3A); one seropositive patient had a lesion in the hypothalamus and one seronegative patient had a lesion in the corpus callosum. MRI lesions in only one patient (NMO-IgG seropositive) met criteria for classification as MS.<sup>14,16</sup> Clinically, this boy's relapses were restricted to optic neuritis (multiple episodes) and LETM (one episode); a single clinical relapse involving the brain was accompanied by a cerebral white matter lesion (figure 4A). Sequential brain MR images in this child met criteria for lesion dissemination in space<sup>14</sup> (more than

three lesions in the periventricular area, one juxtacortical and one infratentorial) but the multiple ovoid lesions typical of MS were never observed. Spinal MRI demonstrated LETM (figure 4B) and, over time, numerous lesions classifiable as MS-like (not shown). Fatigue has resolved and no relapses have occurred in the past 12 months following monthly IV cyclophosphamide pulse therapy.

After a median follow-up of 36 months (range 1.2 to 126 months), 6.3% of children with NMO were wheelchair-bound and 25% had severe visual impairment requiring visual aids (table 1).

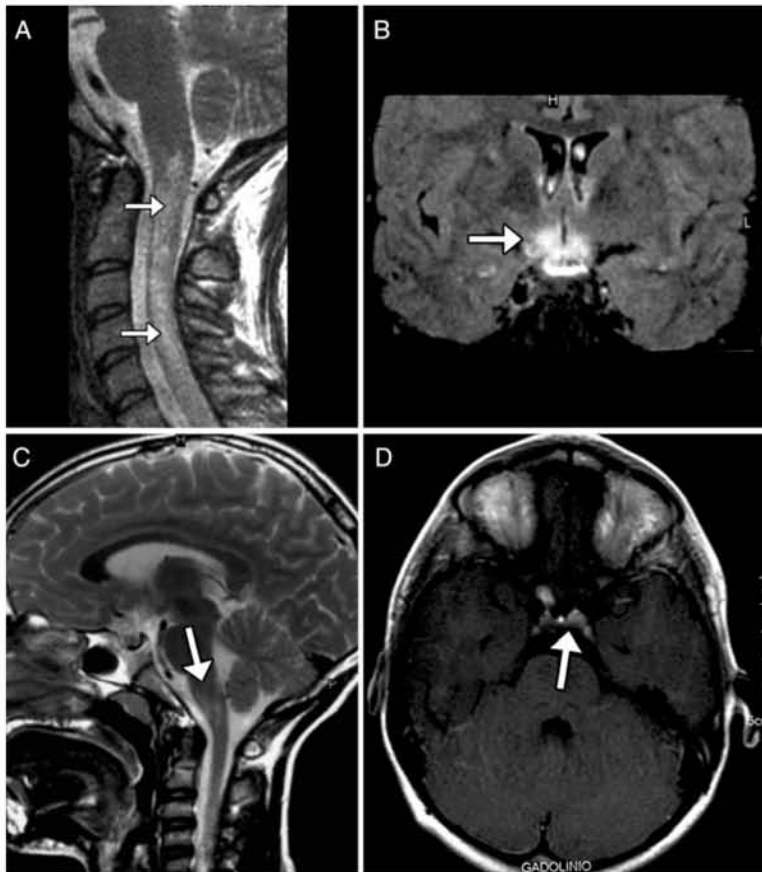
**Group II (optic neuritis).** Among five children with relapsing optic neuritis (annualized relapse rate 1.19, range 0.2 to 2.8), a single boy was seropositive. He presented at age 14 years with unilateral optic neuritis and experienced seven relapses. Two attacks were accompanied by nausea and intractable vomiting. Spinal cord involvement was not evident clinically or radiographically, but lesions were noted in the medulla (consistent with nausea and vomiting) and hypothalamus in a pattern reported previously in children with NMO<sup>7</sup>

**Figure 2** Distribution of neuromyelitis optica (NMO)-IgG titers (reciprocal of last dilution positive by indirect immunofluorescence [IF] in doubling dilutions) tested by IF assay in serum samples of patients from groups I-V and 30 healthy control patients



Values below the horizontal line are negative. †Detected only by immunoprecipitation; no healthy control was positive by either assay. RRMS = relapsing-remitting multiple sclerosis; ON = optic neuritis; TM = transverse myelitis; LETM = longitudinally extensive transverse myelitis; ADEM = acute disseminated encephalomyelitis; M = monophasic; R = relapsing or recurrent. Each black dot represents a patient. \*Nine of 12 patients with monophasic TM had LETM on MRI spine (one did not have neuroimaging, one had MS-like lesions, and one had a normal scan), †single child with recurrent LETM, ‡single NMO-IgG positive patient with recurrent ON and LETM who fulfilled 2006 Wingerchuk criteria for NMO<sup>17</sup> but had brain MRI fulfilling Barkhof criteria for MS.<sup>14</sup>

**Figure 3** MRI spine and brain abnormalities in patients seropositive for neuromyelitis optica (NMO)-IgG



(A) Sagittal T2-weighted cervical spine image in a 15-year-old girl with NMO (second relapse of myelitis) demonstrates a contiguous hyperintense lesion extending from the lower medulla oblongata to C7 (arrows). (B) Coronal fluid attenuated inverse recovery weighted image in a 14-year-old boy with optic neuritis (third episode complicated by refractory vomiting) demonstrates high signal in the hypothalamic region extending to the optic chiasm (arrow). (C) Sagittal T2-weighted brain-cervical spine image in the same boy (B) demonstrates a hyperintense lesion involving the anterior and dorsomedial medulla (arrow). (D) Axial T1-weighted image with orbital views in a 9-year-old girl with monophasic NMO demonstrates gadolinium enhancement of the right optic nerve and chiasm (arrow).

(figure 3, B and C). The boy was relapse-free during 12 months of IV pulse therapy with cyclophosphamide. Of the four seronegative children with relapsing optic neuritis, two had normal brain imaging and two had multiple white matter lesions not meeting criteria for a diagnosis of MS (table 3). Longer term clinical and radiographic observation of these children is required to determine whether they will ultimately fulfill diagnostic criteria for MS or NMO. None of the eight children with monophasic optic neuritis were seropositive. MRI revealed a few transient white matter lesions in two children and no abnormality in five; MRI information was not available for one child.

At last follow-up, the seropositive boy with recurrent optic neuritis had severe visual impair-

ment requiring visual aids. The 12 seronegative patients had either normal vision ( $n = 9$ ) or impaired vision without limitation of daily activities ( $n = 3$ ).

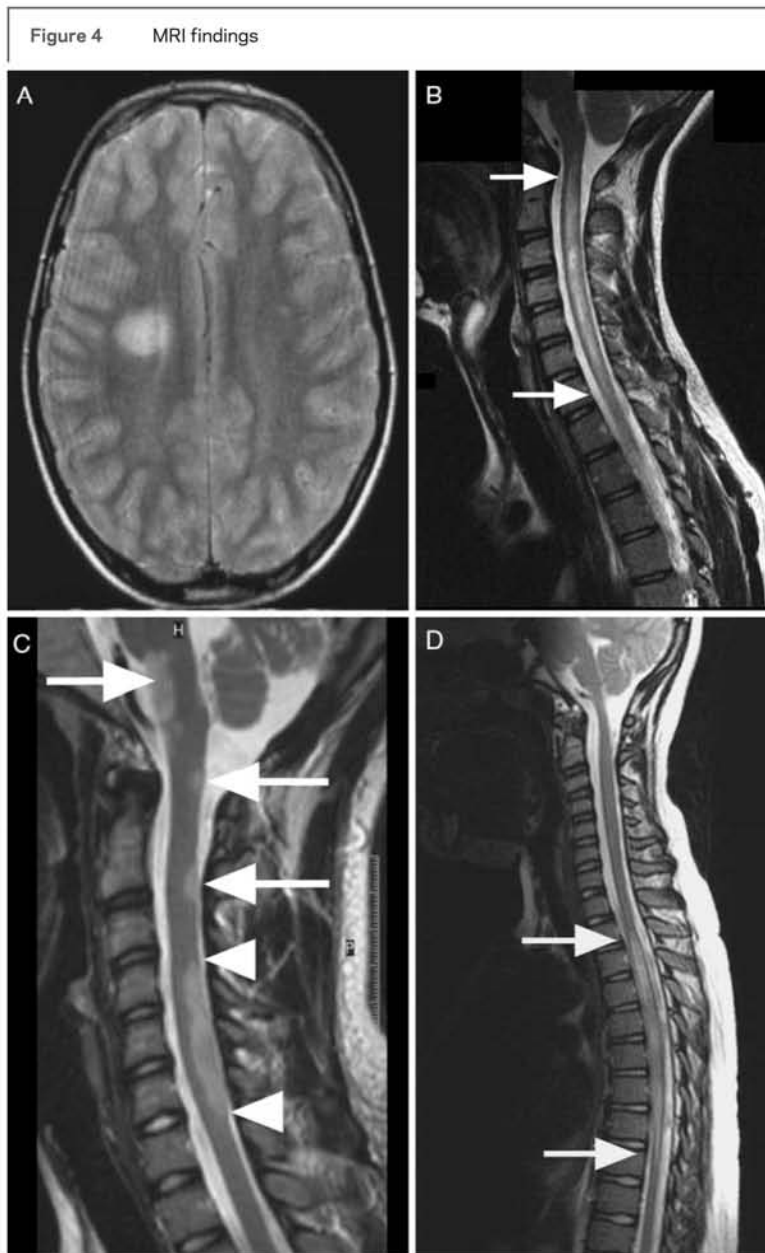
**Group III (TM).** The single child with recurrent LETM was seropositive. All 12 children with monophasic TM were seronegative; 9 had LETM on spinal imaging (figure 1) and 6 had clinically silent brain lesions; 5 had brainstem lesions contiguous with cervical spine lesions, and 1 child had transient multifocal supratentorial white matter lesions (table 3). At last follow-up, a median 21.1 months after onset (range 2.4 to 44.4 months), 30.8% of these children were wheelchair-dependent.

**Group IV (LETM with ADEM).** None of these three children were seropositive for NMO-IgG. All three had symptomatic brain MRI lesions (table 3). The brain lesions in one child fulfilled diagnostic criteria for dissemination in space at presentation and hemorrhagic demyelination was evident in both thalami. Initial lesions resolved completely in two children; the third child had large residual lesions. No new demyelinating lesions were detected on subsequent imaging in any child.

**Group V (RRMS).** None of these 41 children were seropositive for NMO-IgG (annualized relapse rate 1.14, range 0.1 to 4.3). Of the 31 children for whom spine MRI scans were available for review, 22 (71%) were abnormal. MS-like lesions were identified in 86%. The patient in figure 4C had MS-like lesions in brainstem and spinal cord and, additionally, had a long cord lesion measuring nearly three vertebral segments but involving only a portion of the cord diameter. Lesions extending greater than three vertebral segments were identified in 14% of the RRMS group (table 4, figure 4D).

Only 2.4% of the children were wheelchair-bound and 5% had severe visual impairment (table 1) after median follow-up period of 51.6 months (range 2.4 to 133.2 months).

**DISCUSSION** NMO-IgG was detected in 11% of children with acquired CNS demyelinating disorders. The clinical diagnosis in 100% of seropositive children was NMO, recurrent optic neuritis, or recurrent LETM, which in adult patients are considered collectively as NMO spectrum disorders.<sup>2-4</sup> The 78% seropositivity rate for children with relapsing NMO approaches that of 86% reported for North American adult patients.<sup>2</sup> Similarly, the low seropositivity rate in children with



(A) Axial T2-weighted brain image showing lesion in right cerebral hemisphere of a neuromyelitis optica (NMO)-IgG seropositive boy with NMO (recurrent optic neuritis and longitudinally extensive transverse myelitis [LETM]) who had a single cerebral attack and whose brain MRI fulfilled criteria for multiple sclerosis (MS). (B) Sagittal T2-weighted cervical spine image in the same boy (A) demonstrates a longitudinally extensive lesion in the cervical spinal cord extending seven vertebral segments (arrows). (C) Sagittal T2-weighted cervical spine image in a child with relapsing-remitting MS (RRMS). The top three lesions (brainstem [1] and spinal cord [2]) appear typical of MS (arrows). The lower lesion (arrowheads) is three vertebral segments. (D) Sagittal T2-weighted cervical spine image in a child with RRMS showing a longitudinally extensive (seven vertebral segments) thoracic cord lesion. LETM was identified in 1.4% of children with RRMS.

monophasic NMO (12.5%) was equal to that encountered in adults with monophasic NMO (only one of the eight adult North American patients reported in 2004 with monophasic NMO<sup>2</sup> was NMO-IgG positive). The data we report for pedi-

atric patients support NMO-IgG as a sensitive marker only for relapsing NMO.

The differences in NMO seropositivity between relapsing and monophasic NMO observed in both the adult and pediatric population suggest that the biologic determinant of relapse may be different from the factor initiating the first attack. A confounder in this study is the shorter duration of follow-up observed in children with monophasic NMO compared with children with relapsing NMO. A longer duration of follow-up will be required to determine whether some children with monophasic NMO convert to a relapsing course.

The immunopathology of monophasic and relapsing NMO appear to be the same.<sup>17</sup> If NMO-IgG is pathogenic, it is plausible to suggest that there is a threshold effect with monophasic patients having levels of antibody that are lower or undetectable (by current assays) compared with patients with a relapsing course. It is notable that the single seropositive patient with monophasic disease in this study had a lower serum titer than any of the patients with relapsing disease.

In a prospectively ascertained cohort of 45 adult North American patients with NMO, 82% had documented relapses and 18% were considered monophasic.<sup>2</sup> In the present pediatric study, relapses were documented in only 50% of the children with NMO. The limited duration of follow-up for these pediatric patients with NMO precluded determining whether a lower proportion of children have relapsing NMO compared with adults. In adult patients, relapsing NMO portends a very poor clinical outcome: within 5 years of disease onset 50% are paraplegic and 30% are dead.<sup>1</sup> Of the 17 pediatric cases of NMO in this report, 16 patients were ambulatory without need for assistance after a median disease duration of 3 years. Thus, the short-term impact of NMO may be more favorable in children than in adults. Whether this is due to a reduced tendency for repeated optic neuritis or TM episodes remains to be determined. Larger NMO pediatric populations must be studied to evaluate this clinically relevant issue.

The MRI brain abnormalities that were observed in children with NMO are similar to those previously described in both pediatric and adult patients.<sup>7,18,19</sup> As in adult patients, 53% of children with NMO had MRI evidence of brain lesions.<sup>7</sup> Brainstem lesions were most common, with a majority characterized by signal abnormalities extending from the medulla to the cervical spinal cord. Diencephalic (hypothalamic) and corpus callosal lesions also were identified.<sup>7,18,19</sup> A



single pediatric patient with NMO had multiple brain lesions that were somewhat atypical for MS but fulfilled MRI diagnostic criteria for lesion dissemination in MS. In adult patients with NMO, 10% have MS-like lesions that in some fulfill diagnostic criteria for MS.<sup>7</sup> These cases illustrate the clinical and radiologic difficulties inherent in classifying some patients with inflammatory CNS diseases into different diagnostic and presumably pathogenic groups. Continued histologic study of brain lesions in patients with NMO should clarify whether these lesions are immunopathologically typical of NMO or MS.

The 20% frequency of NMO-IgG seropositivity in children with recurrent optic neuritis was similar to the 25% frequency reported for adult patients.<sup>2</sup> NMO-IgG was not detected in any child with a single episode of optic neuritis. NMO-IgG is similarly rare in adult patients with monophasic optic neuritis (S.J. Pittock and V.A. Lennon, unpublished observations).

The single child with relapsing LETM was seropositive for NMO-IgG. NMO-IgG seroprevalence in adults with relapsing LETM is 60%.<sup>2</sup> The rarity of recurrent LETM in children will delay ascertainment of the true frequency of NMO-IgG seropositivity in pediatric relapsing LETM. No child with monophasic LETM, with or without ADEM, was seropositive. A longer period of observation will be required to determine whether NMO-IgG seronegativity is predictive of a monophasic course of LETM in children, as it is in adults.<sup>4</sup> In a recent study, no seronegative adult patient with LETM relapsed or developed optic neuritis during 1 year of follow-up as opposed to a 56% relapse rate in the seropositive group.<sup>4</sup>

The single most useful diagnostic feature associated with NMO or NMO-spectrum disorders in adult patients which aids distinction from MS is the neuroimaging finding of a longitudinally extensive spinal cord lesion.<sup>16,20</sup> MRI cord lesions in adult MS are characteristically well-circumscribed foci of increased T2-weighted signal that involve the parenchyma asymmetrically and span only a short distance longitudinally.<sup>21</sup> The majority of children with RRMS had spinal lesions like those of adult MS. However, 14% had longitudinally extensive spinal cord lesions, exceedingly rare in adult North American patients with MS and an important observation that distinguishes the MRI appearance of MS in children from that in adults.<sup>22</sup> Thus, a longitudinally extensive spinal cord lesion does not exclude the diagnosis of MS in a child and LETM is less predictive for a NMO-spectrum disorder than in

adult patients.<sup>16</sup> Detailed MRI review of spinal cord images in large cohorts of children with MS, isolated TM, and NMO is required to determine the relative frequency of longitudinally extensive lesions in each of these pediatric entities.

#### ACKNOWLEDGMENT

Members of the Wadsworth Pediatric Multiple Sclerosis Study Group include Lauren Krupp, SUNY, Stony Brook, NY; Silvia Tenenbaum, Hospital de Pediatria Dr. J.P. Garrahan, Buenos Aires, Argentina; Anita Belman, SUNY, Stony Brook, NY; Alexei Boiko and Olga Bykova, Russian State Medical University, Moscow, Russia; Jayne Ness, Children's Hospital of Alabama, Birmingham; Jean Mah and Cristina Stoian, University of Calgary, Canada; Marcelo Kremenchutzky, London Health Sciences, Canada; Mary Rensel, Cleveland Clinic Foundation, OH; Jin Hahn, Stanford University, CA; Bianca Weinstock-Guttman and Ann Yeh, SUNY, Buffalo, NY; Kevin Farrell, University British Columbia, Vancouver, Canada; Mark Freedman, University of Ottawa, Canada; Emmanuelle Waubant, UCSF, San Francisco, CA; Martino Ruggieri, University of Catania, Italy; Matti Iivanainen, University of Helsinki, Finland; Virender Bhan, Dalhousie University, Halifax, Canada; Marie-Emmanuelle Dilenge, Montreal Children's Hospital, Canada.

Received April 4, 2007. Accepted in final form May 22, 2007.

#### REFERENCES

1. Wingerchuk DM, Hogancamp WF, O'Brien PC, et al. The clinical course of neuromyelitis optica (Devic's syndrome). *Neurology* 1999;53:1107-1114.
2. Lennon VA, Wingerchuk DM, Kryzer TJ, et al. A serum autoantibody marker of neuromyelitis optica: distinction from multiple sclerosis. *Lancet* 2004;364:2106-2112.
3. Lennon VA, Kryzer TJ, Pittock SJ, et al. IgG marker of optic-spinal multiple sclerosis binds to the aquaporin-4 water channel. *J Exp Med* 2005;202:473-477.
4. Weinshenker BG, Wingerchuk DM, Vukusic S, et al. Neuromyelitis optica IgG predicts relapse after longitudinally extensive transverse myelitis. *Ann Neurol* 2006;59:566-569.
5. Roemer SF, Parisi JE, Lennon VA, et al. Pattern-specific loss of aquaporin-4 immunoreactivity distinguishes neuromyelitis optica from multiple sclerosis. *Brain* 2007 Feb 4 (Epub ahead of print).
6. Misu T, Fujihara K, Nakamura M, et al. Loss of aquaporin-4 in active perivascular lesions in neuromyelitis optica: a case report. *Tohoku J Exp Med* 2006;59:566-569.
7. Pittock SJ, Lennon VA, Krecke K, et al. Brain abnormalities in neuromyelitis optica. *Arch Neurol* 2006;63:390-396.
8. Jeffery AR, Buncic JR. Pediatric Devic's neuromyelitis optica. *J Pediatr Ophthalmol Strabismus* 1996;33:223-229.
9. Lucchinetti CF, Kiers L, O'Duffy A, et al. Risk factors for developing multiple sclerosis after childhood optic neuritis. *Neurology* 1997;49:1413-1418.
10. Transverse Myelitis Consortium Working Group. Proposed diagnostic criteria and nosology of acute transverse myelitis. *Neurology* 2002;59:499-505.
11. International Pediatric MS Study Group. Consensus definitions of acquired CNS demyelinating disorders of childhood. *Neurology* 2006;66 (suppl 2):A380. Abstract.
12. Krupp L, Banwell B, Tanenbaum S. Consensus definitions proposed for pediatric multiple sclerosis and related childhood disorders. *Neurology* 2007 (in press).

13. Poser CM, Paty DW, Scheinberg L, et al. New diagnostic criteria for multiple sclerosis: guidelines for research protocols. *Ann Neurol* 1983;13:227-231.
14. McDonald WI, Compston A, Edan G, et al. Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the diagnosis of multiple sclerosis. *Ann Neurol* 2001;50:121-127.
15. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology* 1983;33:1444-1452.
16. Wingerchuk DM, Lennon VA, Pittock SJ, et al. Revised diagnostic criteria for neuromyelitis optica. *Neurology* 2006;66:1485-1489.
17. Lucchinetti CF, Mandler RN, McGavern D, et al. A role for humoral mechanisms in the pathogenesis of Devic's neuromyelitis optica. *Brain* 2002;125:1450-1461.
18. Poppe AY, Lapierre Y, Melancon D, et al. Neuromyelitis optica with hypothalamic involvement. *Mult Scler* 2005;11:617-621.
19. Pittock SJ, Weinshenker BG, Lucchinetti CF, et al. Neuromyelitis optica brain lesions localized at sites of high aquaporin 4 expression. *Arch Neurol* 2006;63:964-968.
20. Wingerchuk DM, Weinshenker BG. Neuromyelitis optica: clinical predictors of a relapsing course and survival. *Neurology* 2003;60:848-853.
21. Thielen KR, Miller GM. Multiple sclerosis of the spinal cord: magnetic resonance appearance. *J Comput Assist Tomogr* 1996;10:434-438.
22. Hahn CD, Shroff MM, Blaser SI, Banwell BL. MRI criteria for multiple sclerosis: Evaluation in a pediatric cohort. *Neurology* 2004;62:806-808.

### 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. The newsletters are not included in the new membership packets.

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](http://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](mailto:jlubin@myelitis.org)

### We've made our website talk! ReadSpeaker Added to [www.myelitis.org](http://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 im-

portant 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 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.



Reprinted with permission from *Neurology*, *Neurology*, 2008;70:334-335. *Neurology* is a copyrighted publication of Lippincott Williams & Wilkins (LWW).

## EDITORIAL

## Finding NMO

### Neuromyelitis optica in children

Michael Levy, MD,  
PhD  
Julius Birnbaum, MD  
Douglas Kerr, MD,  
PhD

Address correspondence and reprint requests to Dr. Douglas Kerr, Broadway Research Building, Room 759, 733 North Broadway, Baltimore, MD 21205  
dkerr@jhmi.edu

*Neurology*® 2008;70:334-335

Since the discovery in 2004 of NMO-IgG, the autoantibody associated with neuromyelitis optica (NMO),<sup>1</sup> neurologists are increasingly relying on the NMO-IgG test to rule in or rule out NMO. Related disorders like optic neuritis (ON), transverse myelitis (TM), acute disseminated encephalomyelitis (ADEM), and longitudinally extensive TM (LETM;  $\geq 3$  spinal cord vertebral segments) can all be monophasic or multiphasic, can occur together or individually, and can occur in adults or children. Similarly, multiple sclerosis (MS) is often confused with these disorders, especially early in the disease. But little is known about the prevalence of NMO-IgG in children presenting with these disorders. In the current issue of *Neurology*<sup>®</sup>, Dr. Banwell at the Hospital for Sick Children in Toronto, Canada, along with colleagues in Argentina and Montreal, and Dr. Pittock and colleagues at the Mayo Clinic in Rochester, Minnesota, aim to determine the seroprevalence of NMO-IgG in children with NMO and related disorders.<sup>2</sup>

This is the first published characterization of NMO-IgG seroprevalence in children and includes 87 patients with NMO, TM, ON, ADEM + TM, and MS from two centers, Toronto and Buenos Aires. Diagnoses were based on well-established clinical and radiologic criteria, and clinicians were blinded to the NMO-IgG status for the purpose of this study. The results show that 8 out of 17 children with NMO were seropositive for NMO-IgG, largely in those with recurrent disease (7 out of 9). In children with TM, NMO-IgG status absolutely correlated with recurrence in that 12 out of 12 with first episode TM were seronegative and 1 out of 1 with recurrent TM was seropositive. Out of 5 patients with relapsing optic neuritis, only one was NMO-IgG positive. TM in the context of ADEM and MS is not associated with NMO-IgG seropositivity. The authors conclude, therefore, that the prevalence of NMO-IgG seropositivity in NMO, re-

lapsing ON and TM, and the prevalence of NMO-seronegativity in MS, are similar to those in adults.

So, where are we then in understanding the nosology of NMO and its cousins, and in understanding the role of NMO-IgG in diagnosis and in pathogenesis? In adults, the most recently revised 2007 diagnostic criteria for NMO,<sup>3</sup> as well as prior suggested criteria,<sup>4,5</sup> have emphasized that the myelitis component of NMO has important distinguishing clinical and radiographic features from MS and that these features may reflect unique mechanisms of disease. The myelitis of NMO is defined by a longitudinal inflammation spanning more than three vertebral segments.<sup>6</sup> Such a pattern of myelitis is likely to be associated with loss of antigravity strength and sphincteric deficits at attack peak severity. In comparison, the myelitis seen in relapsing-remitting MS exhibits sharply marginated, perivenular, T-cell-mediated demyelination with much less severe clinical manifestations. The NMO-IgG test is specific in that a very small percentage of patients with MS or idiopathic TM demonstrate NMO-IgG seropositivity while a substantial percentage of patients with NMO or recurrent LETM do.

Recently, the NMO-IgG autoantibody test has been incorporated into the updated 2006 diagnostic criteria for NMO.<sup>3</sup> The target of the NMO-IgG autoantibody is the aquaporin-4 (Aqp4) water-pump channel<sup>7</sup> localized on the abluminal side of blood vessels and astrocytic foot processes.<sup>8</sup> The spinal cord pathology in NMO features hyalinized small vessels, intense perivascular neutrophilic and eosinophilic infiltration, and deposition of immunoglobulin and neocomplement C9.<sup>9</sup> These changes suggest that there is humorally mediated microangiopathy leading to cylindrical spinal cord necrosis and cavitation.<sup>10</sup> Appreciation that the myelitis of NMO may be initially characterized by a transient inflammatory phase has led to suggestions that early use of

See page 344

From the Department of Neurology (M.L., D.K.) and Division of Rheumatology (J.B.), Johns Hopkins Hospital, Baltimore, MD.  
*Disclosure:* The authors report no conflicts of interest.

B-cell targeted or depleting treatments, such as rituximab,<sup>11</sup> may prevent the grim prognostic features of wheelchair dependence, blindness, or premature death associated in more than 50% of adult patients within 10 years.<sup>12</sup>

Significant advances have been made in understanding both the clinical and basic science of NMO. We have gone beyond the questions of whether NMO is distinct from MS or from idiopathic TM: it is. We have gone beyond the question as to whether NMO spectrum disorders, like LETM and ON, can behave like NMO in terms of recurrence: they do. And whether the NMO-IgG is a specific marker for NMO and for disorders that behave and have pathologic similarities to NMO: it is. These are important steps forward.

There is still a lot we do not know. The role of NMO-IgG in the pathogenesis of NMO has yet to be worked out. We do not yet know whether NMO-IgG is simply a valuable biomarker for a primary autoimmune disease underlying the NMO spectrum disorders, or whether the autoantibody causes the damage that defines it. Further, this study emphasizes that 100% of children who tested positive for NMO-IgG had recurrent disease of some variety along the NMO spectrum and the authors suggest that the NMO antibody may play a role in the pathogenesis of recurrence. We do not know if NMO-IgG is positive in these children at their first attack. If so, NMO-IgG defines a group of patients who are likely to have recurrent disease and therefore might benefit from immunomodulatory therapy to prevent subsequent disability. Some data exist to suggest that the NMO-IgG test may distinguish monophasic from recurrent patients at first attack<sup>13</sup> but we need more data both in adults and in children in this area. It remains possible that the children with recurrent disease in this study became NMO-IgG positive only after they have had several attacks as a result of recurrent “immunization.” In this scenario, repeated inflammation and CNS injury unrelated to NMO-IgG present Aqp-4 or a breakdown product in the context of inflammation to the immune system leading to the generation of autoantibodies against it. The NMO-IgG test, in this scenario, would not be helpful until after the patient has presented with recurrent disease by clinical criteria.

Nonetheless, we are learning progressively more about NMO, driven by good science and good clinical neurology. This study provides an excellent addition to the growing literature of NMO as it is the first study in children and serves as a foundation for other studies to more precisely define the prevalence of NMO-seropositivity in NMO and NMO spectrum diseases in children.

## REFERENCES

1. Lennon VA, Wingerchuk DM, Kryzer TJ, et al. A serum autoantibody marker of neuromyelitis optica: distinction from multiple sclerosis. *Lancet* 2004;364:2106–2112.
2. Banwell B, Tenenbaum S, Lennon VA, et al. Neuro-myelitis optica-IgG in childhood inflammatory demyelinating CNS disorders. *Neurology* 2008;70:344–352.
3. Wingerchuk DM, Lennon VA, Pittock SJ, Lucchinetti CF, Weinshenker BG. Revised diagnostic criteria for neuromyelitis optica. *Neurology* 2006;66:1485–1489.
4. de Seze J, Stojkovic T, Ferriby D, et al. Devic’s neuromyelitis optica: clinical, laboratory, MRI and outcome profile. *J Neurol Sci* 2002;197:57–61.
5. Wingerchuk DM, Hogancamp WF, O’Brien PC, Weinshenker BG. The clinical course of neuromyelitis optica (Devic’s syndrome). *Neurology* 1999;53:1107–1114.
6. Matiello M, Jacob A, Wingerchuk DM, Weinshenker BG. Neuromyelitis optica. *Curr Opin Neurol* 2007;20:255–260.
7. Lennon VA, Kryzer TJ, Pittock SJ, Verkman AS, Hinson SR. IgG maker of optic-spinal multiple sclerosis binds to the aquaporin-4 water channel. *J Exp Med* 2005;202:473–477.
8. Lennon VA, Wingerchuk DM, Kryzer TJ, et al. A serum autoantibody marker neuromyelitis optica: distinction from multiple sclerosis. *Lancet* 2004;364:2106–2112.
9. Lucchinetti CF, Mandler RN, McGavern D, et al. A role for humoral mechanisms in the pathogenesis of Devic’s neuromyelitis optica. *Brain* 2002;125:1450–1461.
10. Lefkowitz D, Angelo JN. Neuromyelitis optica with unusual vascular changes. *Arch Neurol* 1984;41:1103–1105.
11. Cree BA, Lamb S, Morgan K, et al. An open label study of the effects of rituximab in neuromyelitis optica. *Neurology* 2005;64:1270–1272.
12. Wingerchuk DM. Neuromyelitis optica. In: Minagar A, Alexander JS, eds. *Inflammatory Disorders of the Nervous System. Pathogenesis, Immunology, and Clinical Management*. New Jersey: Humana Press; 2005: 203–214.
13. Weinshenker BG, Wingerchuk DM, Vukusic S, et al. Neuromyelitis optica IgG predicts relapse after longitudinally extensive transverse myelitis. *Ann Neurol* 2006;59:566–569.

### **TMA Grant to the Accelerated Cure Project: A Progress Report**

In November 2008 The Transverse Myelitis Association awarded a grant of \$10,000 to the Accelerated Cure Project to enroll patients with ADEM, NMO, ON and TM into the repository. Through a matching funds program, ACP will be able to devote \$20,000 for the purpose of enrolling people with the rare neuroimmunologic disorders.

The Transverse Myelitis Association has established a partnership with the Accelerated Cure Project. In November 2007, the TMA awarded a \$35,000 grant to ACP for the purpose of enrolling people with TM, NMO, ADEM and ON into the repository. The entire TMA grant was used during the past year to enroll 63 people into the ACP repository who are diagnosed with NMO (7), ON (1), TM (51) or ADEM (4). Each one of the six collection sites played a role in enrolling these people.

The Accelerated Cure Project represents a wonderful opportunity to foster and facilitate research on these rare neuroimmunologic disorders. Researchers are provided with access to a large database of information and samples that would not otherwise be available to any single medical research institution. The TMA is actively engaged in recruiting adults and children with TM, ADEM, NMO and ON into the ACP repository. The TMA is represented on the ACP oversight committee.

The samples collected from our grant have been used in five research studies:

David K. Simon, M.D., Ph.D. Beth Israel Deaconess Medical Center  
Variations in mitochondrial DNA

382 cases (346 MS, 6 NMO, 2 ON, 19 TM, 1 ADEM, 8 CIS) and 31 controls;

Brian Weinschenker, M.D.  
Mayo Clinic  
Genetic and immunogenic analysis of AQP4 in neuromyelitis optica  
5 NMO subjects who have tested positive for NMO-IgG antibody;

Philip DeJager, M.D., Ph.D.  
Broad Institute  
Validation of genetic determinants of disease course in MS  
735 cases (640 MS, 11 NMO, 3 ON, 54 TM, 4 ADEM, 23 CIS) and 242 controls;

Nir Dotan, Ph.D. Glycominds Ltd.  
The ability of anti-glucose antibodies to diagnose and stratify MS patients  
868 cases (743 MS, 71 TM, 13 NMO, 4 ON, 6 ADEM, 31 CIS), 140 unrelated controls and 251 related controls

Michael Demetriou, M.D.  
University of California Irvine  
Gene alleles that affect protein glycosylation  
871 cases (746 MS, 13 NMO, 4 ON, 69 TM, 8 ADEM, 31 CIS) and 18 unrelated controls.

ACP continues to receive research proposals; there will be many more opportunities for current and future samples to make a significant contribution to research. It is so important to keep in mind that for each of the studies identified, the scientists are developing profiles for each of the disorders; all of the data is generated by individual sample. This means that the information being entered into the ACP database includes data about each of the disorders. The information is not being aggregated as "other neuroimmunologic disorders" or as controls. This approach will facilitate meaningful analysis of the data to learn about each of these disorders.

During the Rare Neuroimmunologic Disorder Symposium held this past July in Seattle, eligible attendees were given the opportunity to enroll in the ACP repository. Thanks to the efforts of Johns Hopkins neurologist Dr. Ben Greenberg, study coordinator Jana Goins, and their top-notch nursing staff, 39 people were enrolled in the repository in just one day. This represents a nearly 50% increase in the number of subjects in the repository with TM, ADEM, and NMO! ACP and the TMA express their gratitude to the Johns Hopkins staff, and also to the central laboratory vendor, Sera-Care, for handling this major (and exciting) influx of subjects.

With the enrollment bump from the symposium and the continued efforts of all six collection sites, the number of enrollees in the repository continues to swell! As of October 2008, there were 1351 people enrolled, 1011 case subjects (those with MS - 837, TM - 109, ADEM - 9, NMO - 18, ON - 5, or a single MS-type event - 33) and 340 controls. The growing number of enrollees increases the power and usefulness of the repository to researchers studying the causes of these diseases. Currently, 13 research studies are being supported with samples and data from the repository, with additional research proposals pending approval. Visit [www.acceleratedcure.org/repository/status.php](http://www.acceleratedcure.org/repository/status.php) to see regular updates on the status of the repository.

The ACP repository could help us find the causes and possible cures for TM, NMO, ADEM and ON. But this will only happen if we can raise the money to support specific research projects on these rare disorders. At present, almost all of the ACP repository studies are focused on MS. When scientists learn about MS, they are also learning about these other disorders. The more they understand about the immune system and the more they understand how and why the nervous system is vulnerable to these attacks, the more they

may gain insights into each of these disorders. To learn the causes of TM, ADEM, ON or NMO and to develop better diagnostic tools, researchers need to specifically study these disorders. The TMA will be targeting fundraising efforts in order to specifically support TM, ADEM, NMO and ON studies from the ACP repository. We will need your help to make this happen.

## Studies and Clinical Trials

### Recruiting for ACP Repository: Help us to Find the Causes and Cures for TM, ADEM, ON, NMO, MS

Jana Goins

The Johns Hopkins University is working in conjunction with the Accelerated Cure Project for Multiple Sclerosis (ACP) to conduct a large scale research study which will play an important role in determining significant causal factors and disease trends for demyelinating disorders such as Multiple Sclerosis (MS), Transverse Myelitis (TM), Optic Neuritis (ON), Devic's Syndrome (NMO), Acute Disseminated Encephalomyelitis (ADEM) and other related diseases.

Several major academic centers located throughout the country will serve as coordinating project sites, creating a national network of collection sites. Study enrollment is targeted at 10,000 subjects over ten years. Enrolled subjects will be asked to contribute personal data (such as medical history and family information) and a blood sample. The personal data collected from all subjects will be combined into a single database while the blood samples will be processed at a central laboratory and stored. The complete

anonymity of study participants will be protected. The result will be the creation of a comprehensive information system and specimen repository from which researchers can request samples to conduct in-depth analyses on various disease aspects. This study will play an important role in increasing the current knowledge of demyelinating diseases and therefore aid researchers in the development of better diagnostic techniques and cures for these diseases.

This is your chance to help! We are enrolling patients with multiple sclerosis, transverse myelitis, optic neuritis, acute disseminated encephalomyelitis, neuromyelitis optica (Devic's) or clinically isolated syndromes (one demyelinating attack, but not fulfilling the diagnostic criteria for MS). Those who are currently patients at Johns Hopkins will be able to join the study without a referral from their physician, and will just need to contact the Johns Hopkins project coordinator for study enrollment information. Johns Hopkins patients who are aware of their next scheduled clinic date may get in touch with the project coordinator *beforehand* in order to schedule a study meeting during this clinic visit. Subjects participating at Johns Hopkins will be offered a \$25 check to compensate for lunch and parking on the day of the visit, but will not be reimbursed for any travel expenses. At this time, patients receiving care outside of Johns Hopkins will be subject to additional enrollment requirements.

Please note, the enrollment requirements and participant compensation may vary by study site. If you are interested in getting involved, please contact your nearest participating center for further information regarding the enrollment process.

In addition to enrolling subjects with one of the specified demyelinating

diseases, we are asking participants to refer affected and unaffected relatives as well as unaffected matched "controls" (such as a childhood friend who grew up in the same area as you or a spouse) for participation in the study.

This is a very exciting opportunity for both patients and researchers around the country to take part in a large-scale dynamic project that will work to improve our knowledge about demyelinating diseases. By volunteering your time and effort to this project, you will be making a significant contribution to the development of new treatments, and ultimately a cure, for these diseases.

### Participating Centers

Johns Hopkins Medical Institution  
(Baltimore, MD)

Jana Goins  
acp-study-hopkins@acceleratedcure.org  
(410)502-6160

UMass Memorial (Worcester, MA)  
Janice Weaver  
acp-study-umass@acceleratedcure.org  
(508)793-6562

Shepherd Center (Atlanta, GA)  
Elizabeth Iski  
acp-study-shepherd@acceleratedcure.org  
(404)350-3116

University of Texas Southwestern  
(Dallas, TX)  
Gina Remington  
acp-study-utsw@acceleratedcure.org  
(214)645-0560

Multiple Sclerosis Research Center of  
New York (New York, NY)  
Lauren Puccio  
acp-study-msrcny@acceleratedcure.org  
(212)265-8070

Barrow Neurological Institute  
(Phoenix, AZ)  
Breanna Bullock  
acp-study-barrow@acceleratedcure.org  
(602)406-3109

**Study Sponsor**

Accelerated Cure Project  
Sara Loud, Repository Director  
300 Fifth Avenue  
Waltham, MA 02451  
acp-study-director@acceleratedcure.org  
(781)487-0032  
www.acceleratedcure.org

Neuroimmunologic Disorders Sample  
Repository:  
[http://www.acceleratedcure.org/  
curemap/tissuebank.php](http://www.acceleratedcure.org/curemap/tissuebank.php)

### The Use of Magnetic Resonance Spectroscopy and Cytokine Measurements to Investigate Depression in Autoimmune Neurologic Diseases

Johns Hopkins is currently enrolling TM, MS and non-autoimmune myelopathy patients in a prospective study (6 months follow-up) to investigate the epidemiology of cytokine-mediated depression and cognitive impairment in TM subjects compared to MS and non-autoimmune myelopathy controls.

Subjects will be followed longitudinally to determine if changes in cytokine levels and brain metabolites parallel changes in mood, cognition and neurologic outcomes. Acute new onset TM and MS patients between the ages of 18-65 years will be enrolled in this study.

Interested patients should contact the study coordinator, Carrie Trecker, at 410-502-2574 for more information.

Principal Investigator: Adam Kaplin, MD/PhD  
Registered Protocol Number:  
03-07-03-09



### Risk Factors for Acute Idiopathic Transverse Myelitis

Johns Hopkins is currently enrolling new and recently diagnosed patients with idiopathic acute transverse myelitis (IATM) to study risk factors for the disease. This is a study conducted in collaboration with investigators at the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins Transverse Myelitis Center, under the auspices of the Centers for Disease Control and Prevention. In this exploratory study, patients will be asked to complete a questionnaire detailing demographic, socioeconomic data, information regarding illness and underlying diseases, medications, immunizations, travel history and other physician visits in the preceding 24 months prior to the onset of idiopathic acute TM.

Interested patients should contact the study coordinators: Yandong Qiang (410-955-2955), Chitra Krishnan (410-955-3129), Rosanna Setse (410-614-7797), Megan Quigg (410-955-3129), Doug Kerr (410-955-3129), and Neal Halsey (410-955-6964).

### Research Volunteers Needed for a Pain Study

We are seeking individuals with pain following spinal cord injury or disease for a research study of an investigational medication being conducted at Brigham and Women's Hospital.

You may be eligible if you are:

18-55 years old;  
Have been diagnosed with a Spinal

Cord Injury or Disease;  
Have had chronic neuropathic pain for at least 3 months

For more information please call 617-525-PAIN (7246), or email; [paintrials@partners.org](mailto:paintrials@partners.org)

### Social Security Administration Launch of Compassionate Allowances Process Will Fast Track Applications for People with Cancers and Rare Diseases...What does this mean for people with TM?

Sandy Hanebrink

The Commissioner of Social Security, Michael J. Astrue, announced the national rollout of the agency's Compassionate Allowances process. The purpose of Compassionate Allowances is to expedite the processing of disability claims for applicants whose medical conditions are so severe that their conditions obviously meet Social Security's standards. The process is designed to result in decisions being made in days, rather than months or years. Social Security is launching this expedited decision process with a total of 50 conditions. Over time, more diseases and conditions will be added. A list of the first 50 impairments -- 25 rare diseases and 25 cancers -- can be found at [www.socialsecurity.gov/compassionateallowances](http://www.socialsecurity.gov/compassionateallowances). (Thus far, ADEM, NMO, ON and TM are not listed).

Compassionate Allowances is the second piece of the Social Security Administration's two-track, fast-track system for certain disability claims. When combined with SSA's Quick Disability Determination process, and once fully implemented, this two-track system could result in six to nine percent of disability claims, the cases for as much as a quarter million people, being decided in an average of six to eight days.

For anyone with TM who has paralysis, if the paralysis is listed in your medical records as permanent, you already fall under immediate processing instructions. Problems arise when physicians misdiagnose or list as temporary or non-static or possible MS with prognosis potential or prognosis unknown. This is the primary reason for initial denials along with what is known as “durational denial,” because the person has filed too soon secondary to uncertain prognosis being documented.

The main point is to educate physicians about properly diagnosing TM and other rare neuroimmunologic disorders so that earlier approval of Social Security and other critical benefits can be made. When you apply for Social Security and other benefits, provide the medical records that best describe your condition and do not provide them with copies of records with conflicting information. You have to complete the medical forms and list all your information, but if you only give them what they need, many times they will not take the time or money to get other information. If you have information that documents your condition (especially if there is paralysis), then faster decision times are likely and you will have success in getting the benefits you need.

For more information on Social Security: [www.socialsecurity.gov](http://www.socialsecurity.gov).

If you have questions or need some advocacy assistance, contact Sandy Hanebrink, OTR/L at (864)225-1356 or [wheeldogs@charter.net](mailto:wheeldogs@charter.net) (Diagnosed with TM since 1987).

### United HealthCare Announces Medical Assistance Grants

The United Healthcare Children’s Foundation is offering support to meet the needs of children across the United

States with assistance grants for medical services not fully covered by health insurance. Parents and caretakers across the country will be eligible to apply for grants of up to \$5,000 for healthcare services that will help improve their children’s health and quality of life. Examples of the types of medical services covered by UHCCF grants include speech therapy, physical therapy, and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids, and eyeglasses; and orthodontia and dental treatments.

Any child 16 years old or younger living in any United Healthcare region of the United States (all 50 states) and in need of financial assistance for healthcare services will be considered eligible for a grant. Families must meet economic guidelines, reside in the US, and be covered by a commercial health insurance plan.

Visit United Healthcare’s website to learn more about these grants.  
<http://www.uhccf.org/>

*my* Daily Apple™

### The new MyDailyApple: Learn your Health and Help Others.

MyDailyApple has always included excellent and objective health information. But sometimes news and medical research is not enough. Often, it’s a real person’s experience that helps you gain that key insight to better understand your health.

MyDailyApple now includes the discussions from the **best on-line health communities**. Real patient experiences - relevant to your interests - will be on display in a new your *Communities* tab. You will have the ability to read posts and in-

teract and discuss with real people - similar to you.

The community discussions are just the start. You will also be able to **critique and/or recommend** to other members of the MyDailyApple community. Reading and commenting on an article is just one of the ways MyDailyApple is making it easier to learn about your health while helping others.

MyDailyApple has also made a few other improvements to make your health exploration easier:

**New site organization** making it easier to find and read the information you’re looking for.

A **remember topics** section to more easily remember your health interests.

A **medical expertise selector** that lets you control the type of content displayed by your level of expertise and comfort.

The ability to view your new **just for today**, or to catch up on developments over the **past week**.

Now more than ever, **in one place** you can find the right health information - whether it’s news, research, blogs, discussions, medical references, or clinical trials - relevant just for you - right when you need it most. And all with the opportunity to learn from and inform other patients like you.



NATIONAL FAMILY CAREGIVERS  
ASSOCIATION

**SpeakUp**  
National Family Caregivers Month

REACH OUT  
PROTECT  
BELIEVE

The TMA Celebrates  
National Family Caregivers Month



National Family Caregivers Month, celebrated every November, is a nationally recognized time set aside every year to thank, support, educate and empower more than 50 million family caregivers across the country currently providing over \$350 billion in “free” caregiving services.

The Transverse Myelitis Association is pleased to be an endorsing organization of NFC Month, created by the National Family Caregivers Association to bring attention to the needs of family caregivers. “This year we are encouraging people to speak up during National Family Caregivers Month,” said Suzanne Mintz, NFCA president and co-founder. “One of the most important attributes of being an advocate for your loved one is the ability to speak up to health care professionals protecting not only the health and safety of your loved ones but for yourself as well.”

Remind family caregivers to *believe* in themselves, *protect* their health, *reach out* for help, and *speak up* for their rights. Encourage family caregivers to identify themselves as a family caregiver in conversations with others, including friends and family as well as healthcare professionals.

<http://www.nfcacares.org>

### **Know Your Patient Rights: Important Tips for Patients and Caregivers**

Sandy Hanebrink

As many of us already know, individuals who have rare neurological and autoimmune disorders often face challenges with healthcare providers. Misdiagnoses at onset and post onset are among these challenges. For those already diagnosed, here are some tips to help ensure you get the medical treatments you need... Be your own advocate!

- ◆ Share copies of the TMA Articles, Newsletters and Journals, especially the document on how to diagnose TM, with your physicians, local Emergency Rooms and other local hospitals and clinics. You may even want to keep a copy of this with you.
- ◆ Get a copy of your diagnostic test reports and a summary write up from your diagnosing physician. Make sure a copy is in your file at your primary care physician’s office and keep a copy with you at all times. Keeping a copy can be critical to you receiving proper care in emergency situations or when you move or go to a new physician or facility.
- ◆ Make a document that lists your name, address, phone, date of birth, and insurance information. This document should also include the name and contact information of your primary physician, neurologist and any other specialists you see routinely. If the diagnosing physician is not your current doctor, you may want to include this information, as well. In addition to the contact information, include all your diagnoses and date of diagnoses, current medications, allergies and past surgeries and dates. Keep this document up to date and with you, along with the diagnosing physician note and test reports.
- ◆ When you go to any medical appointment, provide a copy of these documents to the treating physician and ask that it be included in your record. You will also want to make a list of your current complaints or concerns and how they are different or changed. Do not assume the physician knows or remembers how you were previously or that he/she will know by looking at you. This is especially the case if the physician does not know you.
- ◆ If you get a physician who will

not accept your documents, listen to you, or acknowledge your history, **FIRE THEM** and ask immediately for a second opinion. If you are in an emergency room, ask for a different physician and if needed, the patient advocate. You are in charge. It is your health. They work for you. You pay them. They are not in charge.

- ◆ If you receive an incorrect diagnosis and you are aware of this at the time, request that your medical documents you brought with you be added to the record. Also request that a statement that you do not accept the diagnosis and that refers to the documents you brought with you be added to the record. Additionally, request that the physician giving you the incorrect diagnosis contact your primary and diagnosing physicians. This is critical as incorrect diagnoses confuse things later, can cause a mess with insurance reimbursement, and will prevent you from getting the care you need. If you find out later that a misdiagnosis is in your file, ask that the record be amended with your statement and records. This will help document for the future and help ensure proper treatment of your conditions.

- ◆ After any tests, emergency room visits or other major medical appointments, treatments or hospitalizations, request a copy of the complete record including all notes and bills. This is the only way you will know what is in the record. This is critical for those who have been misdiagnosed. When you request the records, tell them you are picking the records up to hand deliver to your appointment with one of your physicians. Doing this usually keeps them from being able to bill you for the copies. The itemized bill allows you to check for billing errors and saves valuable insurance and personal dollars.

- ◆ Once you have your files, review them carefully and take any necessary



actions to amend the record, contest a bill or seek additional healthcare. If you have to amend the record, again ask that your statement and records be added. You may also want to ask your primary care and/or diagnosing physician provide a note to be added to the record, as well. Finally, follow up and verify that your amendments are part of your permanent record and that the treatment notes state you wanted the record amended.

- ◆ You can keep a paper copy in your car, in your purse or backpack. You can also keep copies on a jump drive that you can keep on your key ring. When keeping a jump drive, make sure you put a card in your wallet that identifies your medical record is located on the jump drive attached to your key ring. This card should be with your ID and insurance cards. Emergency medical personnel will usually look for identifying information when you cannot respond. Keeping the information where it can be found is critical. It is also good to give a copy to the family member(s) or friend(s) who go with you or who may transport you in emergencies. Make sure they understand your condition, the importance of providing this information and the true need of their support.

- ◆ Take charge of your healthcare. Keep your records up to date. Communicate your needs. Take action when necessary. Keep your support network informed. Keep all your physicians informed of care by other physicians. Keep your information where it can be found. Stay informed and stay healthy.

If you have questions or need some advocacy assistance, contact Sandy Hanebrink, OTR/L at (864) 225-1356 or wheeldogs@charter.net (Diagnosed with TM since 1987).

## **Pediatric MS Centers: Caring for Children and Teens with ADEM, MS, NMO, ON and TM**

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 psychosocial 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 work together to:**

- ◆ Improve evaluation and management strategies 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.

### **Recent Progress**

- ◆ Over 600 children and their families have received services at the six centers. The centers are able to provide all families with a child with MS or other central nervous system related disorders with the kind of help they need.
- ◆ The network of centers has established work groups to achieve consensus on protocols they will all follow related to collecting data, MR imaging, and neuropsychological testing, and they are working on an algorithm, or formula, for making treatment decisions.
- ◆ To enhance the ability of the centers to share data and conduct research, a national pediatric MS data center is working with the centers to store, monitor, and analyze aggregate data collected by the network of pediatric MS centers.

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](http://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/](http://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](http://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](http://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](http://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 Karpinski, MSW  
Phone: (877) 878-7367  
Email: [PedMS@thejni.org](mailto:PedMS@thejni.org)  
Web: [www.pedms.com/](http://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](mailto:info@pediatricmscenter.org)  
Web: [www.pediatricmscenter.org/](http://www.pediatricmscenter.org/)



### 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 were 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 fami-

lies 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 Sandy Siegel (614-766-1806).

We have tried to identify as many children as possible in our community, and Linda has attempted to reach many of you via emails to request this information. 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.

**The TMA Helps to Fund Clinical Care and Research at the Johns Hopkins TM Center: Julius Birnbaum, MD**

When Mrs. K, a 19 year-old woman from Africa, came to The Johns Hopkins Transverse Myelitis Center (JHTMC) to see Dr. Julius Birnbaum she had only one wish: to see and hold her newborn baby. Mrs. K had been in her normal state of health until half-way through her pregnancy when she lost her vision and all upper arm mobility. With only a cursory investigation, Mrs. K was diagnosed with Multiple Sclerosis (MS) and treated with interferon therapy; but Mrs. K got worse. Upon seeing Dr. Birnbaum months later, a new diagnosis was formulated based on a more thorough examination. Mrs. K had Neuromyelitis Optica (NMO)/Devic’s syndrome, an autoimmune inflammatory disorder that attacks the optic nerves and spinal cord. Within a week of the appropriate treatment (plasma exchange followed by immunosuppression treatment), Mrs. K regained her arm mobility and 20/20 vision—an incredible recovery.

Often faced with challenges cases, Dr. Birnbaum has established a clinic in conjunction with the JHTMC and Dr. Douglas Kerr devoted towards the care and investigation of patients with neurological complications of

rheumatic disease. No other clinic in the country is exclusively dedicated towards managing patients with neurologic disease occurring secondary to rheumatic disease. Such rheumatic syndromes include, lupus, Sjogren’s syndrome, rheumatoid arthritis, scleroderma, and vasculitis. Dr. Birnbaum’s research focuses on the diagnostic and clinical criteria used to differentiate between rheumatic disease and MS. This distinction is critical to the proper treatment plan, as seen with Mrs. K. The MS treatment exacerbated her symptoms while the proper diagnosis and treatment plan restored her vision and arm function. Thanks to Dr. Birnbaum, Mrs. K was afforded the bonding with her child she so desired.

We are very pleased to announce that The Transverse Myelitis Association will be helping to fund Dr. Birnbaum’s position at Johns Hopkins. The clinical care provided by Dr. Birnbaum and his research offers a very significant contribution to our community. We are grateful for his interest in the neuroimmunologic and rheumatologic disciplines and for the wonderful care he provides to patients.

Dr. Birnbaum is a regular contributor to the TMA newsletters and Journals, and enjoys receiving questions from patients with NMO or TM and the rheumatic diseases.

**Important Reminder About The Transverse Myelitis Association 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](http://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](mailto: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.

### 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 7,000 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 also been registered with the National Organization of Rare Disorders since 1994.

### 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](mailto: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.

### 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!

## Geoff Treglown

Geoff Treglown recently passed away. Geoff was such a kind, caring, and



loyal friend. I don't remember the details as to how or when we met, but Geoff must have contacted me after he found the TMA on the internet. That's the way I meet most people in the TMA community; particularly when they don't live in the United States. Geoff had TM and he also had Parkinson's disease. Geoff was the consummate British gentleman.

In our telephone conversations and our emails, Geoff was always concise and to the point. I don't know whether Geoff found my lengthy emails and long conversations entertaining or bewildering; he was always too polite for me to tell. Geoff was such a good man. Geoff described his life to me in one of our hundreds of email exchanges:

*I am a bachelor whose parents and only (much older) brother all died many years ago. In fact the only relations I have are two cousins who live at the opposite end of the country. We exchange Christmas cards and only ever meet when there is a funeral! I am very content with my lot. I have retired (5 years ago) to a very beautiful part of the country after 37 years as a teacher. It is a lovely backwater with negligible crime or problems; England pre 940. A sizeable proportion of the village's population (a third?) are retired off-comers, like myself. Everything is done in a very relaxed manner. I am 65 and usually the youngest at any meeting. Before that I lived just*

*outside Oxford and taught at a fee paying boarding school, Radley College, at various times being i/c of chemistry, science and IT).*

In 2000 Geoff volunteered to be the TMA support group leader for the UK and to handle all of the mailings to the UK. As the UK represents the largest number of TMA members outside of the US, this was an enormous help to us and also a tremendous savings in postage. Geoff mailed the newsletters and journals and he also mailed the new member packets that are sent to people when they sign up for TMA membership. At first, I sent boxes of materials to Geoff for the mailings. Then Geoff found Lew Grey who was able to help Geoff with the printing of the materials. So, Geoff and Lew were able to take over the entire printing and mailing operation. Also, Geoff volunteered to take over the mailings for all of our members in Europe. I know that Geoff paid for a lot of the materials and the postage out of pocket. He never talked about it or asked for recognition for it; Geoff was so generous and he was very private and quiet about his generosity. Whenever Geoff created a new membership packet, he would send me one so I would have a sample of what he was sending out. And I always remarked to Geoff that what he was sending to our members looked better than what I was sending – and it did! Geoff was a perfectionist and a professional; even in his volunteer work. Geoff was so dedicated to his work for the TMA.

Geoff made himself available to so many people across the UK and Europe. I know that Geoff helped so many people by listening to their issues, by offering excellent guidance and information and by sharing his own experiences. Geoff was there to help people through their most challenging experiences.

Ann Moran held a wonderful support group meeting in Ireland and Dr. Kerr and Chitra Krishnan attended and made a presentation to our members. Geoff was able to attend the meeting in Ireland. I saw Dr. Kerr just before he left for Ireland and I told him all about Geoff and asked him to be sure to find Geoff; I told Dr. Kerr what an enormous contribution Geoff was making to the TMA community. I never had the opportunity to meet Geoff face to face. I am so pleased that Dr. Kerr and Chitra were able to meet him.

Geoff had experienced a fall and was in and out of hospitals for months. It was such a difficult and frustrating time for him. Lew and Margaret were able to stay in touch with him by phone, but the rest of his friends had a difficult time communicating with him. We all sent Geoff cards so that he knew we were thinking of him. And so, that's how it was. I received a phone call from Margaret, our support group leader in Scotland, and she gave me the very bad news about Geoff's passing. I just stood in my kitchen and cried. I felt so helpless and empty. What a horrible loss.

My heart is just totally broken.

I had mailed Geoff a card about a week and a half before he died. Margaret had phoned Geoff and a friend told Margaret that my card was on his bed stand and that she had read it to him. I at least felt relieved that Geoff knew that he was in my thoughts and in my heart; it helped me to know that he knew just how much I cared for him.

I am so grateful that Lew (our support group leader in the UK) and Federica (our support group leader in Italy) were able to attend Geoff's memorial service and represent all of us from the TMA community who were not able to be there.

Geoff helped so many people over the

years, as a teacher and in all of the wonderful work he did for the TMA. Geoff is going to be missed so much by everyone who knew him and cared for him. He made such a difference in so many people's lives, and especially mine.

We love you, Geoff.  
Sandy

Our memories of Geoff should serve as a blessing for all of us.

---

**From Margaret Shearer, Transverse Myelitis Scotland Support Group Leader**

**Geoff was such a special person** and a great ambassador for the TMA over this side of the pond. A Perfect English Gentleman! Our group benefited greatly from his continuous support and advice and I will miss him so much. I will miss my frequent telephone conversations with him.

My first call with Geoff was when I was in Mount Sinai Hospital in Florida in 2002; flat on my back and diagnosed with TM. He told me he would keep in contact with me and call me as soon as I arrived back home in Scotland. It took me three months to get back and he called me within two days and offered his support. I have had it ever since!

A year later I met Geoff in Manchester at his group meeting. I also met Margaret and Sandy Smith who, like me, had travelled from Scotland; none of us having met another person with TM. From that meeting and with the support of Geoff, Sandy Siegel and Jim Lubin, the Transverse Myelitis Scotland Support Group was started in 2003. We have continued to flourish with Geoff's support and to grow to over 45 members in 2008.

In 2004 I was asked by Geoff to contact Sally Rodohan in London as she was interested in starting up a support

group in the city. From those conversations, the TMS was later formed. Geoff was inspirational in assisting me with setting up the Scotland Support group. Geoff's and my conversations with Sally over several months helped to start up the London Group. The rest is the history that Geoff should always be remembered for by all TMers in UK and Europe as the TMA UK Coordinator.

What a legacy to leave! He will be sadly missed by all who had the privilege to have been in his presence or in contact with him.

People like Geoff are very special and can never be replaced, But he will be remembered for the rich full life he led, For the things he accomplished throughout the years, For the times he made us laugh and comforted us when we were upset, For his thoughtfulness, warmth and unselfishness, But he will especially be remembered for making such a positive difference in so many people's lives. Wonderful memories like these make him a **special person**.

-----  
The lyrics in the song by Anne Murray (Canadian Folk Singer) reflect my thoughts and feelings about Geoff; he was such an inspiration to me when I was so ill and has continued to be over these last years.

Anne Murray - You Needed Me  
I cried a tear  
You wiped it dry  
I was confused  
You cleared my mind  
I sold my soul  
You bought it back for me  
And held me up and gave me dignity  
Somehow you needed me.

You gave me strength  
To stand alone again  
To face the world  
Out on my own again

You put me high upon a pedestal  
So high that I could almost see eternity

And I can't believe it's you I can't believe it's true  
I needed you and you were there  
And I'll never leave, why should I leave  
I'd be a fool  
'Cause I've finally found someone who really cares

You held my hand  
When it was cold  
When I was lost  
You took me home  
You gave me hope  
When I was at the end  
And turned my lies  
Back into truth again  
You even called me friend

Yes, Geoff, you were my friend and I will miss you so much.  
Love,  
Margaret

---

**From Jane Batho, Member of the TM Scotland Support Group**

I had spoken to Geoff a few times on the phone. I once had the opportunity to see him on my way south. We had lunch together. Geoff was such an easy person to speak to; the kind you felt you had known all your life. No one can replace Geoff - he was one of a kind. Every time I visit the Lake District, I will think of him with fond memories.

---

**From Ursula Mauro, TM Support Group Leader, Germany**

We didn't have much time to get to know each other. When the UK TM Society decided to take the task of sending the TMA New Member Packets and the newsletters and journals to all of Europe in 2006, our email conversations started. Geoff was a much bigger help for me than I for him. He was such a polite, smart and friendly gentleman and he always was ready to

help. He set priorities and always tried to find easy and reasonable solutions. He never pressured me and he gave me the feeling of being important and helpful although I often was behind on many of my duties. And he always answered my emails; I never take this for granted.

I already missed him during the time of his last long stay in the hospital. And I regret very much that I couldn't call him, because the hospital wouldn't allow calls from outside of UK. But I was able to send him postcards. My last one arrived two days before his death.

I'm thankful that I had the chance to get to know Geoff. I'll miss the good and valuable cooperation and help from him. I will miss him in so many different ways and I know many others will miss him too!

**2008 Rare Neuroimmunologic Disorders Symposium**

Paula Lazzeri

The TMA and Johns Hopkins Project RESTORE teamed up in July 2008 to present the 2008 Rare Neuroimmunologic Disorders Symposium in Redmond, Washington. More than 25 medical presenters attended from various Medical Centers and Universities from across the country. Most of the TMA Medical Advisory Board was there. The presentations covered everything from a description of each of the rare neuroimmunologic disorders, the acute therapies, the most effective symptom management strategies and the most promising rehabilitative and restorative research. Chitra Krishnan has designed our program over the years and it has to be the most comprehensive and intensive education program for people who have these disorders and their families.

We had almost 200 in attendance from across the United States and from around the world. Three of our international support group leaders attended: Ivan Fernando from Sri Lanka, Lew Grey from the UK, and Nana Yaa Agyeman from Ghana. Our state support group leaders were also well represented at the symposium. Having the symposium in Seattle also allowed Jim Lubin, TMA Officer and Board Member, to attend. It was really special for all of us to have Jim participate in the entire symposium.

It was great seeing old friends and meeting new members I can now call friends. For those of you unable to attend the symposium, all of the presentations have been posted on the TMA website.



Allen Rucker's presentation:  
*The Best Seat in the House*



Nana Yaa (Ghana) and Ivan (Sri Lanka) enjoy the banquet dinner



Medical panel participating in the symposium question and answer session



### TMA 2008 Distinguished Service Award

The Transverse Myelitis Association 2008 Distinguished Service Awards were presented to Pattie and Kyle Petty and to Dr. Peter Sim. The awards were presented during a ceremony at the 2008 Rare Neuroimmunologic Disorders Symposium in Seattle and recognize the wonderful contribution that is made to the TMA community by Victory Junction Gang Camp. VJGC is one of Paul Newman's Hole in the Wall Gang Camps and is located near Greensboro, North Carolina. The camp was started by the Petty's to honor the memory of their son, Adam. It was Adam's idea to establish the camp to help children with serious illnesses. Kyle and Patty have built and operate a camp that has a NASCAR theme and feels like Disneyworld to the children. The facilities and the recreation program are totally accessible. The directors and staff at the camp are exceptional, providing children a safe and loving place to spend a week or a weekend and giving them the opportunity to leave their challenging physical conditions behind them. And there are many volunteers who come to the camp to provide their time, energy and care. VJGC is just a remarkable place. Jim, Debbie, Paula and I are regularly astonished that our very grassroots organization that advocates for such rare disorders and with just 7,000 members who are spread around the globe have been afforded such a wonderful opportunity and generous gift.

It was evident from very early in the TMA's existence that children and families in our community shared special issues and concerns. We've estimated that about 20% of our membership are children with TM, ADEM and NMO. The TMA wanted to do something for children and their families. The Children's and Family Workshop was held in Columbus in the summer



**Peter Sim, MD, FACEP**

of 2002. It was an amazing experience. Our medical advisory board doctors and their families attended. The physicians presented a great educational program to the parents along with pediatric specialists from the Columbus Children's Hospital. The physicians' families served as companions for the children who attended from across the country and around the world. We developed a recreation program for the children with the help of adaptive recreation specialists from the Columbus Recreation Department and Children's Hospital. For most of the children, it was their first opportunity to meet another child with TM.

I spent the entire year planning the workshop and fundraising so that there would be no cost for the parents. When the workshop was completed, Pauline told me that I had accomplished an incredible feat and that she would never allow me to do anything like it ever again. And as with most things, Pauline's response was reasonable and correct. I had been so immersed in this work that I was not able to get anything else done for the Association. There were no newsletters published during that year. It had been an amazing experience, but it was not a judicious use of the president's time for an entire year.

I knew we needed to do something for the children and families in our Association, but we needed to find a better way to do it. Leslie Cerio, Shannon O'Keefe and Stephen Miller volunteered to serve on a committee to find a camp that would provide a great experience for our children. They searched for a very long time and they didn't meet with very much success. The search was so difficult because we had challenging needs and most camps serve a specific group or a particular geographic area. Finally, Leslie found the medical director at Victory Junction Gang Camp, Dr. Peter Sim.

Our search committee had a long and complex list of needs and desires for our camp experience. The camp needed to be totally accessible – the facilities and the recreation program, and there had to be a staff with expertise in working with children with disabilities. The camp had to have a medical staff that could manage the complex issues that many of the children experience. The camp needed to be able to accept ventilator dependent children. The camp needed to accept children and families from across the United States and from around the world. The camp had to accept that we represented very rare and little understood disorders. We wanted for the physicians from our medical advisory board to be able to attend the camp so that they could offer an education component during the camp. And we wanted for siblings and parents to be able to attend with the children who have TM, NMO, ADEM and ON. And the camp needed to be free for the families!

Leslie initiated a series of discussions with Dr. Sim. Leslie told me that Dr. Sim understood our needs from the outset and that he reacted very compassionately to the difficulties we had been experiencing in finding a camp that would entertain the idea of accommodating such a rare disorder community. She asked me to call Dr. Sim and

to share my passion for our cause, which I did. I found Dr. Sim to be incredibly sensitive to our issues and he was filled with such heartfelt compassion for our children and our families. Through his conversations with Leslie, Dr. Sim became a wonderful advocate for the TMA and for our children. Dr. Sim made our case to Pattie and Kyle Petty and to the other directors at Victory Junction. Shortly thereafter, I received a phone call from Leslie. She said that our children and our families were going to have a weeklong family camp the following summer and that VJGC was thrilled to work with us to structure the camp experience in the fashion we had suggested. And Pattie Petty had also suggested that they could offer a weekend during the fall for an older teen and young adult weekend for people with TM, ADEM, ON and NMO who are 16 to 21 years old.

I finished my conversation with Leslie, I hung up the phone, and I stood in the middle of the kitchen and just cried uncontrollably. Of course, Pauline totally freaked out, because she assumed that someone had died.

So, that fall, we had the first retreat weekend. The following summer, we had our first family camp. These were transforming experiences for all who attended. It is difficult to describe the VJGC experience. After being at the camp for a few hours, Pauline announced to me that she wanted to quit her job and come to work full time at camp. VJGC committed to working with and serving our community when no other camps or programs were interested. They accommodated every complicated request we made of them and they fashioned a wonderful experience for the families that included recreation, education, and social and emotional support.

The material contribution that the Petty's and Victory Junction Gang Camp make to the TMA community

represents the most generous gift offered to our community. And yet when we assess the true value of this experience for our children, teens, young adults and families, the greatest gift is measured not in dollars and sense, but rather, in smiles, laughter, joy, and peace. To watch a child that has been paralyzed by TM speed down a water slide, have their hair dyed pink and blue, bowl, fish, ride a horse, dance, and spend a week playing with their families, is beyond words to describe.

The work VJGC does is a blessing. These kids face such formidable challenges in their lives. I know the difficulties that Pauline has experienced; in fighting so hard to get back her life and her livelihood and her happiness. Every day can be a struggle to feel good and to feel good about oneself. It is the same for these kids – only more complicated - complicated by the biological, emotional, psychological and social issues surrounding their growth and development. There is no society on the face of the earth that rewards difference. Culture is by definition the constant pressure to conform. It is a battle for these kids to not be able to walk or run. It is a struggle for the kids to deal with the anxieties and emotional discomfort surrounding bowel and bladder dysfunction. They suffer with pain and they struggle with the debilitating burden of fatigue. And there is the insidious force of depression that can magnify the intensity of every horrible symptom and suck the energy and enthusiasm out of the very goodness of life.

VJGC gives these kids a place where they are not different. VJGC gives them an experience where they can be enveloped in inclusiveness, safety, care and love. VJGC gives them an environment where there are no physical barriers, or social barriers, or emotional barriers. This is the closest these kids are going to get to

experience being a kid – a carefree kid who can experience the joy of childhood. That is indeed a blessing. And the siblings can share in this experience as equals – they, too, can be the centers of attention. And the parents can spend a week watching and experiencing their children in this environment. You cannot put a value on this experience – it is beyond our ability to measure, because it has a value measured in how we feel. This is an experience that is measured in our hearts – and in the hearts of these families and in the hearts of these very special and beautiful children.

The TMA thanks Pattie and Kyle Petty and Dr. Peter Sim for turning our wildest dreams into a reality. Thank you for creating an environment where all children can be children. Where a child with a debilitating and horrible disease that has no cure gets a vacation from being different. Where a child who faces barriers from participation in daily life only knows inclusion. And where a child who is faced with so many reasons to be in pain can experience unbridled joy for all of life.

Dr. Sim attended the 2008 Seattle Symposium with his wife, Anna. It was an honor to have Peter and Anna there for the meeting and it was our highest honor to recognize Dr. Sim and Pattie and Kyle Petty for their distinguished service to our community.

Previous awardees of The Transverse Myelitis Association Distinguished Service Award are Chitra Krishnan, Cathy and Dan Dorocak, Jeanne and Tom Hamilton, Amy and Darian Vietzke, and Pamela and Morgan Hoge.

The photographs from the symposium were taken by Susan Daniel from Port Orchard, Washington. Susan has TM and is a wonderful photographer. We appreciate her permission to use the photographs for the newsletter.

## The 2008 Seattle Symposium Videos

You can order DVD sets from The TMA and Johns Hopkins Project Restore 2008 Rare Neuroimmunologic Disorders Symposium. The DVDs can be ordered individually or as the entire set. Each DVD contains multiple presentations and is close to 120 minutes in length. All recordings include the speaker's powerpoint presentations, lectures and questions from the audience. The order form enumerates the presentations that are included on each of the thirteen DVDs. In addition to the physician presentations, the sets include the welcoming talks by Dr. Douglas Kerr and Sandy Siegel, Allen Rucker's presentation, the Physician Discussion Panel and the Banquet Ceremony.

The symposium DVD order form is available from the following link:

<http://www.myelitis.org/rnds2008/RNDS2008-orderform.pdf>

## Learning about TM and the Other Neuroimmunologic Disorders: Bibliography and Videos on [www.myelitis.org](http://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 Multimedia link from our main web page or by typing <http://www.myelitis.org/multimedia.htm> into your web browser.

## Medical Advisory Board

Gregory N. Barnes, M.D., Ph.D.  
Assistant Professor of Neurology and Pediatrics; Divisions of Child Neurology and Epilepsy  
Department of Neurology  
Vanderbilt University  
School of Medicine  
Room 6114, MRBIII Building  
465 21st Ave. South  
Nashville, TN 37232-8552

James D. Bowen, M.D.  
MS Center at Evergreen  
12333 NE 130th Lane Suite 225  
Kirkland, WA 98034

Benjamin M. Greenberg, MD, MHS  
Assistant Professor,  
Department of Neurology  
Director, Johns Hopkins Encephalitis Center  
Co-Director, Johns Hopkins Transverse Myelitis Center

Johns Hopkins Hospital  
600 North Wolfe Street  
Pathology 627C  
Baltimore, MD 21287

Adam I. Kaplin, M.D. Ph.D.  
Consulting Psychiatrist, JHTMC  
Departments, Psychiatry and Neuroscience  
Johns Hopkins Hospital  
Meyer 115  
600 North Wolfe Street  
Baltimore, MD 21287

Douglas Kerr, M.D., Ph.D.  
Assistant Professor, Neurology  
Director, Johns Hopkins Transverse Myelitis Center  
Johns Hopkins Hospital  
600 North Wolfe Street  
Pathology 627C  
Baltimore, MD 21287

Chitra Krishnan, M.H.S  
Assistant Director, Global Services,  
Johns Hopkins Medicine International  
Adjunct Research Associate, Neurology,  
Johns Hopkins University

Charles E. Levy, M.D.  
Assistant Professor, Orthopaedics and Rehabilitation  
Chief, Physical Medicine and Rehabilitation  
North Florida/South Georgia Veterans Health Service  
University of Florida  
1601 SW Archer Road  
Gainesville, FL 32608

D. Joanne Lynn, M.D.  
Associate Professor, Neurology  
Multiple Sclerosis Center  
The Ohio State University Medical Center  
2050 Kenny Rd Suite 2250  
Columbus, OH 43221

Frank S. Pidcock, M.D.  
Associate Director of Rehabilitation  
Assistant Professor of Physical Medicine and Rehabilitation and Pediatrics  
Kennedy Krieger Institute  
Johns Hopkins University  
School of Medicine  
707 North Broadway  
Baltimore MD 21205



**The Transverse Myelitis Association 2007 Statement of Financial Activities (in US Dollars)  
Corrected Annual Report**

The following is a revised 2007 annual report. The change was due to an error in the expense line item totals. The 'Domain/Web-site/Webhosting' expenses included in the original report should have been broken out into a number of different categories. This corrected annual report enumerates the revised expense categories.

<b>INCOME</b>	<b>TMA Funds</b>	<b>Total Donations and Expenses to Benefit TMA</b>
Amazon.com Commissions	435	435
CafePress Commissions	25	25
Children's Camps	10,950	10,950
Donations made by Board of Directors	0	9,948
Endowment Interest	320	320
General Donations	74,801	74,801
iGive.com Commissions	143	143
Interest	2,728	2,728
Mission Fish.com Commissions	95	95
Paypal/NFG	14,021	14,021
Recycling Commission	1,489	1,489
Research Donations	7,864	7,864
Support Group Donations	378	378
Wristband Fundraiser	442	442
<b>TOTAL INCOME</b>	<b>113,691</b>	<b>123,639</b>
 <b>EXPENSES</b>		
ACP Support	35,000	35,000
Bank Fees	75	75
Children's Camp Expenses	8,033	8,033
Domain/Web-site/Webhosting	2,229	2,229
Internet Service Provider	0	929
JH Research Coordinator Position	19,016	19,016
Membership Fees	0	110
Mileage and Parking	0	76
Office Supplies	3,732	4,543
Postage	15,175	15,844
Printing	27,032	27,063
Secretary of State Registrations/Annual Reports	220	220
Software/Computer/Projector	1,916	4,265
Telephone	0	1,812
Travel Expenses	0	3,161
	<b>112,428</b>	<b>122,376</b>
<b>Net Income/Loss</b>	<b>1,263</b>	<b>1,263</b>

**Transverse Myelitis Association 2007 Statement of TMA Account Balances**

<b>Children's Camp</b>	<b>11,313</b>
<b>Richard Charles Gilmur Endowment Fund</b>	<b>11,603</b>
<b>Endowment Interest</b>	<b>1,223</b>
<b>Operating Fund</b>	<b>167,200</b>
<b>Research Fund</b>	<b>80,326</b>
<b>Support Group Fund</b>	<b>1,354</b>

# Support Groups

## Northern California Bay Area Support Group

My name is Doreen Christensen and I live in Vallejo, California, near San Francisco. I have had TM for over 50 years, having been diagnosed at the age of 19 months. I, personally, have no memory of the onset of this disease, only what my mother and father have told me. There was no forewarning: no illness, no pain, no weakness. I was walking at 10 months. Then one day, within twenty minutes, I was paralyzed from the waist down. That's it! Back in the 50's, diagnostic tools and treatments were very different; MRIs were non-existent. In fact, I did not see an MRI of my spine until 2002. Growing up with TM, for me, was a journey I took alone. There was not a TM Association, no support groups, and I never met another person with TM until I was forty-five years old. That was when I attended the TM Symposium in Baltimore. What an eye-opener! I felt like I'd found my second family. I am so grateful that finally we are making headway in understanding the mysteries of this disease and heading toward a cure. Thanks to all of you out there, who are making this happen.

As a child with TM, most of my health issues revolved around orthopedic abnormalities of my legs, hips and feet. I have had several surgeries over the years that have enabled me to live a very full and happy life. I walked on crutches most of my life, up until 1999, when I had back surgery and now use a wheelchair. I live alone, along with five cats and my service dog, and I am self-employed as a transcriber. Yes, life has changed. I am getting older, slowing down a bit and have more aches and pains, both age-related and disease-related. What I see

as my goal in the future is a desire to reach out and support others with TM, as well as the caregivers of an individual with TM.

Recently, an article was featured in two local newspapers. From that story, which expressed my desire to start a support group in the Northern California Bay Area, three people, ranging from college-age to seventy-two years of age, have contacted me. They all have TM, and each of them has expressed an interest and enthusiasm to have a support group formed. In addition, I was fortunate enough to meet a group of people at the TM Symposium in Seattle this past July, who also exhibited an interest. My hopes are that before, or shortly after the first of the year, we will have our first meeting. We are one in a million and we need each other: to share our stories, our trials and tribulations, our grief, our joy, our knowledge. So, please join me and let's be there for one another. Thank you. Please note contact information:

Doreen Christensen  
(707)644-3231

Email: fresprit@ix.netcom.com

## New Jersey TM Support Group

The New Jersey TM Support Group held its second meeting ever on November 2<sup>nd</sup> at the Robert Wood Johnson Hospital in Rahway, NJ. We obtained access to a large and comfortable conference room through the efforts of one of our members, Janet Coughlin. She is the head nurse at this facility. The attendance far exceeded my expectations. We had eleven TM'rs and an equal

number of family members.

We went around the room with each member telling their story, including their doctors, medications, when the onset occurred and how it was initially treated. Each story was unique, yet each story had something that we all could relate to. With just a couple of exceptions, I was amazed that most of the members had never previously met face to face with anyone sharing their condition. It was wonderful and emotional to realize that "we are not alone."

I then proceeded to discuss places they could go to have their questions answered. Two of the resources mentioned were the TM Internet Club, and the videos posted on line by Jim Lubin from the last two symposia. Finally, we agreed to make this a quarterly meeting and perhaps to try to discuss various topics at subsequent meetings.

It is very uplifting to see so many of us who share the same condition, yet all with unique difficulties. All of the members I met had one thing in common ... TM did not define their lives. Yes, it makes all of our lives far more difficult, but perhaps it also teaches us how wonderful life can still be. I started the support group to try and help others and found that the person I helped most is me!

We truly are not alone!

Rob Pall in New Jersey  
Robthecfo@aol.com

## New York TM Support Group: Meeting with Dr. Julius Birnbaum

Pamela Schechter  
Littleprincess900@hotmail.com

The NY Support Group was started through my efforts to have the New York State Legislature declare "Transverse Myelitis Awareness Day"

so as to promote public recognition of TM. Fortunately, and with the help of Assemblyman McLaughlin of the State Legislature, these efforts were rewarded and the resolution/proclamation was passed by the Legislature. June 6, 1999 was designated TM Awareness Day.

On Sunday, June 29th, 2008 the principal speaker at our luncheon and support group meeting was Dr. Julius Birnbaum. We were joined by the Sjogren's Syndrome Foundation, New York City Support Group. The inclusion of this group at our meeting was related to the neurological symptoms that can develop with this disease (i.e., transverse myelitis).

Dr. Julius Birnbaum has worked with Dr. Douglas Kerr at the Johns Hopkins Transverse Myelitis Center. Dr. Birnbaum has focused on the proper diagnosis and treatment of patients with rheumatic syndromes and inflammatory neurologic disease. No other clinic in the country is exclusively devoted towards managing neuroimmunologic complications in patients with rheumatic disease. Dr. Birnbaum received his MD from Columbia College of Physicians and Surgeons and completed his residency in Neurology at Mount Sinai Medical Center in New York. Dr. Birnbaum recently completed a Rheumatology Fellowship at Johns Hopkins Hospital. Dr. Birnbaum discussed the diagnosis and care of patients with neurological disease occurring secondary to rheumatic diseases, such as Lupus and Sjogren's Syndrome; although, attacks of optic neuritis and TM can be associated with Multiple Sclerosis, as well as rheumatoid diseases. Dr. Birnbaum was interested in talking to people in the support group who have co-existing rheumatoid diseases and MS with neurological complications, as well as transverse myelitis. A question and answer period followed his presentation.

## TM Support Group in Upstate New York

I would like to start a TM Support Group in Upstate New York. I have had TM since December, 1964; almost forty-five years ago. I was twenty years old.

My attack was sudden and dramatic. A short period of time prior to the attack, I had been a finalist in the Miss Ottawa Rough Rider Beauty Pageant and had a budding future ahead of me as a fashion model and commentator which I had been aspiring to since the age of fourteen. This all took place in Ottawa, Canada where I was born, the eldest of seven children.

One night I had been feeling a sensation of ringing in my ear and was not feeling well. My parents contacted our physician who made a house call (as they did in those days). He checked me over, was not able to determine anything, and just told me to rest. The next morning I awoke and tried to get out of bed. My sister, with whom I shared our bedroom, saw me begin to fall and ran to catch me. Her foot got caught in the bed sheets and we both fell to the floor. I was in a state of total paralysis and an ambulance took me to the hospital. My family was totally devastated. I spent the next three months hospitalized.

The initial tests that were done were a Spinal Tap and Myelogram; the MRI had not yet been invented. Back in 1964 not very much was known about TM. If you can imagine, I was a total quadriplegic with no sensation whatsoever from the neck down, and I remember those tests caused such pain that I was screaming. I was diagnosed after a process of elimination. They determined that I had Acute Transverse Myelitis, an inflammation of the spi-

nal cord located at the base of my neck. I remember during my stay in the hospital that I always gave permission to the many doctors who wanted to come visit me, because this condition was so rare and they wanted to observe my symptoms. I also remember visits from doctors from the Montreal Royal Victoria Neurological Hospital. I was given daily injections of what I believe was Vitamin B12. I received other medications.

I started physical therapy and occupational therapy. During this period my dear father visited me twice daily, offering constant encouragement. I received visits from the rest of my family giving me the support needed to endure this difficult time. My mother made delicious homemade food packages for me and being of very strong faith went so far as to make a promise to G-d that if I got better, she would completely quit her habit of chain smoking. (My mother never smoked a cigarette again in her life.) Eventually, after three months, I was able to walk out of the hospital with the use of only one cane. I used this cane for only a short period of time. I was very determined that I was not going to spend the rest of my life in bed. Thank G-d, I had the support of a wonderful family.

In 1965, my father and sister accompanied me on a trip to Quebec City, a few months after my discharge from the hospital. We made a special pilgrimage to St. Anne de Beaupre, located 20 miles from Quebec City. There is a Holy Shrine dedicated to St. Anne. I left my cane behind in the main church with the thousands of others I saw there.

Fortunately, I had a miraculous recovery and completely regained the use of my limbs. I was able to live the next forty years of life in relative normalcy; no cane and no physical therapy. I had only a slight limp as there was damage

on the right side of my body. I did not have much feeling and especially in the right foot. My life as a model, walking down a ramp, was over. I was asked to judge beauty pageants, organized and was the commentator for many fashion shows, appeared several times on television and taught others how to model and show clothes. I never talked about my illness to anyone and literally forgot about it.

My family eventually moved to Montreal where I had a career as a make up artist and skin care specialist. Then I became a key representative for a major cosmetic company. I did a lot of traveling, drove a car, got married to a wonderful man and moved to Syracuse, New York. I lived a relatively normal existence during those many, many years. I was able to complete my college education, acquire a real estate brokers license in New York State and in Florida and even traveled extensively for several years in the capacity as representative of the women of my church in my region and also on a national level. I compiled a cookbook which was sold with all proceeds going to benefit my church. I never sat idle and lived a very full, meaningful life.

Then age hit me. It was when I was around the age of fifty-six or so. I started to have problems with my legs, spasticity, and bladder problems. Most of the doctors did not know what to do for me. I finally went to visit a neurologist who sent me to an urologist. I received the help needed to treat the bladder issues. I tried the pills for spasticity which did not help; they just put me to sleep. So I got off of these medications and I am happy to say that now I only take the minimum of medications.

Then in 2004, I fell to the floor on three different occasions. I was petrified, because I thought I was getting another attack of TM. For a period of

time, I had to walk with crutches and then two canes. Finally, after x-rays and other tests, it was determined that I needed a full right knee replacement. I started physical therapy to strengthen my legs before the needed surgery. I had the knee replacement in June 2005.

One day while I was at Physical Therapy, the therapist left me alone in the room. I was unable to stand on my own and was not able to get to the door to call anyone. This was a very scary feeling. After a while, somehow my legs got better and when I was able to stand, I asked the therapist to please walk me to my car. I was not sure I would make it home. When I got home, I had to sit on the stairs and go up the twenty-eight stairs backwards, one step at a time, just to get up the stairs of my house. I live in a tri-level house.

It was about this time that I went to visit my OBGYN doctor for an annual visit. He asked me how I felt. I responded that I did not feel great. I feel I am getting older and no one knows anything about Transverse Myelitis to be able to help me. He asked if I knew how to use a computer. I told him that I did. He told me to try to Google Transverse Myelitis and see what happens. I followed his advice and was absolutely shocked to discover a TM Organization. It blew me away. I started to search, read and devour the site. I contacted Sandy Siegel and was so happy when he actually telephoned me. This was just before the Symposium held in Baltimore in 2006.

Sandy advised me to try to find a physiatrist and I did (after I said a what? I had never heard of a physiatrist.) They put me into an AFO for a period of time and gave me the confidence to try to learn to walk again after the surgery. Having surgery on a leg that does not have total sensa-

tion and has muscles suffering from spasticity, did not lend itself to an easy recovery. The Orthopedic Surgeon told me the recovery should be about three to six months, at most. In actuality, I was not able to drive for two years after the surgery. Three years after the surgery, I am still going to physical therapy three times a week. I work very hard just to maintain the ability to walk using a cane and regain a sense of balance. This was the third time in my life I had to learn to walk. All of this has been very taxing on me and has held me back in my ability to maneuver in my occupation as a real estate broker.

Sandy Siegel with his kind words convinced me that if I was at all able to attend I should not miss the Baltimore Symposium. Thank G-d I have a wonderful husband who was able to drive us to Baltimore. I found what I learned at that Symposium to be revolutionary, and I thank G-d every day that I did go, because I learned things that have actually helped me in my everyday life. It was also the first time in my life that I actually met others who were suffering with TM. Only after this trip was I able to start opening up and started talking about my experience with TM to others.

In 2008 we decided to attend the Seattle Symposium. After attending this symposium, I decided that I would like to start a support group in my area. I feel that if I can help even one other person suffering with this ailment, my life would have been worth all the suffering I have endured. The realization hit me that my suffering was nothing compared to the many others with TM that I have met. I wondered why I was miraculously spared a life spent in a wheelchair. I want to share my experiences and encourage others to keep a positive attitude; to live life one day at a time, to make the best of what you have, and, above all, to never give up hope. As Dr. Kerr has told me on two



different occasions, someone suffering with TM for 45 years is now prone to post TM syndrome caused from aging. This has led me to believe that it is very important to keep exercising, stretching and moving to fight the onset of age. If I do not, I will end up in a wheelchair.

I was not able to participate in the Accelerated Cure Project because I do not have any medical records from the time I was diagnosed with TM. It is so important to keep copies of all of your medical records. I would encourage you to do this. I also encourage everyone to enroll in the ACP repository.

If you live in the Upstate New York area and would like to get involved in a support group, please call or send me a letter or email. I look forward to hearing from you.

Laraine Mahshie  
313 Wedgewood Terrace  
Syracuse, New York 13214  
(315)446-0611  
lmahshie@myelitis.org

### Sharecare Ghana: Support for people with neuroimmunologic disorders in Ghana

*Reprinted with permission from The Accra Daily Mail*

#### Facing the challenges of autoimmune diseases in Ghana...

##### Only 4 Doctors Available

By Kofi Agyepong, The Accra Daily Mail, June 20, 2008

In a country with a population of over twenty million people, there are only four doctors qualified in the field of neurology to confront such a vast area of medicine; this came to light yesterday during the launch of an advocacy NGO – Sharecare Ghana – for people with autoimmune conditions. The organization has attained interna-

tional recognition and is affiliated to the Transverse Myelitis Association in the US.

In Ghana, the Noguchi Memorial Institute for Medical Research (NMIMR) has signalled its willingness to begin a study into autoimmune diseases and the College of Physicians and Surgeons has also agreed to lend support to the organization's efforts.

Speaking at the launch, the Coordinator of Sharecare Ghana, Nana Yaa Agyeman said the aim of the organization is to "reach out to people who have had or are living with long-term illnesses and want to share their experiences, expectations and treatment options".

"One of our objectives is to campaign towards the inclusion of autoimmune conditions in the National Health Insurance Scheme...At the moment, even though some of us pay our premiums, we still have to pay for expensive tests and medicines," she said.

Sharecare, she said, is seeking research, better diagnostics and treatment in the area of autoimmune conditions that has been largely ignored in the country. "For example, MRI scans are vital in monitoring many autoimmune conditions and yet, there is only one functioning MRI scanner in Ghana," she said.

Nana Yaa Agyeman said the unfortunate situation in the country is that some doctors do not accept that Africans are now getting these disorders. "This is unfortunate because although they were traditionally classified as rare, the diseases have actually been found to be not so uncommon within our society," she said.

Those living with these illnesses, she said, are not alone. "If you are

lonely, this is your chance to meet people who understand and can empathize."

The National Co-ordinator revealed that the organization has a website through which those affected can share their experiences, expectations and treatment options. "If you log on to www.sharecare.com, you can read other people's experiences and also share yours," she said.

In an address read by Alhaji L. M. Muniru, Deputy Director of Policy Planning, Monitoring and Evaluation at the Ministry of Health, for the Minister of Health, Major (Rtd) Courage Quashigah, the Minister said even though there is no separate policy and programme specific to autoimmune diseases, it can be said that government's policy on autoimmune disorders falls within the overall policy, goals and strategies of the health sector.

"It is government's policy to develop systems to reduce the burden of disease, mortality and disability suffered by those afflicted with the disorders and to reduce inequality in access to health and health services," he said.

Government, he said, cannot achieve all the health policies on its own due to the complex and multifaceted nature of the disorders. Major Quashigah called for private participation in financing health care, since according to him, "the cost of financing health care especially chronic disorders such as autoimmune disorders is very huge".

He said the government would continue to improve access to health services by expanding health facilities throughout the country. Autoimmune diseases and diseases of the central nervous system often don't show a clear pattern of symptoms and are therefore difficult to diagnose.

The symptoms may include some or all of the following: numbness, vomiting, loss of body co-ordination and muscular spasms, vision impairment or loss, fatigue, tingling sensation, weight changes, depression, constipation, diarrhea and others.

Autoimmune diseases include the following: Rheumatoid Arthritis, Acute Disseminated Encephalomyelitis (ADEM), Multiple Sclerosis (MS), Transverse Myelitis, Neuromyelitis Optica (Devic's Disease), Lupus and others. Ghana's healthcare delivery system is more geared towards the treatment of diseases like malaria, HIV/AIDS, the five killer diseases in children with very little attention being paid to other equally debilitating ailments.

There are practically only two practicing neurologist in the country, whose work load gets heavier by the day as a result of the rising numbers of people being diagnosed with autoimmune diseases.

Presentations were made by Drs. Albert Akpalu (Neurologist) and Ida Kuwornu (Internal Medicine) both of Korle-Bu Teaching Hospital on the definition and clinical manifestations of autoimmune diseases and Dr. Michael Ofori (Immunologist, Noguchi Memorial Institute for Medical Research) spoke on the "Scientific background to autoimmune diseases".

Professor Paul Nyame, Rector of the Ghana College of Physicians and Surgeons, who chaired the launch called for the strengthening of the National Health Insurance Scheme. He expressed the regret that it had been unduly politicized and called on Ghanaians to support it to make it work so that the most vulnerable in society could enjoy quality medical and healthcare.

The function was attended by sufferers

of autoimmune diseases, their families, members of the medical profession, the media and related NGOs.

The Accra Daily Mail  
Editorial, June 20, 2008

#### **What are you suffering from?**

Malaria, HIV/AIDS, tuberculosis, and the five or six childhood killer diseases are among a host of popular ailments that receive the bulk of many countries' health care delivery efforts, but are they the only diseases that afflict and eventually kill people? The answer is a deafening NO!

Yesterday an advocacy group, Sharecare Ghana was launched at the Ghana College of Physicians and Surgeons to highlight autoimmune diseases in Ghana.

It is an area that has received scant attention from the Ghanaian medical community, including the policy formulators at the Ministry of Health and the clinicians themselves, but there is evidence that autoimmune conditions are on the rise and may probably account for a large number of ailments that present themselves as the popular ones mentioned above.

The presentations made at the launch by a number of medical experts pointed clearly to a very troubling and troublesome medical area that needs more support, more research, more understanding and certainly a national policy on treatment and care. For a country of over twenty million people, there are only four neurologists! Incredible! Until fairly recently, there was no MRI scan in the country. Now there is one at Korle Bu to serve a nation of 20 million plus people.

What Sharecare Ghana has started needs our support. We are pleased that the Noguchi Medical Research Institute has agreed in principle to

conduct research into the area and the Ghana College of Physicians and Surgeons has also signalled its support.

In his launching address, the Minister of Health did also give the indication that it is the government's policy to make Ghanaians healthy to live long productive lives and therefore would support efforts of groups like Sharecare Ghana. That is welcome news, because that feverish feeling you may be thinking is malaria, could be the beginning of a long and debilitating autoimmune condition....

#### **Transverse Myelitis Scotland Support Group: Meeting with Dr. Anu Jacob**

The TM Scotland Support Group was so privileged to have Dr. Anu Jacob attend one of our meetings on October 16th 2008 in Glasgow. Dr Jacob is a Consultant Neurologist at The Walton Centre for Neurology and Neurosurgery NHS Trust in Liverpool specializing in MS and other demyelinating disorders, including neuromyelitis optica (Devic's disease), transverse myelitis, acute disseminated encephalomyelitis and optic neuritis. This was Dr. Jacob's first visit to the Scotland group and 22 members attended, including four with Devic's disease. He gave a talk about NMO and took questions from our members. He described the treatment trials he has undertaken showing the efficiency of certain medications. After lunch we had an opportunity to exchange experiences of diagnosis, managing symptoms, coping techniques, and carer's issues.

#### **A Support Network for people with both Neuroimmunologic Disorders and Rheumatic Disorders**

Hello! My name is Sharon Robinson and I've volunteered to be a Support

Group Leader for those of us who have both neuroimmunologic disorders (TM and NMO) and rheumatic disorders (Lupus, Sjogrens, Sarcoidosis). I have TM and Lupus. When Sandy asked me to write a little bit about myself for the newsletter, I started to launch into yet another version of "How I got TM." It seemed only natural since (a) this is for the TMA, and (b) TM seems to occupy 90% of my mental energy some days. But instead, I thought that I'd start out by writing about who I am and what I do – because we are all individuals with lives and families and hopes and dreams, besides having TM.

I was born and raised in Northwest Ohio, but after going to college in Syracuse and Milwaukee, I moved to Bellingham, Washington, a small-to-medium sized town about 80 miles north of Seattle. I am an owner and principal in a busy 16-person architectural firm. We do all sorts of projects from custom homes to schools, fire stations, office buildings and condominiums. In addition to my work, I am on the City Planning Commission, the board of my Rotary Club and volunteer for a couple other community non-profits. I'm almost 48 years old. (Hey, "almost" is important when you start getting this close to the big Five-Oh!) I live in an 80-year old constantly-being-remodeled house with Greg, my significant other, and Milo the Great Pyrenees (that's the dog, not the mountain range, although he sort of resembles a hairy white mountain, if a mountain could bark). We also share the house with Peep the lovebird and Birdie the African Gray parrot.

Some of my passions are SCUBA diving, kayaking, gardening, and (usually) Seattle Mariners baseball (but we won't talk about that this year). Before TM, I was learning Irish step dancing, and I guess my one-quarter Irish blood must be strong, because the latest hobby I've taken up is learning to play the harp. Something about

Celtic music appeals to me, and it's a very relaxing and de-stressing pas-time.

OK, enough about me. Let's get back to TM. I want to commend Sandy for taking the initiative in organizing these various sub-groups of TM'ers. I know how hard it is when it feels like there is no one else in the world who has the same condition you do. For a while I thought that really might be true! When I was attacked by TM in March of 2006, it was enough of a struggle to try to find anyone who had even heard of TM much less anyone who had it.

Thanks to the wonders of the internet, I found the TMA, all the fantastic information on their web site, and best of all, the site's forum, where there were dozens of other people just like me, trying to come to grips with a weird new malady and being supported by many other people who'd had TM for years, who could offer us support and understanding. I'm still a fairly active participant on the board, and try to help respond to the newcomers who are more often than not in a shell-shocked state. I post under the pseudonym "Sheryl" because I'm a little reluctant to post my full real name in public forums, but now you all know the secret identity of Sheryl!

During the month after my attack, I made the usual rounds of specialists and tests. Most of the people I saw focused on MS. Because my first attack was relatively mild, and because there is such a cluster of MS in this region, it was almost assumed that my TM was the first sign of MS. My primary provider even sat me down and had the standard, "learning to live with MS" talk, complete with informative brochures. However, none of the other symptoms that would have confirmed or even pointed toward MS were present.

I was referred to a rheumatologist, because some specific antibodies in my blood work made my primary care provider suspicious. The rheumatologist confirmed what we had already started figuring out. It sounded like the punch line to a bad joke: "The good news is you don't have MS. The bad news is you have lupus." It was also explained to me that the high levels of the anticardiolipin antibody in my blood indicated that I probably had another autoimmune condition, antiphospholipid antibody syndrome (called APS in the US, and APLS or Hughes Disease in the UK).

Sheesh! Now not only did I have this rare few-in-a-million thing called Transverse Myelitis, but I was one of the small percentage of cases that is caused by an underlying autoimmune disease. To fast forward a little bit, I found out in October of 2007 that I am *also* one of the even-more-rare cases of recurrent TM. My symptoms of the first attack were only sensory – numbness, pain and loss of proprioception. But last fall I started to develop weakness in my right leg, and over the course of about four days, it became completely paralyzed. My doctors said it was clear my immune system was running amok, and we decided to try six monthly doses of the chemo drug, cyclophosphamide (Cytoxan). While still on that drug, I had a second but more mild relapse. In April of this year I was able to go to Baltimore to consult with Doctors Kerr and Petri at Johns Hopkins. They recommended that I begin taking CellCept, an immune suppressant given to transplant patients. Since then, I've had no relapses (knock on wood), and have regained most of the use of my leg. It's still weak. I walk with a limp and can't run (yet), although I'm still hopeful that I'll get back enough strength for that.

So, that's the story. I have this weird form of lupus that causes no other

typical lupus symptoms but goes straight for the spinal cord. Thanks to Sandy and the TMA, I know that there are others out there like me – or at least others whose TM is caused by or overlaps with lupus or one of the other rheumatic disorders such as Sjogren's disease or APS. We've decided to start this group in order to support each other and any new members of the TMA who indicate that they are interested in reaching out to others.

I currently have a list of 21 people who have requested to be included in the Neuroimmunologic/Rheumatic Disorders Group, and Sandy will be relaying to me the names and contact information of new members who indicate an interest in our support group. Of course, anyone reading this who would like to be included is encouraged to e-mail or call me. I plan to contact new members to "welcome" them to the TMA and let them know about our support group. I also plan to contact everyone I have on the list now by e-mail in order to make sure our information is current and that they still want to be included in the support group. If you haven't received an e-mail from me by the time you read this, and you would like to join the support group, please let me know. I'd also like to hear what support group functions would be most useful for everyone.

I'm new at this role, so I'm looking for input and ideas from anyone who has suggestions. In my mind, the purpose of the group is to support each other and share information about our own experiences. I also want to keep the group informed of any research that is going on in our areas of interest, and to let you know about upcoming TMA symposia or other events in your area.

Jim Lubin has set up an area for us on the TMA message forums:  
<http://myelitis.org/phpBB2/viewforum.php?f=98>

This will allow us to communicate with each other in addition to using e-mail, phone and/or regular mail. We certainly are a diverse group - of the 21 folks now on the list, we are spread to all four corners of the US and three other countries, as well. There are five TM/Sjogren's sufferers and 16 who report having lupus and TM.

I'm really looking forward to getting in touch with our little community and hope that we can all help to create a supportive network for each other!

Sharon Robinson  
 2716 Walnut Street  
 Bellingham, WA 98225  
 (360) 671-8415  
[rufusandchi@yahoo.com](mailto:rufusandchi@yahoo.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.

1. Recurrent Transverse Myelitis
2. Transverse Myelitis or NMO with HIV
3. 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](mailto: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](mailto: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](mailto: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](mailto:Rufusandchi@yahoo.com). A directory will be published and mailed to everyone who is on the list.

## Awareness and Fundraising

### Heart of Hope Bracelet Benefiting the TMA: A very special friendship

Kathie Ketels-Lichtig

We started out as “professional” friends in October 2004. Cynthia Noonan was the “go to” girl at the Bay Area ALS Association office and the volunteer coordinator extraordinaire! I was a brand new caregiver to my husband, Bill, a newly diagnosed ALS patient. Once we signed up for the annual fundraising walk, we started interacting with the staff and Cynthia. When Bill and I became the honorary walk chairmen for 2005, we began to see more and more of Cynthia. She was a huge help in organizing our friends, and we became two of her “regular” volunteers. She is thoroughly organized, easy to talk to and I think it was her winning smile that helped to quickly move us to a casual, personal friendship.

Intense, life-changing events tend to compound time spent together...kind of like dog years where 1 = 7! While we had only known each other for about a year, I think we covered the ground that some relationships take 7+ to cover! Bill and I had committed to completing all of the walks. So even though he died in the summer of 2005, I finished all seven of the walks with the help of my friends – including Cynthia – who always seemed to be by my side, offering a hug, a smile, a word of encouragement or just a simple hand to hold to steady my voice/nerves before I spoke. She says, “You just gravitate to the good people!” I believe she’s right!

Fast forward two years to the fall of 2007. I am a jewelry artist and had finally come up with a way to combine my jewelry business with a charitable

giving aspect to benefit the ALS Association. Cynthia and the staff were enthusiastic and generous in their encouragement and feedback! In February 2008, the Heart of Hope for ALS bracelet was officially launched!

November 2007 is also the time when Cynthia received her TM diagnosis...an event she compares to “being hit by a really big truck!” Only this time, she found herself on the receiving side of the kindness and generosity of friends and family – somewhat uncomfortable for one who knows only giving! And yet, displaying the same grace and good humor that we have come to appreciate in her, Cynthia has opened her heart and her new life to her friends.

To honor Cynthia and our friendship, I thought it would be fun to create a special bracelet that could be sold to friends and family to help defray some of her medical expenses.

Working with two of her friends/coworkers, we were able to get Cynthia to share some of her favorite colors and I was able to design “Cynthia’s bracelet”. True to her generous spirit, when we got together to show her the prototype and discuss the business details, she 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 my website:  
<http://www.kathielichtigstudio.com/transvers-myelitis.html>

I’ve heard it said that people come into your life for a reason, a season or a lifetime. Originally, I would have bet that my relationship with Cynthia would have earned a “reason” tag. Now...I believe we are on the path to a lifetime friendship...and I am truly blessed!

To learn more about Cynthia:  
<http://noonansupport.blogspot.com>

### Purchase Seasonal or Anytime Cards from Café Press and Support the TMA

Sandy and Margaret Smith are members of The Transverse Myelitis Association from Pittenweem, Fife, Scotland. They are also 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 and proud to be able to offer you these beautiful pieces through Café Press. We urge you to consider using 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. 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 assess membership fees. As TM is a rare condition 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.

I hope you will take the opportunity to enjoy Margaret's work and to support our important cause. Thank you, Margaret, for your very thoughtful donation of your wonderful artwork for all of us to enjoy!

<http://www.cafepress.com/tmagifts>

### 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 proceeds 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>

### The Christmas Card Campaign: Help Us Fund Research on TM, NMO, ADEM and ON

If we are going to raise money for research, the vast majority of it is going to come from you and from your friends and family. Why? Because they are the only people in the universe who know about these conditions and they are really the only people who care! I am not comfortable asking my family for money. I

am less comfortable asking my friends for money. I am no different than you. But I have learned to do it, because I have come to accept that this is the only way I can make the difference for Pauline and the so many others of you whom I have come to love and care about so deeply.

I have an idea which I think might make this easier for you to accomplish. I have written a letter and have posted it on our web site. I have included important information about TM and the neuroimmunologic disorders, about the TMA, and why it is important for the TMA to succeed in raising money for research. The letter is created in Word. Since most people have MSWord on their computers, I am encouraging you to personalize this letter. Please include information about how TM or ADEM or NMO have impacted your lives, and why you need for this research to be done.

When you send Christmas cards this year, and every year, please include a copy of this letter in your card. Just fold it and put it into the card. And, if you don't celebrate Christmas, you can include the letter with any regular correspondence you have with your family and friends.

Please type the following address into your web browser to find the fundraising letter.

<http://www.myelitis.org/fundraisingletter.htm>

Scroll down to the bottom of the page to find the link to this letter in Word. Once you have the Word file open, you will be able to edit the text to personalize the letter for your family and friends. Please do this for yourselves and do it for the other children and adults in our community who need this research and the great hope that this research brings for all of us. The cost of adding this letter to your cards will be minimal. The amount of

time and energy involved in sending this letter with your cards will be minimal. **The positive impact of sending this letter in your cards can be enormous – for you and for everyone in our community!**

## Recycling Programs

First, we want to thank you for having chosen to help all these years with our recycling programs. The Transverse Myelitis Association has received \$9,694.00 from recycling toner cartridges and inkjet cartridges since 2005.

The recycling company we had partnered with since 2005 sent us a letter in the middle of June informing us that they were forced to suspend our program due to rising shipping costs. They said it was no longer cost effective. Apparently they must have stopped sending boxes before notifying us. They would not process cartridges received after June 30, 2008.

When we received notice of the cancellation of the program, Jim searched for another company to partner with, and found Funding Factory Recycling Program. We have now partnered with the Funding Factory Recycling Program to collect empty inkjet and toner cartridges so that we can continue our fund raising efforts. For information, please see 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. That saves the expense of the company sending out the boxes first. If you have already been registered with the old company, we were able to transfer some of the old accounts to the new company. Before registering, try to use your old account. 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 also have a company that recycles cell phones. This is also available from a link on our website at [www.myelitis.org](http://www.myelitis.org). Just click on the logo that says "cell phone donation". This is a bit easier. You can go to the link, print your own label, place used cell phones in a box, tape it shut and affix the label to the box. Then take the box to the post office or give it to your mailman for delivery.

Thanks again for helping us in the past. We do hope that you will continue to help us raise money for all of the important programs and services that are provided by the TMA without charging any membership fees.

## Help Raise Awareness with a TMA Wristband

For the past 3 years, thousands of our members have been helping to raise awareness of transverse myelitis 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](http://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 transverse myelitis, ADEM, NMO, optic neuritis and the other rare neuroimmunologic disorders.

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](http://www.myelitis.org/wristbands.htm).

For check payments, you would 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 you shipping for you, you can send an email to [wristbands@myelitis.org](mailto: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 informa-



tion.

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

## Where in the world are the TMA Wristbands?

As part of the TM Awareness campaign, we are collecting photos of people from around the world wearing the signature TMA wristbands. If you would like to send us a photograph of you, your family, or friends we would love to have it for our collection.

Here's is what we would like for you to do. Please have a photograph taken of you or a family member and be sure that the wristband is clearly visible in the frame. Tell us who you are and identify where the photograph was taken. If you live by, or will be traveling to, a famous landmark, it would be great to include these places in the photograph. When you take the photograph, please be sure that the landmark appears in the background. We encourage you to be creative! Any background will do; we would love to see you wearing the wristband in the photograph. We will be posting many of your submittals on our website.

TM touches lives all over the globe and this is a simple, tangible way to show we are all connected.

To submit a photo, e-mail it to [wristbands@myelitis.org](mailto:wristbands@myelitis.org)

We can't wait to see you!

## Helping to Fund the Work of Your TMA

The TMA does not charge membership fees. 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.

### GoodSearch

The TMA can earn money every time you search the Internet. The Transverse Myelitis Association is participating in GoodSearch, a new Internet search engine that donates half of the advertising revenue it earns to charity. Each time you use GoodSearch and designate the TMA as your charity of choice, GoodSearch will donate a portion of the advertising revenue earned from the search to the Transverse Myelitis Association.

It's easy to use. Just go to the GoodSearch homepage [www.goodsearch.com](http://www.goodsearch.com) and type 'myelitis' into the "Who do you GoodSearch for?" box, and click verify. After the first time, each time you return to the home page, The Transverse Myelitis Association will appear as your designated charity. There is even a button you can click to see the number of searches and the amount raised.

Add GoodSearch to your bookmarks or make it your homepage to make it easier to use. Also, spread the word to your family and friends to help generate more contributions. GoodSearch estimates each search will raise \$0.01 for your designated charity. The pennies quickly add up. If 100 people searched twice a day, we would receive \$730 a year; 1000 people could earn \$7,300; and 10,000 people could generate \$73,000.

With your help, GoodSearch can generate donations, at no cost to you, that will help fund the TMA's programs: <http://www.goodsearch.com/?charityid=607112>

### 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.

**iGive.com** You can shop at more than 650 stores through iGive.com. You can find books, CDs, videos, software, office supplies, groceries, gifts, flowers, cookware, greeting cards and more at the iGive Mall and from top merchants like Barnes & Noble, Drugstore.com, Harry and David, Best Buy, Sharper Image and Dell.

**Café Press** You can purchase TMA logo items through Café Press.

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

### 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.



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.

### Donating by credit, debit, or gift card has never been better!

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. TMA will receive 100% of your donation using Google Checkout until 2009. 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!

### 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/donation-form.htm](http://www.myelitis.org/donation-form.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!

## The TMA Equipment Exchange

Please participate in the TMA Equipment Exchange on [www.myelitis.org](http://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

1. 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.
2. 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.

3. 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.

4. 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](mailto:exchange@myelitis.org)

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

6. 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.

7. If you have any comments or questions regarding the TMA Equipment Exchange, please send an e-mail to [exchange@myelitis.org](mailto:exchange@myelitis.org). Thank you.

## Support Group Leaders

### Support for Women during Pregnancy and Preconception

Donna Chattin  
 (410)459-4195  
[donna\\_chattin@comcast.net](mailto:donna_chattin@comcast.net)

### ADEM Support Group

Barbara Kreisler  
 (703)753.4000 (Home)  
 (571)436.9034 (Cell)  
[bkreisler.imprint@verizon.net](mailto:bkreisler.imprint@verizon.net)

**Devis-Support**

Pamala (Grace) Mitchell  
(724)966-8157  
gmitchell@myelitis.org

Sandy Barry  
(978) 282-1825  
sbarry@myelitis.org

**Devic's Syndrome/NMO Support Group**

Gaylia Ashby  
United Kingdom  
gayle@devic.org.uk

**TM and Rheumatic Disorders**

Sharon Robinson  
(360)671-8415  
Sharon@zervasgroup.com

**Optic Neuritis Support Group**

Kristin Lee  
(724)847-7999  
kmarie1016@hotmail.com

Jenn Nordin  
(714)231-1808  
Jenn@jenndesigns.com

**Arkansas**

Pat and Al Tolle  
(870)435-2760  
ptolle@gassville.net

**California**

Deborah Capen  
(951)658-2689  
dcapen@myelitis.org

Cindy McLeroy  
(714)638-5493  
cindymcleroy@socal.rr.com

**Northern California**

Judy Melcher  
(209)334-0771  
judymae@pacbell.com

**California Bay Area**

Doreen Christensen  
(707)644-3231  
fresprit@ix.netcom.com

**San Diego**

Christine Davis  
DrDavis@SDOptometry.com

**Florida**

Brad Highwood  
(772)398-3340  
wheels1@comcast.net

James G. Jeffries  
(352)249-1031  
mojimjeff@embarqmail.com

**Georgia**

Charlene B. Daise  
(404)289-7590  
cdaise@bellsouth.net

CSRA TM Support Group - serving the  
Central Savannah River Area of SC & GA  
Vicki McKie  
(803)278-4819  
mamamckie@hotmail.com  
**Support Group website:**  
<http://myelitis.org/local/csra/index.htm>

**Idaho**

John Craven  
(208)939-7968  
jscraven@msn.com

**Illinois**

Nicolette Garrigan  
(773)774-6554

Jeanne & Thomas Hamilton  
(847)670-9457  
jeannemarieh@msn.com

**Kentucky**

Andy Johnson  
(859)552-5480  
andy.johnson@uky.edu

**Louisiana**

Delores Graham  
Home: (504)469-4465  
Cell: (504)258-4413  
E-mail-deegraham4@gmail.com

**Maine**

Colleen Graff  
cjc@kynd.net

**Maryland**

Alan & Kelly Connor  
(410)766-0446  
aconnor@myelitis.org

**Massachusetts**

Leslie Cerio  
(781)740-8421  
lccerio@comcast.net

**Michigan**

Lynne Myers  
lynnemyers1@yahoo.com  
(269)789-0452

**Minnesota**

Karen Nopola  
(612)270-1122  
Nopola@comcast.net

Dean H. Peter  
(651)492 0074  
Neuaubing1962@yahoo.com

Darian Vietzke  
(763)755-3515  
vietzke@myelitis.org

**Missouri**

Rhonda Loggia  
(636)537-8471  
rloggia@aol.com

**Montana**

Desiree' and Clint Van Blaricom  
(406)299-2030  
racheldes03@hotmail.com

**Nevada**

Mary Wolak  
(702)645-3657  
Notahorse4@aol.com

**New England Tri-State Area Support Group**

Krissy Zodda  
(603)589-1894  
tmladyk@yahoo.com

**New Hampshire**

Suzanne McCutcheon  
(603)332-9380  
cutch4@aol.com

**New Jersey**

Robert Pall  
(732)536-5308  
robthecfo@aol.com

**New York**

Pamela Schechter  
(718)762-8463  
pamjam7@yahoo.com

Shannon O'Keefe  
(585)330-1125  
shannonjokeefe@hotmail.com

**Syracuse**

Laraine E. Mahshie  
(315)472-2667  
lmahshie@myelitis.org

**North Carolina**

Paul Stewart  
(704)543-0263  
brk4you@bellsouth.net

**Ohio**

Kathleen Karoly  
(419)354-7316  
kkaroly@dacor.net

Stephen J. Miller  
(937)453-9832  
happyfamily@wildblue.net

Margaret Miller  
(614)486-2748  
Magmil1336@aol.com

James E. Tolbert  
(513)724-1940  
jimyt2@roadrunner.com

Linda Garrett  
(740) 674-4100  
Limoga43734@yahoo.com

**Oklahoma**

Ginger Jerez  
(580)342-5144  
luvznushoes@yahoo.com

**Pennsylvania**

Morgan & Pamela Hoge  
(724)942-3874  
Hoge5@msn.com

Sue Mattis  
(814)899-3539  
bobsue6095@adelphia.net

**Puerto Rico**

Yvonne Lugo Del Valle  
(787)312-9711  
yvonne@labelgraphicscaribe.com

**South Carolina**

CSRA TM Support Group: serving the Central Savannah River Area of SC & GA  
Vicki McKie  
(803)278-4819  
mamamckie@hotmail.com  
**Support Group website:**  
<http://myelitis.org/local/csra/index.htm>

**Tennessee**

Mary Troup  
(901)213-1698  
Work7days@aol.com

Richard Ashford  
(901)476-4335  
ashfordr@att.net

**Texas**

Robert W. Cook  
(281)528-8637  
rcookhook@earthlink.net

Cossy Hough  
(512)420-0904  
cossyh@yahoo.com

Barbara Lamb  
(817)239-1972  
Babbsie1982@yahoo.com

**Virginia**

Agnes Killough  
(757)422-4024  
agnesestm@yahoo.com

**Virginia/southwest area support group**

Drema O'Dell  
(540)230-6402  
dho.dell@comcast.net

**Washington & Oregon**

Bud Feuerstein  
(425)398-4365  
budfeuerstein@verizon.net

Mike Hammond  
3jmhammond@clearwire.net  
(360)658-5878

**Wisconsin**

Lynn Seifert  
(715) 442-5205  
tmamnwi@yahoo.com

**International****Argentina**

Marina Lopez  
saubidet@cvtci.com.ar

**Australia**

Ian Hawkins  
61 7 3206 4618  
ihawkins@futureweb.com.au

Errol White  
61 07 3886 6110  
eamjwhite@bigpond.com

**Brazil**

Patricia Sirotheau de Almeida Eichler  
021 83472817  
peichlet@myelitis.org

Ricardo Borges  
55 62 3295 6197  
rborges@myelitis.org

**Canada**

Marieke Dufresne  
(514)489-0471  
marieke@myelitis.org

Kimberley Kotar  
(514)636-9337  
kimberley.kotar@mail.mcgill.ca

Dan Kilborn  
(403) 652-4347  
dan.kilborn@shaw.ca

**Colombia**

Eddy Mesa  
(4 ) 413 69 45  
emesa@myelitis.org

**Denmark**

Mette & Thomas Nybo Jensen  
45 76 90 50 75  
mettenyboj@hotmail.com

**Ghana Support Network**

Nana Yaa Agyeman  
233-21 220084  
sharecare4u@gmail.com

**Germany Austria Switzerland**

Ursula Mauro  
07807 3154  
umauro@t-online.de

**India**

Abhijit Ganguly  
91 9433702379  
abhijitganguly2006@yahoo.co.in

**Ireland**

Ann Moran  
098-26469  
Annmoran99@yahoo.com

**Italy**

Federica Boiani  
+39 (0)6 8547 829  
f.boiani@mielite.it

Andrea Bianchini  
A.bianchini@mielite.it

**New Zealand**

Steve & Alison Alderton  
64 3 3857274  
Seal4@xtra.co.nz

Dyllice Eastwood  
649 8109807  
dyllice@hotmail.com

Jennifer Murray  
09 834 5019  
Murray\_fam@paradise.net.nz

**Romania**

Dan Bucataru  
0040.021.252.59.36  
Skype adress: dan.bucataru (Romania)  
dan.bucataru@yahoo.com

**Scotland**

Margaret Shearer  
01292 476 758  
margaretshearer@hotmail.com

**South Africa**

Jenny Moss  
082 928 3000  
Moss25@mweb.co.za

Mart Uys  
012-361-7671  
martuys@iburst.co.za

**Sri Lanka**

Ivan S Fernando  
94773451279  
Ivan\_s\_fernando@wvi.org

**Sweden**

Ulrika Pettersson  
ulrikap@it.uu.se

**United Kingdom**

Lew Gray  
020 8568 0350  
lewgray@blueyonder.co.uk

Sally Rodohan  
020 8883 2721  
sally@apinfo.co.uk

Officers and Board of Directors of The Transverse Myelitis Association

Sanford J. Siegel  
President  
1787 Sutter Parkway  
Powell OH 43065-8806  
(614)766-1806  
ssiegel@myelitis.org

Deborah Capen  
Secretary  
PO Box 5277  
Hemet CA 92544  
(951)658-2689  
dcapen@myelitis.org

Honorary Board of Directors

Deanne Gilmur  
Founder

Paula Lazzeri  
Treasurer  
10105 167th Place NE  
Redmond WA 98052  
(425)883-7914  
plazzeri@myelitis.org

Jim Lubin  
Information Technology  
Director  
jlubin@myelitis.org

[www.myelitis.org](http://www.myelitis.org)

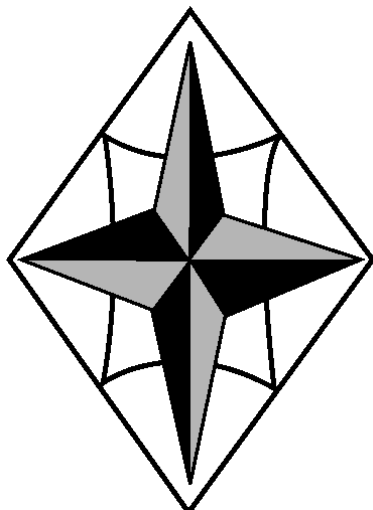
---

The Transverse Myelitis Association

Powell Ohio  
43065

---

Sanford J. Siegel  
1787 Sutter Parkway  
Powell, Ohio 43065-8806



---

*Summer Camp for Kids with TM, ADEM, NMO  
or ON and their Families: August 12 – 16, 2009,  
Victory Junction Gang Camp, Greensboro, NC*

---