The Transverse Myelitis Association Newsletter

The organization advocating for children, adolescents, and adults with the spectrum disorders of acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis

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From the Editor
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Acute Disseminated Encephalomyelitis

The primates who were the common ancestors of humans and apes lived in the trees. That explains why we have eyes in front of our faces as opposed to the sides of our heads. Depth perception is highly valued when your home is up in trees; not judging the distance to that branch could be a fatal mistake. And how would you apply eye liner if you had to close one eye on the side of your head with the other eye located on the other side of your head. Over a period of many many many generations, a phenomenal collection of both behavioral changes and physical changes took place among our ancestry that formed the foundation for our becoming human (*Homo sapiens*).

We came down out of the trees to live on the savanna grasslands of Africa. We likely came to the ground seeking food and because it is very scary and uncomfortable to sleep on a tree branch. We were quadrupeds (walked on all fours) when we lived in the trees and when we first came down out of the trees. Walking upright was more adaptive for our ancestors, allowing them to more easily see predators in the tall grass and eventually to be able to perform text messaging with one's forearms while ambulating. Bipedalism became all the rage and, over a long period of time, caused significant changes in the structure of the pelvis. There was a considerable narrowing of the birth canal from our quadruped existence. Most quadrupeds don't feel the necessity to sign up for a Lamaze class.

At the same time that our ancestors were walking upright and beginning to manipulate objects in the environment with their hands, which were freed up from locomotion, their behavior was also becoming much more complex. These very early humans or hominids were becoming more and more intelligent; their brains were becoming larger. Let's see, brains getting much larger at the same time that birth canals are getting much smaller. There must have been a fairly strong and rapid, in macro-evolutionary terms, selection for individuals who were born with smaller and less developed brains. The selection must have been fairly rapid in evolutionary terms because infants with large brains would likely remove the mothers (and themselves) with the genetic traits for large and highly developed brains at birth from the gene pool. The selection was for individuals who had smaller, less developed brains that would grow after birth.

This change in the size of the head or the underdeveloped brain also meant that the offspring of these early hominids were going to be dependent for a much longer period of time. It has always amazed me just how quickly most animals are up on their feet, eating and exploring their environment almost immediately after birth. Human infants are totally dependent from the time of birth and for a very long time. For those of you with a 24-year-old child living in the basement and self-actualizing with Madden on his xbox 360, you understand how humans have developed this dependency thing into an art form. Luckily for these early hominid infants, at the same time that they were being born totally dependent for their survival, our ancestors were developing groups that would form the basis for stable social relationships over long periods of time. These groups were also developing divisions of labor which allowed a woman to focus on caring for her infant while someone else, like Joe the hunter, went off to find them food.

These humans were developing culture, a way of life that they were going to pass down from generation to generation. Culture is learned and it is shared by a group. Culture is taught by parents and the other members of the group. Culture includes everything we know and all that we believe. Over the many, many generations, our ancestors were developing so much more to learn. For a long time, adults would tell us everything we had to know and we would memorize everything they passed down to our generation. Eventually, the amount and complexity of this culture grew until there was so much information that we had to start writing it down. Small groups could no longer handle teaching all of it on their own, so they developed public education, colleges, and professional and graduate programs. Wow, my brain grew a whole centimeter while I was writing that; it's a good thing that my really large head is balanced on top of my body; I'm not sure how my neck muscles would handle the weight otherwise.

I taught physical anthropology and human evolution for four years at The Ohio State University. I know that many of you don't subscribe to this ex-

planation of our evolutionary origins. I respect your beliefs. I suppose it is possible that fossils are just G-d's chotchkes. Every society has an explanation for how we came to be here; and every explanation is different. This happens to be the one I subscribe to for who, what and why we are human. I used to tell my students who totally didn't believe any of this evolutionary stuff that I wasn't interested in converting anyone to a way of thinking; they just had to memorize every single word that came out of my mouth and be able to regurgitate it on exams. Hey, it wasn't a debating class; it was a course on human evolution.

Opposable thumbs are really cool, but what makes us human is our brains. Since the practice of modern medicine in the nineteenth century, we have learned an incredible amount of information about human physiology. It is amazing that this organ that is so central to who we are and how we function is so little understood. Almost all of what we are and who we are is learned. Talking about language is a good way to describe the important relationship between the physiology of the brain and the influence of culture. Every human being has the capacity for language. This capacity must be structured in our brains as some collection or wiring of neurons, but these are not specifically identified. We know there are speech centers in the brain, because when they are damaged, people lose the ability to speak. But that's about as specific as we are about the physiology. While the capacity exists for every human to speak, what we are speaking depends on the language you learn from infancy. If you are born in Japan, you are going to learn Japanese and if you are born to Hopi parents, you are going to speak Hopi. The ability or capacity to use language is biology and what language we speak is learned. And speaking a language is more than the grammar and words we use to communicate. Language structures the way we perceive and make sense of the universe around us. Language creates categories that structure how we experience our world. Language is a fundamental part of and inextricably linked to culture.

Human beings are just phenomenally complex on so many different levels. Who we are as humans is a combination of biology and culture. Anthropologists have studied every society on the face of the earth and have developed a list of cultural universals; those institutions and elements that we find in every society. Some of these universals derive from our biological selves; what we have to do to meet our biological needs. Every society has rules about how we procreate and every society has methods for acquiring food, but the specific rules are amazingly diverse. In our society, it is frowned upon to marry a first cousin. In other societies, this person would be the preferred marriage partner. Likewise, what one society defines as a delicacy might be considered inedible or abhorrent to a different society. Every society functions to define how our needs are met, but the ways devised are unique to their way of life. And dare I say it; the differences are, for the most part, entirely arbitrary. Cultural universals reflect basic human needs, but only some of them are rooted in our biology; most of them have nothing to do with meeting our biological needs. Every society has adornment! Every society on the face of the earth has a conception of how to decorate oneself so as to "look good." Every society has an eschatology; a system of beliefs about what happens to the spirit when our physical selves are no longer here on earth. And, again, every society has devised a different description and explanation about what happens to the spirit. And, by the way, every culture has some conception of humans possessing a spirit. Our culture is learned. How we learn is a process or function carried out in our brains and all of what is learned is stored in our brains.

Because of the way we are raised, we "feel" like our way of life is the right way of life and the natural way of life. Our way of life, our way of thinking and believing, feels so natural that it feels as though it was programmed into the cells in our brains. It feels this way, because that is the way culture works. But if at the day of your birth you were adopted by a Kwakiutl family, you would be speaking Kwakiutl and feeling like the Kwakiutl way of life was the right way to think and believe and that all of the rest of the world was more than slightly dazed and confused. Culture is entirely learned; none of our way of life or our specific language is programmed into our brains at birth. There is no genetic basis whatsoever for our culture – our religious beliefs, our political activity, how our society is organized, how we define family, how we find a partner or any of the other important things we do as humans. And amazingly, we feel and think this way about our own way of life even with CNN world news available twenty-four hours a day, almost universal access to the internet and cell phones, supersonic jets and the myriad of other technologies we use that have connected peoples from around the world in very intimate ways and have shrunk the planet earth into a much smaller place. My way is still the right way of life; I just have to make this pronouncement sometimes in a whisper as opposed to screaming it at the top of my lungs while beating a big stick on the ground at my cave entrance. If the world were filled with cultural relativists, it would be near impossible to have people behaving themselves, because there would be no definition for what the correct, appropriate, acceptable behavior was supposed to be. And aren't we doing a wonderful job of behaving ourselves now.

The anatomy of the brain is well understood. I never went to medical school or studied anatomy so I don't know all of the parts of the brain. But I have no doubt that scientists and physicians know all of the structures of the brain; they know all of the different cell types and they know much about the biology and chemistry of the brain. With all that they know, I don't believe they have the slightest idea about what the biology is of a "thought" or the biology of a "belief." Well, that's what the brain is about for all of us. Everything we know and everything we believe is learned from early childhood. We learn from all of the remarkable and unique experiences that we have in our lives. No two people have the same experiences. I am a completely unique individual because I learned my culture from my parents, grandparents, Captain Penny, Barnaby and Ghoulardi. A great deal of what I have learned, I share with Jewish people of Ashkenazic descent who were orthodox and kept a kosher home and then married a Lebanese Catholic woman or that I share with people who grew up in Cleveland Heights and now live in Columbus or that I share with people who got married and had children or who went to college for long enough to be a brain surgeon but only have a degree in cultural anthropology. There is a tremendous amount of life experience that belongs uniquely to me. No one knows all of the same people that I do. No one has had the same collection of life experiences that I have had. And no one thinks about or makes sense of all of this experience in the same way that I do. And all of what I have just described about who I am, what I am, what I think and what I believe is stored in my brain, in all of those neurons that basically all look alike and have the same cell structure and chemistry. There aren't any parts of the brain that are labeled, "the religious belief neurons" or "the political affiliation neurons."

After an inflammatory attack in the spinal cord or brain, the damage to nerve cells does not repair very well as compared to other cells in our bodies, such as skin or bone cells. This is particularly the case in adults. It is possible that this inability to reproduce or repair was the evolutionary tradeoff for the incredibly complex function these cells perform in our brains. They account for us being a unique individual, with a unique personality, with unique attitudes, thoughts and beliefs. What would a person be, who would that person be, if the cells in their brain were entirely replaceable?

What happens to those nerve cells from a massive and destructive inflammatory and demyelinating attack in the brain? What happens to the person? What happens to what they learned and what they know and what they believe and what they remember and who they are; what happens to their personalities and their individuality and their identity? For most of you reading this article, you have an intimate understanding about how complicated these attacks are in the spinal cord. There is often damage caused to myelin and nerves in the spinal cord, but the damage is often not completely across the cord. Most people have some function below the level of the attack on the spinal cord. Some of that function might be sensory, some might be motor; or there might remain bowel and bladder function. And some people have very good recoveries after their attack and from very severe symptoms at onset. What happens during this recovery, if in fact, myelin and nerve cells do not very effectively repair after being damaged? What does it really mean for the spinal cord to go into shock and come out of shock? We've been thinking about all of these issues in the context of a spinal cord, and these are remarkably complex issues with many more questions about the process than answers.

When a person has this horrible inflammatory attack in their brain, there must be similar damage to myelin and nerves, there must be the same kind of shock and recovery from shock and there must be the same type of very complex and incomplete pattern of damage to neurons. Even for people whose brains have been assaulted by their immune system, many do experience a recovery. The brain must be able to relearn what was lost and a part of the brain that was responsible for one kind of activity must be able to be assumed by a different part of the brain, because some people learn to walk, they learn to speak, and they get back memories.

I have been consumed by these thoughts about our brains and our humanness and personalities and our memories and our identities since I met Al, Jessica, Rachel, Ashley, Barbara and Kevin. My relationship with these people and their families has been so profound for me that the word profound really doesn't do justice to what goes on in my own brain about these beautiful people. I cannot say that they are all my friends because I've never met some of them. But they consume my thoughts and draw my compassion from me as though they are magnets for my heart and mind. There is just no other way to describe what is done to me by Al's passion, drive and intensity, or the knowing smile in Ashley's warm, engaging and engaged eyes, or Barbara's earnestness and perseverance and persistence or Rachel's insightfulness, sensitivity, anger and frustration. Al, Jessica, Rachel, Ashley, Barbara and Kevin have forced me to think about "what is mind" and "what is brain." I honestly think about them every single day. It doesn't matter whether I am at work or with Pauline at the dinner table or playing golf with David and Aaron, or driving in my car, listening to Tori Amos; thinking about these people permeates my life current. Their struggles have caused me great sor-

row; their drive and optimism buoys my spirit, their daily challenges move my heart and deepen my compassion. Their minds have totally blown my mind.

I became involved in most of their lives through a family member, a sibling or parent, while they were in the hospital and while most of them were in a coma. Al, Jessica, Rachel, Ashley, Barbara and Kevin have acute disseminated encephalomyelitis. When we started The Transverse Myelitis Association in 1994, we were focused on TM and we really didn't know very much about TM. Over the years, we learned about neuromyelitis optica and acute disseminated encephalomyelitis and optic neuritis because you, our members, taught us about these disorders. It has been such a fascinating journey. You joined the TMA because you figured out the connection between all of these disorders before we did; that they are all immune-mediated or demyelinating disorders of the central nervous system. By showing up, you forced us to think about what you were dealing with and what was going on with these other disorders. That we became an organization focused on advocacy for people with ADEM, ON, NMO and TM resulted from the course of your journeys. Believe me, most of the really insightful and brilliant directions we are going in have nothing to do with any purposeful decisions on my part. I believe in some ways, you not only taught the TMA about the connections between these disorders, you have also forced the medical community to think about these disorders and their relationships in a way that they really weren't focused on previously.

It has taken me a very long time to develop some very fundamental understanding about TM and NMO. ADEM has been a mystery. It is a very complex disorder and perhaps the least understood of these very rare neuroimmunologic disorders. Most of what I have read and learned about ADEM has come from articles about ADEM in children. In many ways, ADEM and idiopathic transverse myelitis in children seem to share a number of important features.

Acute disseminated encephalomyelitis is also sometimes referred to as postinfectious encephalomyelitis. ADEM is more common in children and adolescents than it is in adults. Most of the cases of ADEM, as is the case for TM, are monophasic. And also similar to TM, there does not seem to be any higher incidence of TM among males or females, nor does there appear to be any higher frequency of this disorder among any particular ethnic group. ADEM is an immune-mediated, demyelinating disorder of the central nervous system.

ADEM is believed to be an autoimmune attack that is either triggered by a response to an infection or to a vaccination. For this reason, ADEM is sometimes referred to as post-infectious or post-immunization acute disseminated encephalomyelitis. In about 50-75% of pediatric cases, the attack follows a viral or bacterial infection; the attack and neurological symptoms often begin within a couple of weeks after the viral or bacterial illness. There have been a large number of viruses associated with these infections, including but not limited to measles, mumps, rubella, varicella zoster, Epstein-Barr, cytomegalovirus, herpes simplex, hepatitis A, influenza and enterovirus infections. ADEM seems to occur most often in the winter and spring. Interestingly, this seasonal variation does not seem to take place in idiopathic transverse myelitis. Less than 5% of ADEM cases follow immunization. The association between the attack following an immunization has been temporal; the direct connection between a vaccination and the immune attack has not been established. As in the case of TM, the cause of the autoimmune attack is not known; it is thought that there is an environmental trigger in a person that possesses the genetic predisposition for the autoimmune response. There are different forms of ADEM and some of them are more severe than "typical" ADEM.

The neurological signs from the inflammatory attack often begin with fever, headache, vomiting, altered level of consciousness, acute cognitive dysfunction, behavioral changes, and seizures in about a third of the cases. The altered consciousness can range from stupor and lethargy to confusion to coma. The inflammatory attack can go on for a few days or for a few weeks. The most severe symptoms are ordinarily reached within the first week and the first 2 – 4 weeks are the most severe period for children. ADEM is multifocal; the inflammatory attack occurs in the brain and it can also occur as optic neuritis and as transverse myelitis. Thus, a child or adult with ADEM can have the symptoms of ON (i.e., impaired vision and eye pain) and all of the symptoms from an inflammatory attack in the spinal cord. As is the case with idiopathic transverse myelitis, the symptoms depend on the severity and the level of the attack in the spinal cord; breathing may be impacted, bowel and bladder dysfunction, paralysis or muscle weakness, spasticity, paresthesias or nerve pain, as well as the other symptoms of TM. It is common for the brainstem and the spinal cord to be impacted in ADEM.

The process involved in diagnosing the different neuroimmunologic disorders has been one of the more frustrating aspects of the work that I have been engaged in for the past 15 years. The frustration began with Pauline's nine hour episode in the emergency room trying to convince an emergency room doctor that she was not experiencing a case of psychic paralysis. I am involved with a number of families on a

weekly basis that are going through a difficult process of getting a loved one properly diagnosed with one of these disorders. It is very easy to sit on the sidelines and wonder why these physicians can't get this stuff right. And the urgency and level of frustration is driven by the understanding that diagnosis is going to determine treatment and the treatments for these disorders need to begin to be administered as quickly as possible. Lost time could result in greater permanent damage to the spinal cord or brain. And then I think about the complexities surrounding the ADEM diagnosis, and my wild frustration settles into the very sobering reality about what an incredibly difficult job these physicians have to get this situation all sorted out properly. And I need to add that not only is the guidance provided to these physicians about how to make this diagnosis a moving target; the very definitions of the categories of these disorders are moving targets, as well. ADEM is the perfect case in point.

When a person presents with the symptoms of ADEM, the physician has to rule out that the child or adult actually has a direct infection of the central nervous system. Keep in mind that most cases of ADEM are triggered by a preceding bacterial or viral infection. The physician has to rule out that there is a direct infection of the central nervous system as opposed to an infection that subsequently triggers the immune system to go haywire. As the immune attack is thought to be triggered by a bacterial or viral infection, it's not like bacteria and virus may not be around; it is just not the bacteria or virus that is directly causing the damage in the spinal cord or brain. If it is a direct infection causing the problem, the patient would be placed on an antibiotic and/or acyclovir; they would not want to quiet the immune system, in the process of fighting off an infection. Thus, getting this complicated differential diagnosis correct is incredibly important and sometimes takes time. Then they have to figure out that this is ADEM and not MS or NMO. TM may be the easy rule out. There is no biomarker for either ADEM or MS, so all of these diagnoses are going to be based on clinical features and MRI and CSF analyses and none of these variables are definitive either. Even with the blood test for NMO-IgG in the case of NMO, there are 30% false negatives and people can also have lesions in the brain with NMO. And while oligoclonal bands are more common in the spinal fluid with MS, these bands are sometimes also present in ADEM. If the physician determines that the event is immune-mediated, the acute treatments will be similar regardless of the cause. However, getting these diagnoses correct is imperative, because the long-term treatments are going to be different between NMO and MS, and most ADEM cases are going to be considered monophasic at the outset.

There is no scientific, randomized, controlled data on the diagnosis and treatment of ADEM. This is also the case for idiopathic transverse myelitis and neuromyelitis optica. Decisions about the diagnosis and treatment of these disorders are based primarily on the opinions of experts. Since decisions will be based on clinical judgment, trying to connect people to one of these experts during this critically important time is a significant part of what I do for a hobby.

As noted, an ADEM diagnosis is determined by clinical features and results from MRI, because there is no specific biological marker for this disorder. Often times, a person is placed on antibiotics and acyclovir (an antiviral medication) until the physicians can confidently rule out of an infectious cause.

Spinal cord inflammation is diagnosed in the same manner as idiopathic transverse myelitis. Optic neuritis in ADEM is also diagnosed in the same manner. The difficult and important differential diagnosis involves interpretation of the brain MRIs to distinguish ADEM from MS. The brain stem is often involved in ADEM and spinal cord lesions typically extend over multiple segments of the cord. It is possible that the MRI may be normal early in the course of the disorder and may have to be repeated. The CSF shows evidence of inflammation but can also be normal. Some patients have oligoclonal bands which is more often characteristic of MS. In certain situations when no cause is evident, neither an infectious or immune-mediated cause is apparent, a brain biopsy may be performed. Some physicians also recommend repeating MRIs on follow-up to be sure there are no new lesions which could change the diagnosis from ADEM to multiphasic ADEM or MS.

An important paper was recently published which proposes diagnostic criteria for ADEM in children. The criteria are important for the purpose of arriving at better decisions about treatments and the criteria are meant to facilitate research on ADEM. When physicians and researchers are designing and conducting studies and clinical trials, it is important that they are including patients that they all agree belong to the same disorder classification. The authors of the study consider these criteria as operational and need to be tested and validated by future research. They define child as under the age of 10 and adolescents as 10 until 18 years of age. The following are the criteria developed by the International Pediatric MS Study Group (pp. S7-S8):

Monophasic ADEM

- A first clinical event with a presumed inflammatory or demyelinating cause, with acute or subacute onset that affects multifocal areas of the CNS. The clinical presentation must

include encephalopathy, which is defined as one or more of the following:

* Behavioral change, e.g., confusion, excessive irritability

* Alteration in consciousness, e.g., lethargy, coma

- Event should be followed by improvement, either clinically, on MRI, or both, but there may be residual deficits
- No history of a clinical episode with features of a prior demyelinating event
- No other etiologies can explain the event
- New or fluctuating symptoms, signs, or MRI findings occurring within 3 months of the inciting ADEM event are considered part of the acute event
- Neuroimaging shows focal or multifocal lesion(s), predominantly involving white matter, without radiological evidence of previous destructive white matter changes:

* Brain MRI, with FLAIR or T2-weighted images, reveals large (>1 to 2 cm in size) lesions that are multifocal, hyperintense, and located in the supratentorial or infratentorial white matter regions; gray matter, especially basal ganglia and thalamus, is frequently involved

* In rare cases, brain MR images show a large single lesion (≥1 to 2 cm), predominantly affecting white matter

* Spinal cord MRI may show confluent intramedullary lesion(s) with variable enhancement, in addition to abnormal brain MRI findings above specified

Recurrent ADEM

- New event of ADEM with a recurrence of the initial symptoms and signs, 3 or more months after the first ADEM event, without involvement of new clinical areas by history, examination, or neuroimaging
- Event does not occur while on steroids, and occurs at least 1 month after completing therapy
- MRI shows no new lesions; original lesions may have enlarged
- No better explanation exists

Multiphasic ADEM

- ADEM followed by a new clinical event also meeting criteria for ADEM, but involving new anatomic areas of the CNS as confirmed by history, neurologic examination, and neuroimaging
- The subsequent event must occur 1) at least 3 months after the onset of the initial ADEM event and 2) at least 1 month after completing steroid therapy
- The subsequent event must include a polysymptomatic presentation including encephalopathy, with neurologic symptoms or signs that differ from the initial event (mental status changes may not differ from the initial event)
- The brain MRI must show new areas of involvement but also demonstrate complete or partial resolution of those lesions associated with the first ADEM event

To receive an ADEM diagnosis, the authors require that the patient have inflammatory brain involvement, i.e., encephalopathy. The authors define three different categories of ADEM. Monophasic ADEM is a one-time episode that can develop over a period for as long as three months. They would consider any new or changing symptoms within this three month period as belonging to the one event. They would also consider any symptoms that might occur during an oral steroid taper or within one month of the completion of the taper as also belonging to the single episode. Recurrent and multiphasic ADEM episodes must occur more than 3 months after the initial event and more than one month after the completion of steroids. Recurrent ADEM is defined as a subsequent attack that involves the same symptoms that occurred during the initial attack. The MRI findings would be similar to the initial attack, and there would be no lesions, but there could be an enlargement of the lesions from the original episode. Multiphasic ADEM is defined as an attack that involves new areas of the central nervous system from the initial or previous attacks. There must be signs of encephalopathy, but symptoms and neuroimaging findings are in different areas from the initial attack. There might be new lesions evident on MRI and there might also be evidence of partial or complete resolution of the lesions associated with the first episode.

The International Pediatric MS Study Group authors provide an excellent comparison across a number of variables for making the differential diagnosis between ADEM and MS (Table, p. S11). ADEM more frequently occurs among younger age groups (<10 years) and there does not seem to be a higher incidence between boys or girls. MS occurs more frequently in adolescents and the incidence is higher for girls than for boys. A prior flu-like illness is very frequently the case in ADEM, while it is variable for MS. Encephalopathy is required to arrive at a diagnosis of ADEM while it is rare in the early stages of MS. Seizures are variable in ADEM and rare in MS. A single event in ADEM can fluctuate over the course of 3 months, while in MS a discrete event is separated by at least 4 weeks. Large lesions involving gray and white matter are frequently evident from MRI in ADEM and rare in MS. MRI frequently shows enhancement in both ADEM and MS. Over time, lesions typically appear to resolve in ADEM, while in MS, there is typically development of new lesions. CSF pleocytosis (presence of a greater number of cells than normal) is variable in ADEM and extremely rare in MS (white blood cell count almost

always <50). The presence of oligoclonal bands in the spinal fluid is variable in ADEM and frequently found in MS. The response to steroids appears favorable in ADEM and is favorable in MS.

The authors explain that they expect that there will be specific cases that are exceptions to these criteria and through time with more research and better data, the criteria will change and be improved. The International Pediatric MS Study Group authors explain, *Clinical judgment by the treating physicians is critical to the management of patients whose diagnosis remains unclear and the proposed criteria are not meant to dictate treatment decisions in such cases* (p. S11).

When children present with fever and evidence of inflammation, they are often treated with antibiotics and acyclovir until an infectious cause is ruled out. In an article providing clinical practice guidelines for the management of encephalitis, the Infectious Diseases Society of America graded their recommendations for treatments. The strength of evidence for a recommendation was graded as good, moderate or poor. They also graded the quality of the evidence for the recommendation. The highest quality evidence came from more than one properly randomized, controlled trial. The next level of quality was from evidence derived from well-designed clinical trials without randomization, from cohort or case-controlled analytical studies, from multiple time-series or from dramatic results from uncontrolled experiments. The lowest quality of evidence was from opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees.

All of the treatments for ADEM are graded as the lowest quality of evidence; none of the treatments are confirmed from randomized, placebo-controlled trials. Also, there is no good scientific data to determine an optimal treatment, including dose or duration. Treatments are entirely based on experience and clinical judgment.

High dose intravenous, corticosteroids for 3-5 days are the most often used first line treatment and they can be used concurrently with antibiotics and acyclovir. The authors recommend Plasma Exchange (PLEX) in patients that are not responding to corticosteroids. Intravenous immunoglobulin (IVIG) is then recommended in patients not responding to PLEX.

The strength of evidence for the recommendation of corticosteroids and PLEX are graded as moderate. The strength of evidence for a recommendation of IVIG is poor.

From my own anecdotal experience, I am aware that for patients who present with the most severe symptoms, which may include coma, paralysis and the inability to breathe, some physicians have used Cyclophosphamide or Cytoxan (brand name) to quiet down the immune attack. Cyclophosphamide is an anti-cancer drug and it is not identified as a treatment for ADEM in the Infectious Diseases Society of America guidelines. Greenberg does, however, discuss the use of cyclophosphamide in the retrospective study involving 122 people with a diagnosis of idiopathic transverse myelitis at the Johns Hopkins Transverse Myelitis Center.

The prognosis for most children with ADEM is good. The recovery is usually a slow process lasting from four to six weeks and the majority of children with ADEM make a full recovery. Between 60 to 90 percent are left with no neurological deficits. Those children who do have residual symptoms are reported to have symptoms from transverse myelitis (the spinal cord inflammatory attack), recurrent headaches, and behavioral problems. Interestingly, the location of lesions and the extent of inflammatory lesions do not appear to have any predictive value in regard to outcome. Some physicians recommend that children receive follow-up MRIs for a period of up to five years to ensure that there is no new inflammatory activity after the initial ADEM attack; i.e., to confirm that the diagnosis is not MS.

I have no idea whether my perceptions are influenced by selection bias. It is quite possible that my observations are significantly skewed by who decides to contact me and under what circumstances, and therefore, I am exposed to more severe cases; people who are fully recovered are not looking for me. Having acknowledged that possibility, it is my anecdotal experience that ADEM is more severe among adults and that the recoveries are more challenging than they are for children.

Early in December, 2008, I received an email from Rachel's mother. She told me about her daughter who had ADEM and is 32 years old. Rachel is living with her mother. I also had a few telephone conversations with Rachel's mom. Then in the middle of December, I began corresponding with Rachel directly through emails. Rachel's ADEM attack occurred when she was 24 years old. Rachel was in a coma for 9 months. While we haven't talked about the specific nature of her attack, Rachel must have experienced a severe inflammatory attack in her brain and spinal cord, and it is possible that she also had optic neuritis, as she has communicated about vision problems. She has difficult symptoms from the damage in her spinal cord and she has certainly struggled with the residual symptoms from the inflammatory attack in her brain. Rachel remains unable to speak. She is working with a speech therapist and I have great hopes that I will have a telephone conversation with Rachel sometime in

the not-too-distant future.

Rachel has been on an incredibly difficult journey. From my conversations with Rachel, I have learned that I am communicating with a person that possesses an amazingly vibrant, creative and adventurous spirit.

I am going to share with you some excerpts from a few of the emails I have received from Rachel since we began communicating. I am going to publish these emails as she sends them to me, because they reflect the enormous energy she must expend to get the words out and to get them typed on her computer keyboard. She often expresses that she is totally exhausted at the end of her emails. Rachel's story is so incredibly compelling. Getting to know Rachel has helped me to better understand the challenges that a person with ADEM has to manage during their recoveries and in their daily lives. I am sharing Rachel's words and a small part of her story, because I believe it is important to know about ADEM in the way that Rachel and Ashley and Al and Barbara and Jessica are teaching me about this truly horrible disorder. Yes, ADEM is about the immune system and the nervous system and about many complicated symptoms, but ADEM is, first and foremost, about the human being that has it and the incredible changes and challenges it has caused in their life.

2001 I woke up, I wanted to say something but I couldn't, I couldn't move my legs either, I looked down at my feet they were deformed I couldn't stand up anymore I had a dream that I could grab my blue puffers jacket, my leopard print purse, and my blue back pac, I came to the hospital with those three things now I wanted them back. I wanted to walk out of there into my silver beetle, listening to my house music but something was wrong, my body was stiff and I couldn't say a word, what was going on. I could still think; all of my memory hasn't changed. I even had a dream that I could talk. But this is really weird, all of my family looks the same but the hospital wasn't where I checked into it, 9 months later, after I woke up from my coma the hospital was on the same street but not where it was before. A park was directly across from the hospital and I don't remember that building.

Am I dead or alive? That thought runs through my mind at least everyday. It's scary, I can't explain it to anyone, everything looks the same, your life happened like it should've. I remember my mother in law taking me to the emergency room, I remember staying overnight there and the dr. drew blood from my lungs, I remember my friend and her mom visiting me, my husband eventually came over and stayed with me for a couple of nights, the next thing I remember was meeting all my cousins, my aunts, uncles, and my grandparents, they were all in the family room at the hospital, I remember walking to my bathroom in my room and then I fainted. I guess that's where I almost died, my mom came looking for me, she had me rushed down to emergency, then I woke up, I thought it was all a bad dream that I was stuck in, I couldn't figure out the password to wake myself up from this dream, that is when I noticed everything was different.

No one understands and they r too lame for me to explain it with the board, I think I've tried to tell certain caregivers but they just brush it off, I can not get too deep with them, my friend would understand but he doesn't live with me anymore, and he doesn't email regularly so I haven't told him yet,

Good news, I am alive but I think I am an angel, one lady, who works with my mom she was telling her mom, who is a rn, about me and all that has happened to me, she said u were sitting next to an angel.

Sun 12/14/2008 3:16 PM

i went to brazil to help my friend with a fashion show. i went to fashion school right from h/s that's what i did in London, and brazil. i went via ny.

i went to live with my nonie, her house was cool, i had good memories there, i went back to school to become a hairdresser, i worked as a cocktail waitress, i met my husband there, i loved my nonie very much, she passed away on my winter break from school, i went back to London at the time she passed away

well I'm still in a wheel chair, manual, i use a dynabox, a computerized talker but i can do whatever anyone can do

i was hospitalized from November of 2000 until Feb. 2006, there were no computers in the california hospitals. so i missed out right when the computer age happened, i barely turned 24, when i went into the coma and i was 29 when i finally got out of the nursing home.

my mom and i were very close, i think that was why she has been at my side for the past 8 years. She spends time listening to me or reading my spelling board.

i had to live in the hospital for 6 years, i got sick in November of 2000. i still can't speak, i spelled out for my husband i want a divorce. he just recently gave me a divorce in june of 2005.

if the dr. knew what the hell adem was they could have started rehabbing me right away, instead they just took care of me like the rest of the comatose patients. all my muscles atrophied i am so mad the first thing i wanted to get out of those stinking diapers, and at the rehab center they potty trained me in 3 days i was wearing regular underwear, i am too young to wear an adult diaper. the rehab hospital is full of mainly stroke patients, they keep them for 2 weeks, but me they kept me for a whole month, and it was still too short.

i wanted them to teach me to walk again, they should have never left me in that hospital for 6 years to just rot, i feel i was ready to walk out of there, but they just took care of me, no rehab

i wear an eye patch over my left eye and type with my left pointer finger only, i used to draw, write, with my right hand, but my right hand is curled in. i can't write yet, i learned to use my left hand for most things. i feed myself, brush my teeth, style my hair.

i like sweets, on my 25 birthday, my mom brought a power puff girls cake, but i could not eat any of it, they didn't pass me for eating yet instead i had a stomach feeding tube, this sucks, i thought, so i had the speech therapist test me, and slowly i got to eat things now, i can eat everything, u just have to cut it up small. i can feed myself using my left hand. for 3 years i tried to eat by myself with the supervision of my activities director, i had a special spoon for my left hand, i dirty so many towels, and now i eat with spoons and forks like everyone uses. brushing my teeth, i can do that as well. i stand up at the sink balancing, leaning up to the sink. Dressing i can get myself dressed i can reach my feet so i sit down and put my right leg then my left leg through then i use my hospital bed to stand up and i pull my pants
up, shirts dont work for me, i wear exercise pants i cant zip or button my clothes yet my bra and my top i just slide over my head i still need my tennis shoes put on, tied as well and i cant put on my socks yet
the people at my school call me the disabled diva, i like it, i don't mind, i like being labeled where i stick out from the older people who have had strokes.

i just got my power chair; trying to drive my chair, they put my control on the left side, but my muscles all atrophied, i can't control my power chair very well, plus i don't have my 20/20 vision.

i would have never been able to type such a long email 2 years ago.
I'm tired i go to bed at 7 or 8

Sun 12/21/2008 2:16 PM

I've spent 6 years of my life in the california hospital system, they were all just a bunch of people with brain problems who lived the remainder of their lives there, that is y i am so bitter, i knew i could've recovered in the first year of this damn disease, yet no one would work with me

Sat 1/17/2009 10:48 AM

my recovery sucks! i have too many components, and every therapist wants me to work on her thing throughout the day. i just want my assistant to walk me more,
i have to c a hand therapist, she concentrates on my right hand, a speech therapist because i can't talk at all, a social worker who i hope will get me into c a psychologist, a rehab doctor who taught my assistant how to stretch my feet, i had foot surgery 5 years ago at a childrens hospital, i love it there. but my feet r still curled including my toes, so much so it hurts me to walk in socks
yesterday my assistant massaged each foot for an hour. he found a knot in my right foot, i was looking at my reflexology book, and it was where the bladder pressure point is. last nite i peed 10x, my bladder wasn't emptying. i put on an adult pull up and i went to bed, its a good thing i don't have anyone to impress. geez, i don't know what i would have done. but i woke up at 7am my bladder subsided.

My life sucks
when i wake up at 2am only to fight with my blankets for freedom and then i carefully get into my chair then i have to squeeze through the doorway, go all the way down the hall past the bathroom only to turn my chair around at the end of the hallway so i can park my chair on the left side, i can get in on my left side, but twice this journey's taking me too long by the time i finally make i have already peed, then i get really sad knowing that this is a lifelong problem.

I'm still pissed off because the neurologist diagnosed me with adem while i was in a coma. they knew i had brain activity, couldn't they have ordered the ot's to work with me, set up a computer or something, i could have started my journal writing instead of laying in a hospital for six years amongst half dead people.
the image still haunts me

Sun 2/22/2009 12:14 PM

there r 3 of them, they r very close in age. the oldest is aaron, he is 32 and has a mild case of c.p. he is literally a genius, he got a scholarship to u.c. berkley, but got sick and had to leave. he finished his education at s.j.s.u. and will b graduating in may, stuart is 30, they r all very liberal, we all like the same music, stuart practices brazilian jui jitzu, him and aaron like to work out, he has agreed to volunteer to meet me with aaron at gym, he is a model, so he doesn't have a bunch of free time, he is also in a band, he introduced me to fred. fred is 30, and is also a genius, i went out to coffee with fred and aaron, fred is very organized, he carries around a p.d.a., i aspire to b like him when i can use both my hands, i want a p.d.a. so my emails will b more fun. aaron and i saw a movie, aaron and fred r movie buffs. fred and i will take an art class, and i will possibly take an exercise class, they have an exercise class that gears on balance, we all know, i have no balance so it prevents me from walking. i hired fred, he is going to schedule all my appts and he has nutrition down some people think i have cerebral palsy. at this point i have a lot of similarities with aaron. we r both in a wheel chair, we both had to drink our coffee through a straw, aaron can talk, his toes r curled like mine. and i was surprised he hardly used any napkins but i feed myself with my left hand i

used to b a right hander, i went through all stages of eating feeding tube, blended foods, now i can eat anything if it is chopped. i learn to feed myself, i used to wear a bib but now i just use a bunch of napkins.

Sun 2/22/2009 5:31 PM

thanks to aaron, i felt comfortable being disabled. i know i will get better but not fully. i have the worst case of adem ever. no one has had a case so bad, all the other people with my disease, it is common to b in a coma, but the most i have heard is 2 weeks max, i was in a coma for 9 months
other people can talk, me i can't
i have to relearn to write. I'm originally a right handed person, but all my mucles have atrophied, my hand, my mouth, so i am learning to talk again, but all this therapy takes too much out of me. i get really tired with this disease.

Sun 3/22/2009 10:33 AM

Fred is carer and aaron is his brother. we all get along really well
Fred and I like art so we spend a lot of time at galleries, museums etc.
Aaron is a movie buff; he takes me to c a lot of movies. Fred got me into a rehab facility. I will b taking an adaptive swim class. It was Aaron's birthday party last night so he threw a party he knows a lot of successful people who have been disabled all their lives and who manage to study at berkley. those people still make me sad because i think of how well off i used to b, lets face it i have the worst case of ADEM EVER. my current disabilities r like some of theirs. it makes me sad to hear my friends say that if I i want to go to europe, i have to learn to walk first. i know that isn't true but to do everything that i want to do, yes i better walk. i know it will b so hard for these people in a chair, but they don't have the choice, in many ways i feel blessed.

Rachel signs her emails to me, lr
love Rachel
I love you back, Rachel!

I have great hope for Rachel. I have great hope for her future, because Rachel has great hope for her future! Over the four or five months of communicating, Rachel is becoming more positive and her life is being filled with good people and healthy and interesting activities. Rachel is most definitely getting better. There is recovery from ADEM; even in adults who have incredibly difficult cases with very challenging long-term symptoms. The recovery from spinal cord damage is difficult to understand, but we observe recovery from the damage all the time. It doesn't happen for everyone, but it happens for most. The recovery from the damage done to the brain is so much more difficult to understand. The brain is just so complicated. It may be too complicated for us to ever really be able to understand. Perhaps we just aren't meant to understand the physiology of a thought or the physiology of a belief or the physiology of a memory. But the brain recovers like the spinal cord recovers. People do get better. I think of Rachel, Ashley, Al, Jessica and Barbara every day and I'm pulling so hard for each of them. I hope for them every day; that they are able to find themselves; all parts of their selves; and that they are able to return to the life that they want for themselves.

Shortly after I began writing this article, I received a phone call from a family with a husband/son/father who had been rushed to an emergency room. It had been a couple of days since the beginning of his attack, and he was in a coma, paralyzed from the neck down and ventilator dependent. I was on the phone with this family for the following three weeks, offering information, guidance and support. This family went through the excruciatingly difficult process of standing by while the physicians were ruling in an ADEM diagnosis in order to decide the appropriate treatment course. Just this past week, this gentleman passed away from complications of what was likely ADEM. For the past few days, I have been on the phone with this family, listening, consoling, and grieving with them. What this family is going through is painful and frustrating beyond words to describe. They have a long and difficult emotional and spiritual journey ahead of them to find peace. And that is what I hope and pray for them … just peace; I don't think resolution will be possible.

Please take good care of yourselves and each other.

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ARTICLES

NMO-IgG predicts the outcome of recurrent optic neuritis

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ABSTRACT

Objective: To determine the prognostic value of neuromyelitis optica (NMO)–immunoglobulin G (IgG) in patients with recurrent optic neuritis (ON). The aquaporin-4-specific serum autoantibody, NMO-IgG, is a biomarker for NMO and relapsing transverse myelitis. Recurrent ON may herald multiple sclerosis (MS) or NMO, or it may occur as an isolated syndrome. The prognosis and response to therapy differs in each of these contexts.

Methods: We evaluated 34 patients who were tested for NMO-IgG between 2000 and 2007 and who had two or more episodes of ON without satisfying a diagnosis of MS or NMO prior to serologic testing. Clinical data were available for 25 Mayo Clinic patients (5 NMO-IgG positive and 20 NMO-IgG negative) and for an additional 9 seropositive patients whose serum was referred to the Mayo Clinic Neuroimmunology laboratory for testing.

Results: Twenty percent of the patients with recurrent ON seen at Mayo Clinic were seropositive. All NMO-IgG-positive patients (vs 65% NMO-IgG-negative patients) had at least one attack with visual acuity in the affected eye worse than 20/200 ($p = 0.05$). In seropositive patients for whom long-term follow-up was possible (median 8.9 years after the initial ON), 6 of 12 (50%) experienced an episode of myelitis and fulfilled criteria for NMO. In contrast, 1 of 15 seronegative patients (6.7%) fulfilled McDonald criteria for MS ($p = 0.03$). Seropositive patients had a final visual score which was worse than that of seronegative patients ($p = 0.02$).

Conclusions: Neuromyelitis optica (NMO)–immunoglobulin G seropositivity predicts poor visual outcome and development of NMO. Seropositive recurrent optic neuritis is a limited form of NMO.
Neurology® 2008;70:2197-2200

GLOSSARY

IgG = immunoglobulin G; **LETM** = longitudinally extensive transverse myelitis; **MS** = multiple sclerosis; **NMO** = neuromyelitis optica; **ON** = optic neuritis; **RON** = recurrent ON; **TM** = transverse myelitis; **VA** = visual acuity.

Optic neuritis (ON) is an acute inflammatory demyelinating syndrome of the CNS that may occur in isolation or may herald multiple sclerosis (MS), neuromyelitis optica (NMO), or recurrences of ON without other CNS manifestation (idiopathic recurrent ON [RON]).[1] The diagnosis of NMO, rather than MS, in a patient with a history of ON and myelitis is largely dependent on documentation of longitudinally extensive spinal cord lesions, which are common in NMO and rare in MS. The prognosis for NMO is worse than for MS,[2] and current evidence suggests that conventional immunomodulatory treatments for MS are ineffective for NMO.[3-6] Therefore, early distinction between NMO (and its related spectrum of disorders) from MS is clinically important.

Editorial, page 2192

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Disclosure: Drs. Marcelo Matiello, Anu Jacob, and Sean Pittock have nothing to disclose. Drs. Brian Weinshenker, Vanda Lennon, and Claudia Lucchinetti have intellectual property associated with the discovery of NMO-IgG, which has been licensed to a commercial entity. The NMO-IgG test is offered on a service basis by Mayo Collaborative Service Inc., an agency of Mayo Foundation. Dean Wingerchuk and Brian Weinshenker have served as consultants for Genentech for development of a clinical trial for neuromyelitis optica. Dr. Wingerchuk has consulted for Teva pharmaceuticals. Drs. Weinshenker and Wingerchuk have also been investigators in clinical trials for MS.

The serum autoantibody, NMO-IgG, detected by indirect immunofluorescence,[2] binds to the CNS-dominant water channel, aquaporin-4, and has high sensitivity and specificity for NMO.[2,7] Recent incorporation of NMO-IgG seropositivity as a diagnostic criterion for NMO[8] has been validated independently.[9] Detection of NMO-IgG in patients with idiopathic longitudinally extensive transverse myelitis (LETM) predicts recurrence or development of ON within 1 year in 55% of cases.[10] The goal of the current study was to evaluate the diagnostic and prognostic value of NMO-IgG in patients with RON.

METHODS The study was approved by the Mayo Clinic Institutional Review Board (IRB# 1036-04). Eligible patients fulfilled the following inclusion criteria: 1) tested for NMO-IgG between 2000 and 2007 in the Mayo Clinic Neuroimmunology Laboratory; 2) at least two clinical episodes of ON separated by 30 days or more and documented before NMO-IgG testing; 3) no other neurologic signs or symptoms prior to the NMO-IgG test that suggested a diagnosis of MS or NMO.

Blinded indirect immunofluorescence testing for NMO-IgG was performed on a service basis.[2] We reviewed medical records for patients evaluated at Mayo Clinic (5 NMO-IgG positive and 20 NMO-IgG negative) and abstracted data provided by referring physicians for patients not evaluated at Mayo Clinic. Data for patients evaluated elsewhere were ascertained only for seropositive RON patients (identified serologically in the Mayo Clinic Neuroimmunology Laboratory [n = 9], in the course of contacting physicians of NMO-IgG-positive patients in routine laboratory physician-initiated consultative and quality assurance activities). Thus, only patients evaluated at Mayo Clinic were informative regarding the seroprevalence of NMO-IgG in RON. Data for both groups were used to evaluate demographic characteristics and outcome data associated with NMO-IgG seropositive RON.

Visual acuity (VA) was assessed in each eye by an ordinal scale: 0 = 20/20; 1 = scotoma but better than 20/30; 2 = 20/30 to 20/59; 3 = 20/60 to 20/199; 4 = 20/200 to 20/800; 5 = count fingers only; 6 = light perception; 7 = no light perception.[11] The final visual outcome was the sum of the last assigned visual score for each eye.

Follow-up information included additional relapses of ON, development of transverse myelitis (TM) or other neurologic manifestations, and the patient's most recent visual and motor status.

We determined whether the patients satisfied criteria for MS or NMO.[8,12] We used the statistical package JMP 6.0 (SAS Institute, Cary, NC, 2005) to analyze the significance of differences between the seropositive and seronegative groups using χ^2 or Fisher exact test for frequency data, and Wilcoxon or t test for continuous data, as appropriate. We used a Kaplan-Meier analysis to evaluate differences in incidence of TM in the seropositive and seronegative groups following the first episode of ON.

RESULTS Five of the 25 patients (20%) evaluated at Mayo Clinic were NMO-IgG-positive. Seropositivity was not associated with sex, age at onset, number of ON episodes prior to serologic testing, interval between the first and the second episodes, or occurrence of bilateral episodes of ON. Among patients for whom ethnicity information was available, non-Caucasian ancestry was more common in the seropositives (5 of 12; 41.7%) than in the seronegatives (2 of 19; 10.5%, $p = 0.07$).

The initial ON episode was more severe in seropositive patients ($p = 0.05$) and VA in the affected eye was worse than 20/200 at the nadir in all seropositive patients (one or more ON episodes) compared to 64.7% in seronegative patients ($p = 0.05$). Thirty-one patients had a brain MRI after the first ON; none fulfilled MRI criteria for MS,[12] 6 of 11 seropositive patients (55%) and 12 of 19 seronegative patients (63%) had normal brain MRI or changes restricted to the optic nerve. The remainder had nonspecific MRI signal changes.

Follow-up data were available for 12 seropositive and 15 seronegative patients, representing 79.4% of the population studied. The interval was similar in the two groups: 8.95 ± 2.0 years for seropositive vs 8.02 ± 5.1 years (mean ± SD) for seronegative patients ($p = 0.73$). Four seropositive and 7 seronegative patients had ON relapses after NMO-IgG testing ($p = 0.69$). The final visual status score was worse in the seropositive group: 10.22 ± 9.0 (mean ± SD) vs 6.38 ± 1.0 in the seronegative group ($p = 0.02$) (table).

One seronegative patient (6.6%) and 6 seropositive patients (50%) experienced TM episodes during the follow-up period ($p = 0.03$) (figure). The seronegative patient experienced a band-like sensation around her chest accompanied by paresthesia of the lower extremities; MRI of thoracic spine revealed two small lesions adjacent to vertebra T11 each measuring about 3 mm, likely unrelated to her symptoms considering the dermatome level of sensory disturbance. Minor sensory disturbances accompanied by small spinal cord MRI lesions also occurred in one seropositive patient while she was receiving monthly IVIg therapy. The other five seropositive patients experienced severe TM, leading either to quadriplegia or paraplegia, accompanied by severe sensory and sphincter deficits. Spinal cord lesions longer than three vertebral segments were present in the four patients on whom we had information about their MRI scans. Two seropositive pa-

Table Patient demographic, clinical, and MRI characteristics and outcome information stratified by neuromyelitis optica (NMO)–immunoglobulin G (IgG) serologic status

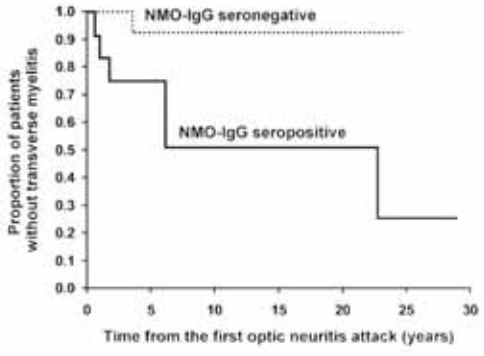
Baseline characteristics (prior to NMO-IgG testing)	Seronegative (n = 20)	Seropositive (n = 14)	p Value
Age at onset, y, median (IQR)	28.9 (14.8-43.7)	31.0 (23.7-42.3)	0.45*
Sex, F:M	18:2	14:0	0.5†
Ethnicity, n (%)			0.07†
Caucasian	17 (89.5)	7 (58.3)	
Other	2 (10.5)	5 (41.7)	
Unknown	1	2	
No. of ON episodes, mean ± SD	3.05 ± 1.65	4.14 ± 2.95	0.14*
Interval between first and second episodes, d, median (IQR)	131 (50.5-912.3)	258 (70.75-1,255)	0.19*
First ON visual score at nadir, mean ± SD	4.53 ± 2.26	6.12 ± 1.12	0.07‡
ON event with visual acuity worse than 20/200, n (%)	11/17 (64.7)	10/10 (100)	0.05†
No. of patients with bilateral episodes of ON	6	3	0.7†
At least one episode with no light perception, n (%)	7/17 (41.2)	7/10 (70)	0.14§
Follow-up outcomes	**Seronegative (n = 15)**	**Seropositive (n = 12)**	**p Value**
No. of patients with ON episodes after NMO-IgG serologic testing, n (%)	7 (46.7)	4 (33.3)	0.69†
Visual score at last follow-up, sum of both eyes, mean ± SD	6.38 ± 3.42	10.22 ± 3.89	0.02‡
Transverse myelitis episodes, n (%)	1 (6.6)	6 (50)	0.03¶

*Wilcoxon test.
†Fisher exact test.
‡t test.
§Chi-square.
¶Log-rank.
IQR = interquartile range; ON = optic neuritis.

tients died shortly after developing TM, one from a pulmonary embolism and the other from uncertain cause.

NMO-IgG titers among seropositive cases were higher in those who developed myelitis than in those who did not. TM developed in 5 of 7 patients (71.4%) whose NMO-IgG was positive at a serum dilution greater than 1:480, but in only 1 of 5 patients (20%) whose serum was positive at a dilution of 1:480 or lower ($p = 0.07$).

Figure Kaplan-Meier analysis for the occurrence of transverse myelitis stratified by serologic status for neuromyelitis optica–immunoglobulin G.



DISCUSSION The 20% seroprevalence of NMO-IgG among patients presenting with RON was similar to the frequency we originally reported for NMO-IgG among patients with RON. In the original report, 2 of 8 patients (25%) with simultaneous or sequential RON were NMO-IgG positive.[2]

The visual disability recorded for patients in this report is consistent with previous reports for patients with NMO. In a study conducted before the advent of NMO-IgG testing, the initial ON episode and final visual outcome of patients with RON were worse in the NMO-conversion group than in those who did not convert to NMO.[1] Similarly, in comparing visual status immediately after an ON episode and then 6 months later in Afro-Caribbean patients with NMO or MS, the number of attacks in the first 2 years (2.0 ± 1.3 vs 0.97 ± 0.7), the annual relapse rate (0.39 ± 0.33 vs 0.27 ± 0.29), and the final visual acuity impairment (20/50 vs 20/25) were greater in NMO than in MS.[13]

NMO-IgG is not restricted to patients fulfilling all criteria for a definite diagnosis of NMO.[10,14-16] The seropositivity rate in patients with recurrent LETM was 52%[2] and 40% in pa-

tients with a single episode of LETM.[10] This study provides support for RON being a limited or inaugural symptom of NMO in at least 20% of patients.

No clinical trial has established the most efficacious treatment for preventing relapses in NMO. However, case series strongly supports the use of immunosuppressant drugs rather than interferon beta.[3-6] Patients with RON who are seropositive for NMO-IgG are at high risk for development of TM and severe disability. Therefore, we advocate testing patients with RON for NMO-IgG and favor use of immunosuppressive therapy in treating NMO-IgG-seropositive patients with RON, as we also recommend for patients with LETM who are NMO-IgG seropositive.[10]

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Synapse 12, 12/11/08 15:43 Page 7.

Transverse Myelitis: diagnosis, treatment and management

Transverse Myelitis is an autoimmune disorder attacking the spinal cord, which presents with a wide variety of symptoms involving sensory, motor and autonomic dysfunction. These symptoms may develop very quickly over a few hours or gradually over a period of several weeks, complicating diagnosis for GPs and casualty staff. Lew Gray, Secretary of the Transverse Myelitis Society provides a guide.

Transverse Myelitis is an autoimmune disorder attacking the spinal cord, which presents with a wide variety of symptoms involving sensory, motor and autonomic dysfunction. These symptoms may develop very quickly over a few hours or gradually over a period of several weeks, complicating diagnosis for GPs and Casualty staff. TM is not common – estimated 300 cases p.a. in UK – but it is both debilitating and treatable in the acute phase. Therefore early diagnosis and referral to a specialist neurologist is important. Primary-care and rehabilitation specialists also bear the main role in managing after-care for TM patients, two thirds of whom suffer from long-term sequelae.

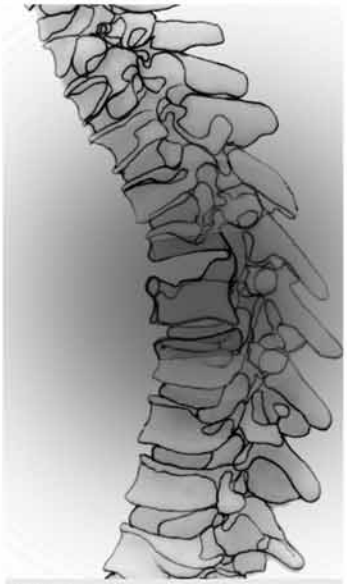
Diagnosis and Treatment

Some patients encounter TM with rapid onset of weakness and/or bladder dysfunction. This group are more likely to visit A&E. But other patients start with subacute onset of sensory symptoms and little motor dysfunction. These patients usually visit their GPs with the symptoms listed below that occur in varying combinations and sequence.

Sensory dysfunction: 80-94% of patients will have numbness, paresthesias or bandlike dysesthesias, although these may not all be present initially. A tight, uncomfortable banding sensation around the trunk is a particularly good indicator of TM. Adults are more likely to present with numbness or paresthesias (ie burning, tingling) with a midthoracic sensory level, whereas children show a higher frequency of cervical spine involvement. Other sensory symptoms include heightened or diminished sensitivity to temperature and allodynia – pain caused by non-painful stimuli such as light touch or even wearing clothes.

Autonomic dysfunction and weakness: Acute urinary retention is typical at the outset, and most TM patients suffer bladder and bowel dysfunction due to loss of sensation, which is often complete in the acute phase. Most patients develop leg weakness. At the maximal level of deficit, 50% of patients have lost all leg movement. Onset of paralysis tends to be rapidly progressive; complete paralysis can occur within hours.

Timely MRI imaging, CSF analysis and lab tests are used for diagnosis, as well as history and physical examination. TM must be distinguished from compressive lesions first of all, and then from other conditions such as Guillain-Barre Syndrome and MS. Rheumatological symptoms must be looked for, as TM may also be a presentation of systemic autoimmune disease eg lupus, sarcoidosis etc. First-line treatment is high-dose IV corticosteroids for 3-5 days to reduce inflammation, followed by oral steroids taper. Plasma exchange should be considered for severe TM that is refractory to corticosteroids, or for patients with suspected antibody-mediated disease eg Neuromyelitis Optica (NMO). When TM seems to be recurrent (NMO-IgG blood test), immunosuppressives should be considered.



TM: Long-term management

Once the acute phase of TM subsides, most patients are left with sequelae that greatly affect their lives and whose course depends on early physical and occupational therapy.

- Physiotherapy is essential not only to improve strength, mobility and gait but also to manage spasticity and improve sensation.
- Chronic neuropathic pain responds poorly to narcotics. GP persistence and attention to side effects is required to find the right remedy(s) in each individual case.
- Anti-spasticity drugs should not be limited to baclofen, and should be used in combination with active stretching exercise to maintain flexibility.
- Most patients continue to have some degree of bladder and bowel dysfunction. All patients should see a urologist for long-term surveillance. Urodynamic studies should be used to diagnose type(s) of bladder dysfunction. Sexual dysfunction often runs in parallel.
- 25% of patients with TM become clinically depressed, irrespective of their level of disability. Patients should be routinely screened for clinical depression. Fortunately, patients with TM seem to respond well.

> "One third recover with little or no sequelae, a third are left moderately disabled, and a third are left severely disabled. ."

Prognosis

Most people with TM experience some degree of neurologic recovery but are also left with neurologic deficits. Though recovery is more rapid in the first six months after onset, patients can experience some improvement for up to two years and physiotherapy should not be terminated prematurely. Around a third recover with little or no sequelae, one third are left moderately disabled, and one third are left severely disabled. Bad prognostic indicators include back pain at onset, rapid progression to maximal symptoms within hours, spinal shock, and sensory involvement up to the cervical level. Little improvement in the first 3-6 months makes significant recovery less likely.

TM is not always monophasic; recurrence affects a small percentage of patients. In all cases of recurrence, the potential for an underlying disorder should be investigated. Patients with lesions over three vertebral segments may go on to be diagnosed with NMO. In some patients TM may be first manifestation of MS – brain MRI and oligoclonal CSF bands are usually indicative of MS. Treatments for MS, NMO and TM are different, hence the need for good diagnosis.
Long-term TM sequelae are often subtle but very disabling. Neurologists do not do a very good job of aftercare and it is up to GPs and rehabilitation specialists to work together to manage chronic pain, continence, spasticity, fatigue and depression.

The Use of Rituximab for Treatment of Neuromyelitis Optica

This summary was prepared by Hanni Siegel from the originally published article, "Treatment of Neuromyelitis Optica with Rituximab: Retrospective Analysis of 25 Patients, " Anu Jacob, MD, MRCP, DM; Brian G. Weinshenker, MD; Ivo Violich, BS; Nancy McLinskey, MD; Lauren Krupp, MD; Robert J. Fox, MD; Dean M. Wingerchuk, MD; Mike Boggild, MD, MRCP; Cris S. Constantinescu, PhD; Aaron Miller, MD; Tracy De Angelis, MD; Marcelo Matiello, MD; Bruce A. C. Cree, MD, PhD, MCR; Archives of Neurology, 2008; Vol. 65 (No. 11), pp. 1143-1448[1]. Hanni works in the Lerner Research Institute at the Cleveland Clinic doing research in transplantation immunology.

Neuromyelitis Optica (NMO) is a rare, usually relapsing, inflammatory demyelinating disorder with a high early mortality rate[2]. In NMO, the optic nerve and the spinal cord are the targets of the immune system. With each relapse, there is an accumulation of the extent of disability, and within five years of the initial attack, half of the individuals diagnosed with NMO require the use of a wheelchair and just over half have become functionally blind[2]. The current options to treat NMO are based on studies of small numbers of patients, and include a variety of immunomodulatory (drugs used in the treatment of MS) or immunosuppressive medications. These drugs can work in a variety of ways. They can bind to immune cells and block their ability to function, prevent them from proliferating, deplete them, or stimulate them to function in a modified way. The goal is to prevent the ramped up immune response that is responsible for damaging the body, and different immunosuppressive medications work in different ways. Although some successes has been reported using glatiramer acetate (two patients were reported to have gone into remission on this MS drug) [3,4], it has been found that immunomodulatory medications such as this do not appear to effectively treat NMO in a majority of patients [5,6]. Additionally, with the immunosuppressive medications that have been tried, patients frequently continue to experience relapses[2]. Azathioprine is the most commonly used of these, but cyclophosphamide, mitoxantrone, cyclosporine, methotrexate and mycophenolate mofetil have also been used[7-10].

The study summarized here examined the experiences of 25 patients who received rituximab for the treatment of NMO, primarily because other treatments were not working effectively to reduce attacks. Rituximab is an antibody that binds to a molecule on the surface of B cells, the cells in the body responsible for producing antibody. These 25 patients were being treated at one of the following centers: University of California – San Francisco, San Francisco, CA; Stony Brook Hospital, Stony Brook, NY; Mayo Clinic, Rochester, MN; Mayo Clinic, Scottsdale, AZ; The Walton Center, Liverpool, England; Mellen Center, Cleveland Clinic, Cleveland, OH; and Mt. Sinai Hospital, New York, NY. Patients were included in the study if they had relapsing NMO (n=23) or NMO-IgG seropositive longitudinally extensive Transverse Myelitis (n= 2), received at least one dose of rituximab, and were followed for at least 6 months after being treated with rituximab.

Patient gender was overwhelmingly female (88%), and the median age was 38 years, ranging from 7 to 65 years. Two of the patients were children. The median time from initial diagnosis to initial treatment with rituximab was four and a half years (range, 0.8 – 17 years). The median time between last relapse prior to treatment with rituximab and initiation of treatment with rituximab was 1 month (range, 0-7 months). Of the 20 patients tested, 70% were found to be NMO-IgG seropositive. For 23 of the patients, rituximab was used due to inefficacy of prior treatment options. The drugs used prior to treatment with rituximab were Azathioprine (n= 14), Interferon-beta (n= 12), Prednisone (n= 10), Mitoxantrone (n= 7), IV-Immunoglobulins (n= 7), Glatiramer acetate (n= 4), Cyclophosphamide (n= 3), Hydroxychloroquine (n= 1), Methotrexate (n= 1), and Mycophenolate mofetil (n= 1). The median number of immunotherapy treatments tried prior to treatment with rituximab was 2 (range, 0-6). Rituximab was the first therapy used for 2 of the patients. Additionally, 5 of the patients were undergoing additional therapies while being treated with rituximab. These treatments were Prednisone (n=2), Azathioprine (n= 1), Azathioprine and Prednisone (n= 1), and Interferon-beta (n= 1). Seventeen patients were re-treated with rituximab, either at planned intervals following a relapse, or because of the identified presence of B cells. The median treatment interval was 8 months (range 4-26 months). The post treatment period for which follow-up information was available ranged from 6 to 40 months following initial treatment with rituximab. During the follow-up time, 7 of the patients stopped treatment for various reasons, including death (n=2), relapses (n=2), and pregnancy (n=1). For the individual clinical profiles of the patients included in the study, please refer to the original study, specifically the Clinical Profile Table, p. 1145.

For all 25 patients, the relapse rate was significantly decreased from a median of 1.7 relapses per year (range 0.5 – 5) to a median of 0 relapses per year

(range 0 – 3.2) following treatment with rituximab. The decrease in annual relapse rate remained significant even after excluding the patients followed for less than 1 year after treatment with rituximab, the patients undergoing concomitant immunotherapies, and the two patients who died. The median Expanded Disability Status Scale (EDSS) score also significantly decreased (demonstrating physical improvement) from the time of commencement of treatment with rituximab (7, range, 3-9.5) to the time of last follow up (5, range, 3-10). When looking on a more individualized level, the EDSS score improved for 11 patients, stabilized for 9 patients, and worsened for 5 of the patients.

There were several adverse events that occurred during the treatment and follow-up periods that must be acknowledged. One patient died following a severe relapse. This individual had also developed recurrent *Clostridium difficile* colitis and a urinary tract infection prior to relapsing. One patient developed fatal septicemia related to a urinary tract infection. Short-term ill effects related to the infusion of rituximab were observed in 28% of the patients. Additionally, 3 patients developed new or reactivated infections; one individual developed herpes simplex and positive tuberculin skin test, one individual developed herpes zoster, and one patient developed a cutaneous fungal infection. Finally, one patient with preexistent seborrheic dermatitis experienced worsening of the condition.

Rituximab is a drug that suppresses the immune system. Although it is an inflammatory immune response that is ultimately responsible for the damage caused to the body in NMO, the immune system is a mechanism that is meant to protect and defend the human body. If some part of the immune system is suppressed, the body can become more vulnerable to other threats. The infections observed in these patients were not definitively linked to the immunosuppressive effects of rituximab, but the safety concerns remain. It has not been determined how the risk of infections with rituximab treatment compares to the risk associated with other immunosuppressive treatments.

There are several factors that limit the conclusions that can be drawn from the data. The treatment regimen was not the same for all patients examined; eighteen patients received 375mg/m² once a week for 4 weeks, four of the patients received 1000mg twice, with two weeks between infusions, and the treatment regimen for the remaining 3 patients was unknown. The presence of B cells was not monitored in all patients; therefore it is unknown how well the treatment worked to actually deplete B cells and if the timing of retreatment was optimal. Potentially confounding factors include the presence of concomitant therapies in 20% of the patients, as well as possible residual effects of medications used prior to treatment with rituximab. Finally, it is possible that, because of the timing of pre- and post-treatment EDSS scores, the improvements seen could have been attributed to recovery after a relapse rather than to treatment with rituximab.

Randomized, controlled clinical trials are the gold standard for determining how well a treatment works. Due to the rarity of this disease, studies analyzing the efficacy of treatment options involve small numbers of patients and the possible confounding variables cannot be eliminated. While the conclusions that can be drawn from a retrospective study such as this are limited, they are still quite valuable and can help clinicians make more informed treatment decisions. Especially given the possibility of severe disability from recurring attacks and the risk of mortality for patients with NMO, any information that can assist with treatment decisions is critically important. It is still not clear whether rituximab should be a first line treatment for NMO; there are other immunosuppressive drugs that are more widely available and less expensive. This study provides evidence that it is possible that the use of rituximab reduces the frequency of inflammatory attacks and could result in actual physical improvements as measured by EDSS scores for people with NMO.

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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 7,200 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.

GUTHY JACKSON
Charitable Foundation

NMO Patient Session - *Living with NMO*
November 11, 2009

The Guthy-Jackson Charitable Foundation is hosting a focus group session dedicated to those affected by Neuromyelitis Optica (NMO) Spectrum Disease (Devic's Disease) during the Foundation's second annual NMO Conference.

Anyone affected by NMO is invited to attend this session to engage in a dialogue with leading NMO clinicians and researchers and learn more about this rare orphan disease.

Admission is free and lunch will be provided. Advance registration is required (see below). Travel stipend may be provided.

Join us at the:
2009 NMO CONFERENCE
NMO PATIENT SESSION
Nov. 11, 2009
12 p.m. - 4 p.m.

Please visit: ***www.guthyjacksonfoundation.org*** for more details.

Session Location:

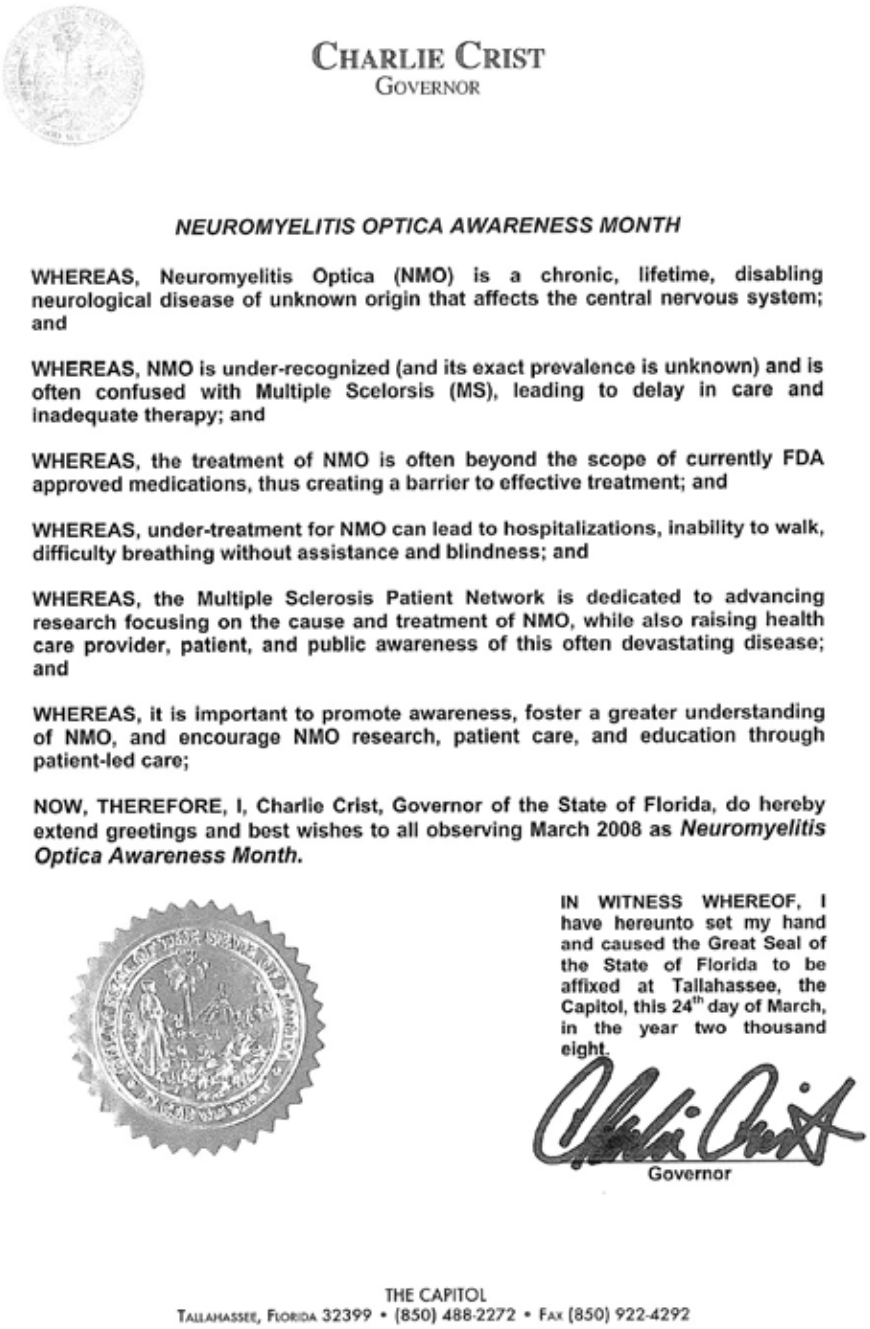
The Tower Beverly Hills
Studio 360 12th Floor
1224 S. Beverwil Drive
Los Angeles, CA 90035
Phone: (310) 277-2800
www.thetowerbeverlyhills.com/

ADVANCE REGISTRATION IS REQUIRED

Please contact Derek Blackway at:
Greater Good Foundation
8910 University Center Lane, Suite 725
San Diego, CA 92122
Phone: (858) 677-0644
Email: ***dblackway@4greatergood.org***

Daniel Kantor, M D: Advocate for N M O Education and Awareness

Dr. Daniel Kantor is an excellent physician and a wonderful advocate for his patients. Dr. Kantor has assumed a more extensive advocacy role by promoting the need for awareness, education and research for neuromyelitis optica. Through Dr. Kantor's efforts, the Governor of Florida on March 9, 2009 signed a proclamation recognizing neuromyelitis optica and making March NMO Awareness Month. We applaud Dr. Kantor for this accomplishment on behalf of his patients and the many people who have this challenging disorder. Dr. Kantor is the Director of the Comprehensive MS & Migraine Center at the University of Florida & Shands Jacksonville. He also serves as the President-Elect of the Florida Society of Neurology.



CHARLIE CRIST
GOVERNOR

NEUROMYELITIS OPTICA AWARENESS MONTH

WHEREAS, Neuromyelitis Optica (NMO) is a chronic, lifetime, disabling neurological disease of unknown origin that affects the central nervous system; and

WHEREAS, NMO is under-recognized (and its exact prevalence is unknown) and is often confused with Multiple Scelorsis (MS), leading to delay in care and inadequate therapy; and

WHEREAS, the treatment of NMO is often beyond the scope of currently FDA approved medications, thus creating a barrier to effective treatment; and

WHEREAS, under-treatment for NMO can lead to hospitalizations, inability to walk, difficulty breathing without assistance and blindness; and

WHEREAS, the Multiple Sclerosis Patient Network is dedicated to advancing research focusing on the cause and treatment of NMO, while also raising health care provider, patient, and public awareness of this often devastating disease; and

WHEREAS, it is important to promote awareness, foster a greater understanding of NMO, and encourage NMO research, patient care, and education through patient-led care;

NOW, THEREFORE, I, Charlie Crist, Governor of the State of Florida, do hereby extend greetings and best wishes to all observing March 2008 as *Neuromyelitis Optica Awareness Month.*

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Florida to be affixed at Tallahassee, the Capitol, this 24th day of March, in the year two thousand eight.

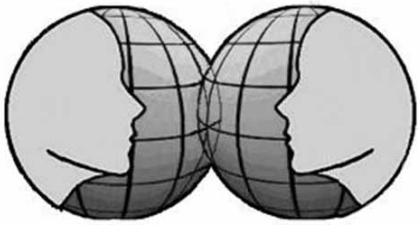
Governor

THE CAPITOL
TALLAHASSEE, FLORIDA 32399 • (850) 488-2272 • FAX (850) 922-4292

New N M O and T M Center and Pediatric Demyelinating Disease Clinic at the University of Texas Southwestern in Dallas

We are thrilled to announce that Dr. Benjamin M. Greenberg has moved from the TM Center at Johns Hopkins to the University of Texas Southwestern in Dallas. Dr. Greenberg has opened a new clinical and research center for Neuromyelitis Optica and Transverse Myelitis and will serve as the Director. The NMO and TM Center is a fully integrated clinical program offering neurology, urology, psychiatry, and physical medicine and rehabilitation, for both adult and pediatric populations. Dr. Greenberg is also establishing a Pediatric Demyelinating Disease Clinic at the Children's Hospital, which will offer a comprehensive clinical program where patients will receive physical and occupational therapy evaluation, case management, cutting edge testing, such as optical coherence tomography (OCT) and neurocognitive testing. Dr. Greenberg will also continue his research in NMO, TM and the other rare neuroimmunologic disorders, including clinical trials for acute and chronic care for people with these diseases, as well as basic science research looking into the causes and better, more novel treatments.

Dr. Greenberg's wonderful nurse, Maureen A. Mealy, also made the move to UT Southwestern from Johns Hopkins and will serve as the Center Clinical Research Manager. Besides coordinating the care of patients at the center, Maureen is leading multiple initiatives to better understand the impact of these various diseases on the lives of patients. An appointment for adults may be scheduled with Dr. Greenberg by calling (214)645-8800, option 5. The main number for the Children's Hospital is (214)456-7000.



FACES 2009
Encephalitis Conference

Las Vegas, Nevada September 18-20, 2009

Encephalitis Global, Inc. will be holding their 7th Annual FACES Conference in Las Vegas, Nevada September 18th – 20th, 2009. (FACES = Friends And Caregivers, Encephalitis Survivors.) This Conference gives survivors, families and caregivers the opportunity to share camaraderie and support in a friendly and compassionate group.

Please go to ***http://www.encephalitisglobal.org*** and click FACES 2009 Conference to view more information. Please advise if you would like to be added to our FACES e-mailing list, to receive new information when it becomes available.

Wendy Station, survivor, HSE 1999, Vancouver Canada
Ingrid Guerci, survivor, HSE 1995, New York, USA
Encephalitis Global, Inc.
admin@encephalitisglobal.org
http://www.encephalitisglobal.org

Accelerated Cure project for multiple sclerosis

New Repository Sites, Initiation of Follow-Up Visits and Neuromyelitis Optica Partnership with the Guthy-Jackson Charitable Foundation

The Accelerated Cure Project is dedicated to determining the causes and accelerating research into finding the cures for NMO, MS, TM, ADEM, and ON. One of ACP's primary initiatives is the building of a repository of blood samples and data from people with these disorders. These samples are distributed to researchers studying the causes of these diseases, thereby accelerating research. One of the frustrations encountered by ACP is when someone wants to participate in the study, but can't as they are not near (or able to travel) to one of the collection sites. ACP is eager to expand the geographic reach and will continue to open new sites as funding allows. ACP is proud to announce new collection sites have been open for enrollment!

One of the new repository collection sites is at The Ohio State University Multiple Sclerosis Center (OSU) in Columbus, Ohio. Dr. Michael Racke, chairman of OSU's neurology department and long-time member of Accelerated Cure Project's scientific advisory board, will lead the collection site at OSU. The study coordinator at the OSU MS Center is Lisa Hafer. The OSU site staff enrolled their first subject on March 30, 2009.

Beth Israel Deaconess Medical Center is a new collection site in Boston. The center's Principal investigator is neurologist, Dr. R. Philip Kinkel with study coordinator, Sarah Konkel. The first sample collection took place Tuesday, March 10, 2009.

A new collection site was also opened at the Rocky Mountain MS Center at Anschutz Medical Campus in Aurora, Colorado, led by principal investigator, Dr. Tim Vollmer. If you are interested in participating in the repository at the Denver location, please call study coordinator, Sydni Edwards at (303)724-2197.

The repository provides a common population of samples useful for a wide variety of studies that enables results from different research perspectives to be easily combined and correlated. The repository contains various types of samples and data that can support scientists working in many fields, such as genetics, nutrition, virology, and more. Researchers gaining access to the repository must return their results to the database to be shared with other researchers; this allows for cross-correlation of their results with all other studies performed using the same samples.

While samples continue to come into the repository through increased enrollment, they also continue to be distributed in support of research into the causes of MS, TM, NMO, ADEM, and ON. Recent sample distributions include the distribution of 987 samples to Dr. Julius Birnbaum of Johns Hopkins in support of his research related to neurodegeneration in people with secondary progressive MS. We also have recently distributed samples from 10 subjects with NMO, along with 5 controls, to Dr. Alan Verkman at UCSF who is investigating the role the antibody NMO-IgG may play in cell functions. You can learn more about

the research being supported by the Accelerated Cure Project repository samples and data by visiting: ***www.acceleratedcure.org/repository/research.php***

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

ACP has announced that the first follow-up visits are now underway. Participants have enthusiastically returned to provide updated data, new blood samples, and to answer the questions that have been added to the interview related to stress and trauma. If you are a repository participant with a demyelinating disease and you enrolled more than a year ago into the repository, you may be getting a phone call or postcard soon asking you to return and continue your involvement. Your continued involvement enhances the value of the repository and accelerates research into the causes of ADEM, MS, NMO, ON and TM.

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

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

Repository Collection Sites

Barrow Neurological Institute
500 W. Thomas Road, Suite 300
Phoenix, AZ 85013
Principal investigator:
Denise Campagnolo, MD
Study coordinator: Breanna Bullock
Study coordinator phone: (602)406-6211
acp-study-barrow0807@acceleratedcure.org

Beth Israel Deaconess Medical Center
Multiple Sclerosis Center
330 Brookline Ave KS 211
Boston, MA 02215
Principal investigator: R. Phillip Kinkel, MD
Study coordinator: Sarah Konkel
Study coordinator phone: (617)667-3726
acp-study-director0807@acceleratedcure.org

Johns Hopkins School of Medicine
Department of Neurology
600 North Wolfe Street Pathology #627
Baltimore, MD 21287
Principal investigator: Arun Venkatesan, MD
Study coordinator: Jana Goins
Study coordinator phone: (410)502-6160
acp-study-hopkins0807@acceleratedcure.org

Multiple Sclerosis Research Center of New York
521 West 57th Street, 4th Floor
New York, New York 10019
Principal investigator: Saud Sadiq, MD
Study coordinator: Lauren Puccio
Study coordinator phone: (212)265-8070
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Shepherd Center, Inc.
2020 Peachtree Road NW
Atlanta, GA 30309
Principal investigator: Benjamin Thrower, MD
Study coordinator: Elizabeth Iski
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Anschutz Medical Campus, University of Colorado
Rocky Mountain MS Center
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University of Massachusetts Medical School
Multiple Sclerosis Center
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University of Texas Southwestern Medical
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Center at Dallas
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Victory Junction Gang Camp and The Transverse Myelitis Association Establish Partner Agreement

In November 2008 the TMA and Victory Junction Gang Camp formally recognized a partnership that has really been in the works since 2005. Leslie Cerio, Shannon O'Keefe and Stephen Miller began the work of finding a camp for the children in our community. A long and complicated journey brought them to Victory Junction Gang Camp in 2006. Our first retreat weekend was held in November, 2006 for teens and young adults with ADEM, NMO, ON, TM and their families. Our second retreat weekend was held in October, 2008. Our first family camp was held in the summer of 2007. The second TMA family camp will be held at Victory Junction Gang Camp in August 2009.

Every trip we make to Victory Junction is magical for all who attend. Our summer camp will be an amazing experience. The camp is a wonderful place, but the magic about Victory Junction is really about the caring and exceptional people who manage the camp and the many volunteers who devote their time and energy to creating an unforgettable experience for these children and their families. For the children and their families who have lives filled with so many complicated challenges, the family camp at Victory Junction is non-stop laughter, fun and excitement. It is energizing beyond words for the families, but it is also transformational for all of us who have the honor of sharing in this week-long celebration of these incredible children and their families.

We are going to have more than 40 families attending camp this summer from across the United States and also from Canada, England and Denmark. For many of these families, it will be their first opportunity to meet other families with children with these rare neuroimmunologic disorders. For other families, the week at camp will be a time to renew wonderful friendships. These families share strong bonds that have been reinforced over the years by their mutual support. We are expecting five of the physicians from our medical advisory board to attend camp this summer with their families. Drs. Barnes, Greenberg, Kaplin, Kerr, and Pidcock will provide an education program during the week for the parents and they will be available all week long to respond to questions. After attending three of our camps, I can say that without any doubt, no one has a better time at camp than the physicians on our medical advisory board. We are also expecting a number of adults from our community to be attending camp this summer as volunteers or as crew chiefs. The crew chiefs are assigned the job of helping the children and the parents have a great time at camp. This is not a difficult job; it is an incredibly rewarding one.

Victory Junction Gang Camp is a year-round camping environment for children, ages 6 to 16, with chronic medical conditions or serious illnesses. Founded by Kyle and Pattie Petty in honor of their son Adam, the camp is located in Randleman, North Carolina with a second location opening soon in Kansas City, Kansas. Victory Junction offers programs for 24 disease groups and maintains strong relationships with 22 partner hospitals. Victory Junction's mission is to provide life-changing camping experiences that are exciting, fun and empowering, in a safe and medically-sound environment. As a not-for-profit organization, the camp operates solely through the support of generous donors to provide this experience at no charge to children and their families. For more information about Victory Junction Gang Camp, please visit www.victoryjunction.org.

The partnership between The Transverse Myelitis Association and Victory Junction Gang Camp has been unique, innovative, and so successful. The partnership is more accurately characterized as between the TMA and the exceptional physicians we have associated with our community and Victory Junction Gang Camp. The presence of these physicians at camp, their active engagement with the children and families and their relationship with the camp staff and directors has been truly remarkable. Victory Junction Gang Camp provides our families with a life-changing camp experience that is exciting, fun, empowering, safe and free.

We can never find the words to properly thank Victory Junction Gang Camp for all of what they give to our families and our community. The relationship we have created in such a short time has been truly exceptional. It takes a very special organization with very special people to be willing to foster this kind of relationship with a very rare disease community, represented by a very grass roots organization. The TMA is so proud of our special relationship with Victory Junction Gang Camp and honored to have this partnership.

Paralysis Population Survey Shows Over a Million More Paralyzed Than Previously Estimated; Five Times More People Live With Spinal Cord Injury and Disease

A survey of over 33,000 households shows that 40 percent more Americans live with paralysis and over five times the number of Americans live with spinal cord injury and disease than previously estimated. Specifically, the survey shows that 1.275 million have had a spinal cord injury and over 5.6 million Americans live with some form of paralysis. The highest previous estimates were 250,000 and roughly four million, respectively.

"That means one in 50 Americans is living with some form of paralysis, whether caused by disease, spinal cord injury or neurological damage," said Peter T. Wilderotter, President and CEO of the Christopher & Dana Reeve Foundation. "Someone you know is living with paralysis – a family member, a friend or a work colleague."

Major Findings The study was initiated by the Christopher & Dana Reeve Foundation and conducted by the University of New Mexico's Center for Development and Disability. More than 30 experts from 14 leading universities and medical centers and the U.S. Centers for Disease Control and Prevention set the parameters for the survey. The development of the survey, acquisition and analysis of the data took over three years.

"This is the first population-based survey to measure the national prevalence of paralysis," said Anthony Cahill, Ph.D., principal investigator for the study and Director of the Division of Disability and Health Policy in the Center for Development and Disability at the University of New Mexico's School of Medicine. "The enormous data set offers a wealth of information about this population."

* Paralysis is dramatically more widespread than previously thought. Approximately 1.9 percent of the U.S. population, or 5,596,000 people reported they were living with some form of paralysis, defined by the study as a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities. This is about 40 percent more Americans living with paralysis than previously estimated (~four million).

* Spinal cord injury is also more prevalent than previously estimated. Data indicate that 1,275,000 people in the United States are living with spinal cord injury; more than five times the number of Americans previously estimated in 2008 (255,702).

* We are more certain about causes of paralysis. The leading cause of paralysis was stroke (29 percent), followed by spinal cord injury (23 percent) and multiple sclerosis (17 percent).

* Paralysis appears to be disproportionately distributed among some minority communities, such as African Americans and Native Americans, but not all. Hispanics who are living with paralysis represent approximately the same percentage as those who report being Hispanic in the United States census.

* People living with paralysis have households with lower incomes. Household income for those with paralysis is heavily skewed towards lower-income brackets and is significantly lower than household income for the country as a whole. Roughly 25 percent of households with a person who is paralyzed earn less than $10,000 per year, compared with only seven percent of households in the general population.

Public Health Implications "This study reveals important findings about the prevalence of paralysis and spinal cord injury, but we must also remember that behind each of these statistics are real people, who along with the rest of their families are facing urgent needs," says Dr. Edwin Trevathan, Director of the CDC's National Center on Birth Defects and Developmental Disabilities. "This is a crucial first step to providing appropriate public health supports for this community in understanding how many people live with the condition, who they are, and what they need. At the CDC it is only when we apply our knowledge to improve the lives of people from before birth and throughout their lives that we can achieve our long-term objectives."

Findings about socio-economic status are particularly concerning. Basic supports are available, such as ramps and in-home caregivers that allow those living with spinal cord injury and paralysis to continue to work and to improve their quality of life. In addition, rehabilitation therapies and medical interventions that restore functionality in some patients exist. Yet these therapies and quality of life supports are all-too-often unavailable, often due to lack of adequate health insurance or limited geographic access.

"The healthcare system is often penny-wise and pound-foolish," said Joseph Canose, Vice President for Quality of Life at the Reeve Foundation. Canose directed the project on behalf of the Reeve Foundation. "For example, many health insurance companies will not pay for a $400 wheel chair seat cushion, but they will pay $75,000 to $100,000 to treat the pressure sores caused by the wrong cushion. The more we can do to help people live independently, to get an education, to work and to live fulfilling lives, the more our entire society benefits."

Methodology Researchers collected and analyzed data from more than

33,000 randomly sampled households with a telephone survey in the United States to document the prevalence of paralysis, including spinal cord injury. With the exception of annual surveys sponsored by the federal government (such as the Behavioral Risk Factor Surveillance Survey (BRFSS) or the National Health Interview Survey), this is the largest population-based sample of any disability ever conducted of which we are aware.

The study comprised four components:

* Assessment of existing surveys, registries, and data collection efforts. A team from the University of Kansas conducted this assessment to determine how paralysis was defined by different organizations and surveys, as well as how data about paralysis had previously been collected. These findings were published in the peer-reviewed publication ***Disability and Health Journal*** in July 2008.

* A "consensus conference"" was held in Atlanta in 2006, convening more than 30 experts in statistics and paralysis to develop a functional definition of paralysis that could be used in a national survey and to draft a survey instrument for it.

* The development and testing of a pilot instrument. Researchers used cognitive testing to create the final instrument–a process that helps to ensure that questions on a newly-developed survey are clear to respondents and mean the same thing as they do to the survey creators. They then administered the instrument by phone to more than 100 people, who then participated in follow-up interviews or focus groups about their understanding of the questions. Next, two waves of 1,000 people each participated in the survey (by phone). These activities led to four revisions of the instrument.

* The final survey was administered by ICR International, a nationally-recognized research and polling firm, during 26 weeks in 2008. ICR conducted telephone interviews nationally between May and August 2008 with adults in 33,348 households in the United States. Since African Americans and Hispanics are usually under-represented in random national surveys, these groups were oversampled.

Conclusion "If Christopher Reeve were alive today, he'd say, 'I told you so; now get to work,'" concluded Wilderotter. In response, the foundation plans to launch a major campaign, and has laid out an ambitious public policy agenda (which is outlined in the One Degree of Separation report.) A full pdf version of the study and report may be found on the Christopher and Dana Reeve Foundation web site:

www.christopherreeve.org

None of the respondents to the survey had transverse myelitis (personal communication). I have no information in regard to whether any of the respondents identified neuromyelitis optica or acute disseminated encephalomyelitis as the disorder that caused their paralysis. In addition to the release of this important study, the Christopher and Dana Reeve Foundation has initiated an awareness program on their web site that includes a cure map. The awareness campaign and map can be found from the following link:

www.campaigntocureparalysis.org/

We urge you to get involved in this effort to ensure that people from our community with acute disseminated encephalomyelitis, neuromyelitis optica and transverse myelitis are counted!

The James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders

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

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

The purpose of the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders is to encourage the development of medical specializations in TM, ADEM and NMO through a year of study under a leading TM, ADEM or NMO specialist. The fellowship is focused on the provision of exceptional clinical care and/or research into these rare neuroimmunologic disorders. Award of the Fel-

lowship will be based on the expectation that the recipient will continue to specialize in ADEM, NMO and/or TM. If the fellowship includes a clinical and basic science research project, the fellowship term may be up to two full academic years.

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

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

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

Cody Unser: A Documentary Oscar Qualifying Run and a Graduation

Christopher Productions and The Cody Unser First Step Foundation announced the theatrical release of the documentary entitled, ***CODY; The First Step***. The Oscar Qualifying runs were held in LA County in April and in New York City in May.

CODY is a powerful documentary, narrated by Glenn Close that charts the extraordinary story of Cody Unser who was tragically struck with Transverse Myelitis at the age of 12. The disease left her paralyzed from the chest down. However, she refused to let that diagnosis define her and instead at age 13 founded the Cody Unser First Step Foundation to ensure that money would be raised to find a cure. For the last five years Cody has lobbied state legislatures and Congress to push for stem-cell research which offers the key to her own recovery. During the film, Cody shares with the viewers her determination to walk again. The film takes the viewers on an intimate journey with Cody detailing her daily emotional and physical struggles. The film also charts where science and politics intersect. Visit **www.cufsf.org** to see the trailer.

Cody Unser said, "I hope my story will shed some light on what it is really like to live with paralysis. I also hope that the film will lead to more research dollars so that paralysis; not just for me, but for all people, will become a treatable and reversible diagnosis."

Chris Schueler, Director/Producer of CODY said, "Cody Unser has become an inspiration to everyone associated with the production. Despite her paralysis, Cody has not only remained remarkably independent but has made some amazing accomplishments. I am honored that Cody was willing to let our film crew into her life and I am confident the documentary will forever change how the public views people who are not disabled but rather differently abled."

Cody graduated from the University of Redlands College of Arts and Sciences in May with a bachelor's degree in Biopolitics through the Johnston Center for Integrative Studies. This program allows students to work with faculty members to create their own majors. Cody defines Biopolitics as the connection between biology and political action in human health. Cody will be the first student to graduate with this major. Cody's interest in biology and politics grew out of her advocacy work focused on the development of restorative treatments from stem cell therapies. She has worked closely with Dr. Douglas Kerr, Director of the Johns Hopkins TM Center and Project RESTORE and the Christopher and Dana Reeve Foundation in these advocacy efforts.

Cody's future plans involve her continued work with her wonderful foundation, the Cody Unser First Step Foundation and the pursuit of degrees in public health and law. Congratulations, Cody; we are all so very proud of you!

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

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

The centers are working together to:

* Improve evaluation and 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***

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
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
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
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
www.mayoclinic.org/pediatric-center

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

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 interact and discuss with real people - similar to you.

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.

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

ReadSpeaker is an innovative program that transforms text into speech. We added ReadSpeaker to our website to facilitate access to information for people who have visual impairment from Optic Neuritis, Neuromyelitis Optica or Multiple Sclerosis. Also, for thousands of people who visit our web site seeking information and support, English is not their first language. Listening to the text could make it easier for people to understand this critically important information.

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

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

We Don't Want to Lose You

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes to me via email at ssiegel@myelitis.org; you can send changes to me by mail, or you can fill out a change of information form on the web site: http://www.myelitis.org/memberform.htm – just click on the box indicating that you are changing existing information.

The Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates. We save a considerable amount of money by doing our mailings in this fashion. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you, after your grace period, and this class of mail is not returned to the sender. The cost to the Association is substantial; the materials we are mailing to a bad address just ferment on some post office floor. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

Support Groups

Arizona Support Group

My name is Barbara Sattler.

While most Americans remember September 11, 2001 as the day the world trade center was attacked, for me it was also the day I was diagnosed with TM. I have read many of the articles where people talk about contracting TM, but unlike many of you, I really don't know when the disease started.

About 6 months before my diagnosis, I began having discomfort in my chest corresponding with the area where I had the largest lesion in my spine. Next I had weird rashes, horrible diarrhea, and then for a time, pain which made my eyes water when I bent down. Finally, I woke up one day with a fever and abdominal pain; what I now know is the girdling effect and a myriad of other weird symptoms. When the fever broke, and I tried to get out of bed, I found both legs were partially paralyzed. Although I consulted numerous doctors, it took a month after that to get an accurate diagnosis.

Now, over 7 years later, I walk, hike, and lead a normal life other than suffering from chronic pain which I deal with by taking narcotics and other pain medication and medications to reduce side affects of the pain medication. I have gone through periods of anger, sadness, "why me" and yet more often, feeling blessed because I could have wound up permanently paralyzed or with other more serious disabilities.

In my worst hours, reading the TMA Journal and web site and hearing about others fighting with TM, has been an inspiration. When I first found the web site and saw there were others out there who knew what I had gone through, as well as reading information about the disease, it made a tremendous difference in my attitude. I felt like I knew Sandy and Pauline from Sandy's articles and even though I never met them, I felt like Sandy, Pauline, and others like them were almost part of my family.

I have recently retired. I was a lawyer for many years and then a Judge. One of the things I most want to do with my time is give back something to the TMA. I am happy to report that Tucson, Arizona had its first support group meeting on February 5th 2009. There were only two of us present, but for both of us it was the first time we had ever met another person with TM. We have been in contact with others and will have our second meeting in approximately a month. If we haven't found you yet, we want for you to join us. You can contact me at bsattler@myelitis.org or call me at (520)325-5861. I would love to hear from you and I would love for you to get involved.

Colorado TM Support Group

Danise and Lamar Burkes moved to Texas and Kevin and Barbara Hession are taking over leadership of the Colorado Support Group. Thank you, Kevin and Barbara!

A Journey

Nothing about this disease is easy. It's absolutely the hardest thing I've ever been through in my life. But I am one of the lucky ones as my son has recovered with only some minor symptoms. My husband was killed in 2000 and then there was 9-11. My mother had a heart attack and my oldest son was diagnosed with a very serious disease. In June, 2006 my sister committed suicide after having a stroke and on Kevin's birthday. But nothing, absolutely nothing prepares you to see your child lying in ICU in a coma and no one knows how to heal him. In the 39 years you've raised him, protected him, nurtured him in any way you could; nothing prepares you for the journey you are about to undertake. I had to stand by and watch my son and know there was nothing I could do except to fight for him. It was out of my hands. Only G-d knew what would happen to him. I was afraid. I felt I couldn't let anyone know how scared I was. There is little known about ADEM. It seems to affect each person differently.

My son, Kevin, was 39 and had never been sick in his life except for an occasional cold. He had his whole life ahead of him. He had dreams of things he wanted to do and then suddenly one day… poof - those dreams were gone. Kevin had done so much already in his short life. He was the manager of the hockey teams for Bemidji State University and the University of Minnesota. He coached the Bantam team of the University of Denver and also worked as an off-ice official for D.U. At the time of his illness he was a realtor and, in fact, had worked as such the day before he became ill. He had traveled all over the world and loved what he did. He was not married and only had his dog and his home to take care of.

Our experience began the first part of September, 2006. Kevin was not feeling well and was being treated by his physician for a sinus infection with Augmentin. On September 12 he asked me to drive him to the doctor's office because he didn't trust himself to drive. I worked a block away and by the time that I arrived there he could hardly walk or talk. Kevin is 6'8" tall and weighs over 300 lbs. I was unable to help him. I called my

boss and she came to help me get him to the doctor. The doctor told us to take him to the ER. He had no idea what was wrong with him. We took him to Presbyterian/St. Luke's Hospital here in Denver. They had no idea what was wrong and thought it might be dehydration from the infection. They wanted to keep him overnight and do a CT scan. By the next morning, he was unable to communicate. An MRI was performed.

They suspected vasculitis. This was just the beginning of a long string of diseases he was tested for, each one proving wrong. We were very lucky to have an intern on the case who never gave up. He was constantly doing research and was the first to mention ADEM. I called my retired physician to ask him to come by and take a look at Kevin. He called back and said he thought maybe it was ADEM. He had a friend who had had it and the symptoms were very similar. Within a few days, Kevin was in a coma and transferred to ICU. Over the next month, he was tested for everything from A to Z and more. He was seen by upwards of 40 medical personnel. It seemed to be one doctor after another. He was catherized, had a trach put in and a feeding tube was inserted. He had numerous MRI's, CT Scans, lumbar punctures. There was a brain angiogram and tube after tube after tube of blood drawn. Still nothing was showing conclusive. They administered IVIG, plasmapheresis, massive doses of steroids and they were considering Cytoxan. There was also a possibility of a brain biopsy which might give them an accurate diagnosis. Kevin's neurologist spoke with a physician at the Mayo Clinic in Phoenix, AZ and he said he thought with everything that had been done they might be on the right track.

In only a few days my entire life had once again turned upside down. I worked every day and also ran to the hospital every day to see him. On my way home I would stop at his house, check to make sure things were ok and take his dog home with me. I already had one small dog of my own and the two became great friends before Kevin got sick, but now they were getting even closer. Sometimes I would go back to the hospital to just sit beside his bed and ask G-d to keep him safe and not to let anything happen to him. He had so many friends who called constantly and once the diagnosis of ADEM was suspected, they all began their own medical research. It soon became clear that the only way to keep in touch with them was through e-mails. I never thought I would appreciate the computer so much. His older brother had become disabled earlier that year, because of diabetes and I would take him with me to just sit there. Nothing ever happened, but at least we were all three together. On the days when I had a chance, I would check in on my mother who was in a nursing home; I was her caregiver. I never knew I could wear so many hats. I knew I had to be as strong as I could be and take care of all of us. Kevin was just getting ready to draw up a will and power of attorney before he got sick, but never got to it. Since I was now taking care of all of his financial issues, I needed to get a power of attorney. I contacted our attorney and we went before the Magistrate and I had to be made conservator and guardian. Once that was done, all the paperwork had to be sent to the different companies that Kevin did business with. I had to get in touch with Social Security and set it up so that he could receive his benefits.

I need to tell everyone that one of the best things you can do when things like this happen to you is to keep a daily journal of everything that happens; events and drugs and doctors. You will not regret it.

On October 4th, a brain biopsy was done. A small part of his brain was taken out and sent to the lab. The hole was covered and four tiny titanium screws were inserted. Now he tells me when he has problems, "Well, Mom, guess you'll have to tighten my screws again." The specimen was sent to the lab and it came back with a diagnosis of ADEM. With that the doctors began treatment as best they could. Kevin was transferred to Select Specialty Hospital in Denver on October 7th. They had put in a pick line for his IV's and meds, which led to blood clots and now the doctors were less optimistic about his recovery. They wanted to start him on Cytoxan. I knew this was a drug used for chemotherapy and something told me not to let them do this. I spoke with his physicians and asked them not to give it to him for a while and to see if he could somehow start to fight it on his own. They agreed.

Soon he developed nystagnus from the Dilantin he was put on and the doctors gave him a new med to counteract the rapid eye movement. They wanted to put in a G-tube but it was too hard to do and they felt they had to operate to put it in. But again, they decided to hold off for a while. No one seemed to know how to continue to treat him. He was getting one infection after another and then they put filters in his legs for the blood clots he kept getting.

On October 22nd, he started to rally. I asked his physician if we could hold off with the Cytoxan for a while to see if he could fight some more and maybe recover on his own. She agreed and the decision was made to hold off with Cytoxan for a few days. He began to rally and surprised everyone. He couldn't move or talk or do anything for himself. He lay in his bed for days on end, but the therapists would get him going. He was constantly doing the therapy they gave him. He did develop a few urinary tract infections, but they were treated and went away.

Most of his days were spent lying in bed watching TV unable to move.

Everyone was amazed at how well he was doing and on November 27th he was transferred to Spalding Rehabilitation Hospital. I tried a couple of times to get him into Craig Hospital, but they weren't able to take him. He again layed in bed and daily he received physical therapy, speech therapy and occupational therapy. He was now able to sit up in the wheelchair and watch TV. Once his trach was taken out, it was discovered that he could speak. He had not lost that ability. He had trouble reading, but he never forgot anything. He was having bowel and bladder problems and that was something they would work on down the road. Spalding worked with him to teach him to eat. For the first few days he was unable to feed himself.

Kevin had some problems with depression, but he would work through them. We all knew he would be ok through hard work. It was his nature. We knew how hard he worked as a hockey player and he was bound and determined to work that hard again. On January 11, 2007 he was transferred to Monaco Parkway Rehab and Nursing Center and this is where he began to improve. Within a week he was walking with a walker. His determination was so great and nothing could stop him. He decided he would get better and he did. He received speech and occupational therapy and improved by leaps and bounds. They had to teach him math again and many other things he had learned in school. They also taught him time. To this day, he still has a bit of a problem with his math and his time, but it is continually improving.

During all this time I had to continue to take care of his finances and I had to put him on Medicaid. I had to spend down everything he had. That was one of the hardest things I've ever done; knowing that I was making my son destitute. He had worked so hard to get where he was and suddenly it was gone. I only hoped he would understand and forgive me. Thank G-d, I raised a very forgiving man and, yes, he understood. I have recently had to put my other son on Medicaid and also my 88 year old mother who is in a nursing home. It was a lot easier, either because I'd done it before or because I just wouldn't let it bother me any more.

Kevin came home on March 23rd to live with me. The only problems he still had were his time and his math. His biggest problem was his right hand. I think over time that he will get full recovery. He was given braces for his wrists and for his feet to be worn at night. After he returned home, he went back to Spalding on a daily basis for more therapy where he continued to recover. He took Access-A-Ride every morning and did very well by himself. I would pick him up every night after work. On June 1st, he began going to C. U. Health Sciences for more therapy. He started on a daily basis and gradually he went two or three times a week, then twice a week and then once a week for quite a while. They treated him with warm water therapy and he loved it. They also made new braces which he still uses to this day when he goes to bed.

We talked to a hand specialist there and she said she would not do a tendon transfer on his right hand, the bad one, and the dominant one. She felt it was a temporary solution to a problem. When Kevin went to see her this last fall she was very pleased and said he should just keep up his hand therapy. She felt he was very ingenius in that when he was there she told him to get some heavier weights to work his wrists with and he went downstairs and got his dad's heavy tools and used those as weights.

By the end of summer 2007, Kevin was mowing my lawn and doing a very good job. He worked so hard getting done what he needed to do. He still has a couple of deficits, small though they are, but I want everyone to know that it can be done. He is back as an off-ice official for the University of Denver Hockey team. He can't drive yet, but I take him there and a friend brings him home. One of these days I know in my heart that he will be back on skates and we will be hearing him gliding down the ice.

I did take him back to Select Hospital when he recovered to see the nurses and doctors, because they were so wonderful to him. They always said they would one day see him walk off the elevator on his own. Well, he did that and they were so surprised, it made the tears flow. They all said that they were glad to see him in a vertical position since the only position they had seen him in was horizontal and they didn't realize how tall he was. Every one of them said they knew he could do it.

I learned a lot through all of this. I knew my son was very strong willed and that he could do anything he set his mind to and this is proof that it can be done. Kevin is proof that there can be recovery, although it is a long, hard journey; one that you cannot give up on. We know that all the prayers that were sent out for him helped him through it all. He was the recipient of many, many prayer circles. His friends helped me a great deal and some of them continue to this day to make sure they come to see him. They know how much it means to him. Keeping in touch is one of the things that helps the most. Letting them know that someone really cares about you; that they will help in any way they can, even if it's just with a small prayer. I thank G-d every day that I have my son back.

We have been in touch with other people with ADEM and have found that each has suffered in different ways.

We are pleased to take over the support group in Colorado. We decided that we needed to do something to help others. Please feel free to get in touch with us and please think about getting involved.

Barbara Hession
1860 S Dahlia Street
Denver, CO 80222
303-757-4317 (H)
303-596-6268 (C)
bahession@earthlink.net

Kevin D Hession
1526 S Garfield Street
Denver, CO 80210
303-757-7638 (H)
303-596-7499 (C)
kdhession@earthlink.net

We are beginning an effort to have a Transverse Myelitis Association license plate available in the state of Ohio. What would this mean? You could order a TMA plate the next time you need to register. You would pay slightly more for your plates and the TMA would get $25. Now how cool is that! While you are being stopped for speeding on the interstate, you can educate the highway patrol officer about the rare neuroimmunologic disorders. Actually, this is such an awesome opportunity for us to do important awareness, and I hope you will help me make this happen.

We need 500 signatures of people who would purchase these plates. Everyone in your household can sign the petition. They are required to have a driver's license and a plate registered on their car. The signature does not count unless you provide all of the information required on the form. I need your help circulating the petitions and collecting signatures. If you are interested in making this happen, please either send me an email or write to me and I will send you a petition. Please get as many signatures as possible and please feel free to make extra copies of the blank petition if you can obtain more signatures. I can also send the petition to you as a pdf file. When you have the petitions completed, please mail them to:

Sandy Siegel
The Transverse Myelitis Association
1787 Sutter Parkway
Powell OH 43065-8806

When I have 500 good signatures (with all of the information), I will ask my representative in the Ohio House to sponsor a bill to create these plates. It is voted on in the house and senate and then is signed by the Governor. We are going to do this! When it happens, I will let everyone know with an email and with newsletter articles, so we can purchase the plates. We have two years to purchase 500 plates or they will discontinue it. We don't have 500 members in Ohio, so we will need to ask family and friends to also purchase the plates. Thank you for helping me make this happen. It is a wonderful way for us to make people aware of transverse myelitis, neuromyelitis optica, acute disseminated encephalomyelitis, optic neuritis and the TMA!

ACP Collection Center at The Ohio State University

One of the best ways to facilitate research on TM, NMO, ADEM and ON is to participate in the Accelerated Cure Project. The TMA supports this program by helping to fund enrollment of people with the rare neuroimmunologic disorders, we serve on the ACP scientific oversight committee, and we encourage research on TM, NMO, ADEM and ON from the repository.

In order to enroll, you must be an adult. If you have TM, ADEM, NMO, ON or MS, we need for you to enroll in the repository. If you are a spouse, you can also enroll as a control. Pauline and I have both enrolled in the ACP repository. We need as many people as possible! If we are going to help doctors learn about these disorders, you can't wait for someone else to do this – it has to be you. There just aren't that many people with these disorders.

To enroll, please get in touch with Lisa Hafer at the number below and she will explain the process to you. It involves filling out a questionnaire and then coming to Ohio State to have a blood draw.

The Ohio State University Medical Center
Multiple Sclerosis Center
1654 Upham Drive, 445 Means Hall
Columbus, OH 43210
Study coordinator: Lisa Hafer
(614)293-7877
acp-study-director0807@acceleratedcure.org

Thank you!

Sandy Siegel
ssiegel@myelitis.org

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

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

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

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

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

Acute Disseminated Encephalomyelitis (ADEM)

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

Neuromyelitis Optica (NMO) or Devics disease

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

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

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

Children's Database

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

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

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

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

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

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

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

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

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

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

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

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

* Parent's names
* State/Country where living

* Child's diagnosis
* Age (birth year) of child with TM/NMO/ADEM/ON
* Parent's email
* Parent's phone

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

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

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

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

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

We 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 T M A Equipment Exchange

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

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

Thank you for your support,
Darian Vietzke

T M A Equipment Exchange Instruction Sheet

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

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

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

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

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

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

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

Thank you.

Fundraising and Awareness

Support the UK Transverse Myelitis Society

The TM Society is a UK registered charity with over 600 members. All members of The Transverse Myelitis Association living in UK are automatically members of the TM Society. TMA and TMS work very closely together. Both organizations are run by volunteers, with no paid staff nor professional fundraising. So we both are 100% reliant on donations. As we have almost no overhead costs, 100% of every donation is used to fund our charitable objectives, i.e., information and support for members and research to cure TM.

T**heGivingMachine™ is a new way to support your favourite UK charity.** Purchases you make via TheGivingMachine™ trigger retailer donations to your good causes. It costs you nothing! **You shop, they give ...** It really is as simple as that. **www.thegivingmachine.co.uk/** Register as a shopper/giver and select the Transverse Myelitis Society for the charity you would like to support.

Shop Amazon.co.uk Every time you buy something through Amazon a 4% commission is donated directly to Transverse Myelitis Society. **www.myelitis.org/amazonuk**

Jodie's Great Adventure and Raising Awareness and Funds for Research on ADEM, NMO, ON and TM

Jodie Douglas will be sailing three legs of a round-the-world yacht race. Jodie will join the boats on New Year 's Day 2010 from Western Australia and race up to Singapore, then on to China; from Qingdao China across the Pacific to California and the Caribbean via the Panama Canal. She will be at sea for up to 35 days at a time and away for five months. The Clipper Round-the-World Race is sailed by ten identical 68 foot yachts, crewed by experienced and inexperienced people of all ages.

Jodie has just returned from a week's training on a 60 foot yacht, which she said, "…was incredibly hard work but fantastic fun. The skipper knew all about my medical history and at the end of the week, said he had no problems passing me." Jodie is committed to spending the time between now and the race in January working on her fitness and stamina. She acknowledged the hard work ahead but believes that she has established a terrific goal for herself.

"I am going to be setting up a website for people to follow my progress and to sponsor me. I hope to get lots of coverage for the TMA and the UK TM Society awareness and to raise as much money as I can for ADEM, NMO, ON and TM Research."

www.jodiedouglas.com

For additional information about Jodie's great adventure, please go to the clipper yacht race website.

www.clipperroundtheworld.com/index.php/home

Jodie got ADEM in June 2006. ADEM is a neuroimmunologic disorder characterized by inflammation of the brain and spinal cord. Jodie was paralysed from the T6 level and was unable to walk. She spent three months at Charring Cross receiving treatment and physiotherapy and eventually regained the ability to walk.

Many of us had the opportunity to meet Jodie in Seattle at the last Rare Neuroimmunologic Disorder Symposium. We all enjoyed her beautiful smile and her wonderful sense of humor. We are grateful for Jodie's willingness to turn her great adventure into an awareness and fundraising opportunity for our community. We urge all of you to provide Jodie with your support, encouragement and to get involved in her generous effort. We are looking forward to hearing back from Jodie about the race. Be safe, Jodie, and have a great time!

Inkjet and Toner Recycling Program

The Transverse Myelitis Association has partnered with the Funding Factory Recycling Program to collect empty inkjet and toner cartridges. This is an important fund raising effort for the Association.

Please go to our web site at www.myelitis.org/recycle/. Once you register, you can order pre-paid UPS return labels that you put on any box you have. When you fill in the information, use your own name as the "Organization" name, but also, **PLEASE USE ID NUMBER 63960 AS THE BENEFICIARY. This ensures that the TMA will be receiving the benefits of the collected cartridges.** When filling out the contact information, the form asks for a "title". You can list "other" and put "supporter" for your title. Once the company has your information and you request shipping labels, they will ship them to you to place on the boxes. Once the boxes are filled, you can take them to any place that picks up UPS packages (such as "Mailboxes, ETC.").

We appreciate your participation in this important program!

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

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

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

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

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

I wanted to use something as beautiful and positive as flowers to overshadow the pain and suffering that these disorders can cause. Flowers bring joy and beauty in very simple, but wonderful ways and they speak to everyone's hearts through their beauty.

For more information, please visit my site or email me at the address below.

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

Thank you and take care,

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

Donating by credit, debit, or gift card: Google Checkout

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

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

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. 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.

www.cafepress.com/tmagifts

Heart of Hope Bracelet Benefiting the TMA

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

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

The Heart of Hope bracelet benefiting The Transverse Myelitis Association is hand-crafted using beautiful 6mm Swarovski® crystals in shades of olive, amber, amethyst and persimmon. Each bracelet is finished with sterling silver COURAGE and awareness ribbon charms. The fold-over, magnetic heart clasp assures a secure closure. While the magnet is not very powerful, please check with your physician if you are pregnant or have a pacemaker! The copyrighted design was inspired by Cynthia's love of fall colors and her courage and determination as she adjusts to life with TM. In Cynthia's honor, $25 of the purchase price of each piece will be donated to The Transverse Myelitis Association in your name and is tax deductible.

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

Thank you, Kathie and Cynthia!

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. 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

Dogs Doing Good for the TMA

A wonderful group in Tennessee held a fundraiser for the TMA in May. Their goal was to raise $5,000 and their program was in honor of their friend, Bruce Cardinal. Bruce developed radiation myelopathy in October 2008. Barry Coggins from Dogs Doing Good has spearheaded the activities. The TMA is grateful for their efforts and appreciate their honoring a good friend who has struggled with this difficult disorder.

You dogs done good!

Help Raise Awareness with a TMA Wristband

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

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

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

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

For check payments, 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 your shipping for you, you can send an email to ***wristbands@myelitis.org*** and we will tell you how much to send. You can also call Debbie Capen at (951)658-2689 to get your total cost and more information.

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

Helping to Fund the Work of Your TMA

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

Search the Internet and Raise Money for the TMA

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

Donate your cell phones

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

Online Shopping

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

Save Gas. Save Time. Raise Money!

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

Café Press Shop for items with The Transverse Myelitis Association logo to raise awareness and show your support!
www.cafepress.com/myelitis

Amazon.com You can shop at Amazon.com for Books, Music, DVDs, Videos, Toys and more.
www.myelitis.org/amazon

Music Downloads for any device!
Shop for your favorite song or album from our mp3 store powered by Amazon and download music that works with an Ipod or any mp3 player.
www.myelitis.org/shopmp3

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

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:
www.readingforrachel.org.

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

Donations by Check

We always welcome and are grateful for a donation to the TMA. You can download a donation form to include with your check from the link: ***www.myelitis.org/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 Membership Directory and Privacy on the Internet?

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

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

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

It is also critically important to bear in mind that The Transverse Myelitis Association does not put membership information on our web site or post it electronically anywhere. We publish the directory in paper copies and we mail these directories only to our members who are listed. We send electronic copies of our member information to the people who do our mailings around the world, but they only receive the information for the people for whom they do the mailings. They do not receive the entire membership database. We expend a great deal of effort in protecting your information and limit to the extent possible, the electronic versions of this database.

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

Important Reminder About The TMA Membership Directory

In order to receive a TMA membership directory, you must be willing to have your name and contact informa-

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

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

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

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

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

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.

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

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

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

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!

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

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

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

Another tremendous resource about TM and the other neuroimmunologic disorders is the streaming video that Jim has posted on the web site. The presentations from the 2008 (Seattle), 2006, 2004 and 2001 Symposia, from the Southwest Symposium (sponsored by the Cody Unser First Step Foundation), and from the 2002 children's workshop are available under the link 'Symposia Information' or by typing http://www.myelitis.org/events.htm into your web browser. Jim has the presentations organized as they appeared in each of these symposia program agendas. You can also find PDF files of most of the handouts and PowerPoint presentations. The video presentations are also available by going through the Streaming Video Presentations link from our main web page or by typing http://www.myelitis.org/multimedia.htm into your web browser.

The TMA Newsletter and Journal Archives

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

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

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

Medical Advisory Board

Support Group Leaders

Support for Women during Pregnancy and Preconception

Donna Chattin
(410)459-4195
donna_chattin@comcast.net

ADEM Support Group

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

Devics-Support

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

Sandy Barry
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sbarry@myelitis.org

Devic's Syndrome/NMO Support Group

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TM and Rheumatic Disorders

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CSRA TM Support Group - serving the Central Savannah River Area of SC & GA
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mamamckie@hotmail.com

Support Group website:
http://myelitis.org/local/csra/index.htm

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Kazu's 2008-2009 Second Grade Class Photo

Officers and Board of Directors of The Transverse Myelitis Association

www.myelitis.org

The Transverse Myelitis Association

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43065

Sanford J. Siegel
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New NMO and TM Center and Pediatric Demyelinating Disease Clinic at the University of Texas Southwestern in Dallas

Summer Camp for Kids with ADEM, NMO, ON, TM and their Families, August 12 – 16, 2009
Victory Junction Gang Camp, North Carolina

NMO Patient Session: Living with NMO
November 11, 2009 The Tower Beverly Hills
Los Angeles, California