
The Transverse Myelitis Association Newsletter

Volume 8 Issue 1

Fall 2007

The Rare Neuroimmunologic Disorders Symposium July 16 – 19, 2008 in Seattle, Washington

We are coming back to Seattle! Our last symposium in Seattle was held in 1999. We made history in 1999. Dr. Douglas Kerr made his first appearance at our meetings and announced his specialization in TM and the establishment of the TM Center at Johns Hopkins. Dr. Brian Weinshenker made his first public presentation of the results from his ground breaking plasma exchange research. It was the first large gathering of the TMA membership.

The Transverse Myelitis Association and the Johns Hopkins Project RESTORE (the TM and MS Centers) are co-sponsoring the 2008 Rare Neuroimmunologic Disorders Symposium. The symposium is for people who have TM, MS, ADEM, NMO and ON, their family members and the medical professionals who provide clinical care to people with these disorders.

Help us make history ... again!

Please mark the dates on your calendar. If you live west of the Mississippi River, you are not going to want to miss this opportunity. If you live east of the Mississippi River, Seattle is absolutely lovely in the summer time. You owe it to yourself and your loved one to make this trip out west. The symposium will be held at the Redmond Marriott Town Center. You can begin making your reservations at the hotel today! To receive our special rate, please ask for the "Rare Disorders Symposium" rate when you call (approximately \$170 without taxes). You can make your reservation by

calling the hotel at (425)498-4000 or reservations at (800)218-7141. We cannot guarantee you either a room in the Marriott or the group rate, if you make your reservations after June 1, 2008. The program will begin on Wednesday evening, July 16th and will be completed with the dinner banquet on Saturday evening, July 19th.

There will be a separate registration fee which will be announced shortly. This fee covers the cost of the education program, breakfast and lunch on Thursday, Friday and Saturday, and a Saturday dinner banquet. The per person registration fee for our 2006 symposium was \$250; we will do our best to keep the registration fee under \$300. We will also distribute the program agenda as soon as it is completed. If you would like to get some idea about the quality of our programs, please visit: www.myelitis.org, click on the 'symposia information' link and review the 2004 and 2006 program agendas. Registration materials will be mailed to our members in the United States and Canada. We will ask our international members to use the registration information and process on our web site.

If you are confused about whether you should come to Seattle, here are the top ten reasons for attending this incredible event.

One. The 2008 Seattle Symposium will be the largest gathering of people with the rare neuroimmunologic

disorders; we anticipate that between 200 to 300 people with TM, MS, NMO, ADEM and ON and their family members will attend. If you have never met another person with your condition, this will be a life-changing experience for you. If you have been to support group meetings or other symposia, it will be an opportunity for you to foster the relationships you have established in the past. If you are a participant in the Transverse Myelitis Internet Club, you will likely meet some of the people that you have been corresponding with for the past decade. No one understands your experience in the same way as the other people who will be attending the symposium. Lifelong friendships are made at our symposia!

Two. You will become a better advocate for your medical care. There is no other medical education program in the world focused on TM, MS, NMO, ADEM and ON that provides the breadth and depth of information you will receive during the meetings. You will come away from the meetings with a clear understanding of your disorder. As most family physicians and pediatricians (and many neurologists) know very little about these disorders, you need to be informed about the effective treatments for all of the symptoms of TM, MS, NMO, ADEM and ON. The more you know, the more you can help your physician understand about what strategies are possible to manage your symptoms. You will learn about the treatment strategies for all of the symptoms of these disorders. You will also receive infor-

mation about emotional support, the role of family in the care process, and other social issues that surround people and their families in coping with long-term illnesses and disability. If you have received one of these diagnoses in the past few years and have never attended one of our educational meetings, you cannot afford to miss this opportunity to educate yourself about your condition.

Three. The Symposium provides exceptional support and information for care givers. You will meet other caregivers such as yourself. Being able to share in your experiences with other caregivers will offer you tremendous emotional support. Many of the connections you make during the symposium will result in lifelong support networks and friendships. You will be provided with information during the presentations that will significantly enhance your own quality of life. You will learn about the importance of taking care of yourself and how your personal well being is critical to the long-term health of your loved one.

Four. All of the physicians from the Johns Hopkins Transverse Myelitis Center and Project RESTORE will be attending the entire symposium and will be making multiple presentations. Many of the physicians from across the country who specialize in these disorders will be attending and presenting at the symposium. Most of the members of the TMA Medical Advisory Board will attend the symposium. You will have the opportunity to meet and talk to all of these physicians at meals, breaks and social events during the weekend.

Five. You will have the opportunity to ask your questions of the world's experts on your condition. There will be informal opportunities for you to approach all of the physicians during the meals and social events. Most of the physicians also offer the opportunity to ask questions at the conclusion of their

presentations. Finally, our symposia conclude with a Question and Answer and Discussion Session. At the Seattle Symposium, this session will take place on Saturday afternoon. You will be given a few hours to ask your own questions and to learn from the responses that are provided to other people's questions. These sessions are so incredibly informative for our members.

Six. Presentations will be made on the latest research for acute therapies, symptom management and restorative therapies. The brilliant scientists in our community are performing the most incredible research about these disorders and about ways to repair the nervous system. You do not want to miss these presentations. If you are seeking reasons to hope for the future, the information you will be provided about research will most certainly give you the most compelling reasons for this hope!

Seven. Many of the support group leaders attend the symposia from across the country and from around the world. Attending the symposium will provide many of you the opportunity to make connections with the people who are leading these efforts in your state and country. Attending the symposia often gives people the motivation to initiate their own support groups or to lend their support to existing groups. The energy and enthusiasm to get involved in this incredible effort to improve the quality of life for people in our community is contagious.

Eight. You will be invited to a banquet that will be held on Saturday evening; this is the last event of the symposium weekend. This dinner is a true celebration of our community. What has happened to you or your loved one has likely been the most difficult and devastating experience in your lives. You have also likely experienced the love, courage, car-

ing, devotion, persistence, fortitude and will that so many people in our community display in their lives after getting one of these disorders. It is also likely that the suggestion that one could celebrate anything remotely connected to getting one of these disorders would not be possible. But come and see and feel and experience for yourself. We are a special community composed of remarkable people. This banquet provides us an opportunity to celebrate **US**. Sharing this event will be an empowering, energizing, emotional experience.

Nine. You will have the opportunity to meet Allen Rucker, author of *The Best Seat in the House: How I Woke Up One Tuesday And Was Paralyzed For Life*. And you will have the opportunity to meet Jim Lubin and to thank him for his incredible 14 years of service to the TMA Community. Debbie, Paula, Pauline and Sandy will be there, as well.

Ten. Your registration fee and travel expenses are deductible as medical expenses on your federal income taxes. Please check with your tax accountant or read the really scintillating Publication 502 for the details and the applicability of this deduction in your specific case.

See you in Seattle!

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Demoralization and Depression in Multiple Sclerosis and Transverse Myelitis

Adam Kaplin, MD PhD

Johns Hopkins University School of Medicine; Departments of Psychiatry and Neurology; Johns Hopkins TM and MS Centers; The Transverse Myelitis Association Medical Advisory Board

Adapted from a presentation at the 2006 Rare Neuroimmunologic Symposium

A man walks into a doctor's office with a duck on his head. The doctor comes out, greets them in the waiting room and asks, "How can I help you?" The duck says, "Can you get this man off my rear end?" This is my daughter's favorite joke. What often happens for people with depression, as well as cognitive impairment, is that these symptoms can be very subtle. Often, like the doctor in my daughter's joke, what they believe to be the problem is not what it first appears. Patients often experience a set of symptoms from their condition and my job often involves helping them to see these symptoms in a new light. Sometimes there is an underlying depression involved in the manner these symptoms are experienced.

This article will focus on the clinical side of depression. To understand depression, first you have to unlearn some myths, the first being that most people with neurologic illnesses are depressed. "Wouldn't you be depressed too, if you had MS or TM?" I often hear this from fellow physicians. Not only is this not borne out by clinical and research experience, but this question all too often is used to justify an individual's suffering and thereby miss an underlying treatable disease. Take the following study as a case and point.

Psychosocial Impact of Multiple Sclerosis: Patient's Perspective (Mohr et. al. 1999)

- Phone interviews used to explore psychosocial functioning, defined as intrapersonal or interpersonal processes excluding physical symptoms.
- Demographics: 100% Relapsing Remitting MS, 75% women, average 43 years old, 63% married, 55% employed.
- Psychosocial impact of MS clustered into 3 factors:
 - Deterioration in Relationships: endorsed overall by 20%.
 - Demoralization: endorsed overall by 30%.
 - Benefit-Finding: endorsed overall by 60%.

This is an interesting study that came out of San Francisco. In the Mohr study, they made phone calls to people in the community who had multiple sclerosis, and they asked, "How's it going? What's going on with your life?" The researchers were able to cluster the responses to these questions into three general areas. One cluster referred to how contracting MS had led to a deterioration in their relationships with their friends and family; that was one in five people. There were 30% of people who responded that they were demoralized in some way. Depression is very common in MS and likely a significant portion of this 30% was people who were depressed. Perhaps most striking, there were 60% of people with MS who said that in some way they had benefited from being afflicted with MS. This meant that somehow the experience of having MS had enriched their lives. There were three times as many people who were enriched by their MS experience as those that complained about troubles with relationships, and twice as many people as those who were demoralized.

Is this a surprising result? The following are some of the responses the researchers referred to as benefit-finding (and the percentage of the responses in parentheses).

Relationships:

My friends and family have become more helpful (77), I am closer to my family (70), I am closer to my significant other (51), I keep in better touch with my family (44).

Interpersonal Skills:

I have learned to be more compassionate (67), to be more respectful of others (58), express more feelings (55), communicate better (48), be a better friend (48).

Perspective:

I appreciate the importance of being independent (83), I appreciate life more (74), I am more introspective (72), more conscientious and self-disciplined (60), more motivated to succeed (59), more spiritual (45), more independent in many ways (38), less inhibited (33).

I am told all the time by my patients that walking is something wasted on the ambulatory. People do not appreciate the ability to be able to get up and move around. You don't think about it unless it is something that has been impaired or lost.

Most of the studies that have been done are on MS. As you will see from the work we have begun at the Johns

Hopkins TM and MS centers, most of the findings reflected in these MS studies also pertain to the whole spectrum of auto-immune conditions, including transverse myelitis, Devic's and ADEM.

There is no despair so absolute as that which comes with the first moments of our first great sorrow, when we have not yet known what it is to have suffered and be healed, to have despaired and have recovered hope.

George Eliot (1819-1880)

Often when initially confronted with these auto-immune illnesses, the vast majority of people are faced with a tremendous transition in their lives. People who get these disorders often do not know anything about them and they do not know what is going to happen to them. The incomprehensible sense of what the future is going to bring is difficult and makes it a struggle for people to cope.

Jerome Frank described and operationalized the concept of demoralization in his work at Johns Hopkins (Frank & Frank, 1993). Demoralization is the state of helplessness, hopelessness, confusion, subjective incompetence, isolation and diminished self-esteem. Demoralization results from a failure to adapt when environmental stress overwhelms an individual's coping capacity. An individual's coping capacity is influenced by constitutional variables and resources. The subjective thoughts, feelings, and beliefs of demoralized individuals are that they have failed to meet expectations; their own and/or other's expectations. They feel overmastered. There is a feeling of being unable to cope with some pressing problem. There are simultaneous feelings of being powerless to change a situation or to extricate themselves from a predicament. There is a sense of isolation; a feeling of being unique and, therefore, not understood. A common subjective experience may be characterized as follows: "I feel aw-

ful. No one else understands it. I'm not going to burden anybody else with how I feel. Therefore, I'm the only one who feels like this." We all have coping strategies that we use to deal with what life throws our way. And, we all have a point beyond which we no longer can cope on our own and become demoralized.

We treat demoralization with remoralization. I try to teach this to the residents at Johns Hopkins and to my patients and their family members. A sense of demoralization often results from the accumulation of a number of hurdles that feel insurmountable when taken together. Problem-focused coping skills can instill a sense of mastery. This can be accomplished by breaking down a large problem into smaller and more manageable tasks that can be approached and mastered.

When I work with patients with transverse myelitis, I often ask them what kinds of things they are concerned about. I've had patients say to me that the worst part of what is going on with them is that they feel as though they've lost their independence. For instance, they tell me that they can't go grocery shopping anymore; that they are just overwhelmed trying to use their walker in the store with all of the people and activity going on around them. I ask them if they can use the cart in the store and if they can go to the store at off hours when it is less busy. If the person can go shopping, this becomes an achievement, which then in turn becomes the start of many future achievements. The journey of a thousand miles begins with a single step. Cumulative small victories can re-instill confidence.

Cognitive reframing will help to combat a subjective sense of incompetence and confusion. This involves helping a person think about a problem in a different way: doing a

"reality check." For example, I have had patients come in and say, "I think I'm demented, I can't remember anything," by which they mean they used to have all of their friend's and relative's phone numbers memorized. I explain to them, "Well, now you will just have to be like the rest of us and will have to write all of these phone numbers down." The untreatable memory disorder becomes merely an organizational problem. Small achievements will help to combat helplessness, diminished self-esteem and frustrations.

Individual and group support and education are also critical components to preventing or overcoming demoralization. Educating yourself is very important as it is often what you do not know that can scare you the most. Once you have information and begin to understand your condition or situation, you can begin to get some control over it. Being a part of a support network helps to combat a sense of hopelessness and isolation. People often need an occasional reminder that it is okay to be merely human. It is important for a person to have a chance to express their feelings in a nonjudgmental setting.

If you can't be normal, be spectacular.
Cody Unser

Cody has overcome some tremendous hurdles; she has made peace with her illness. Cody's quote reflects the end result of someone who has found their way through and out of demoralization. Cody embodies the spirit of what it can be like to truly overcome the obstacles of demoralization and disability and emerge invigorated.

The issue of the caregiver's wellbeing in chronic illnesses is poorly studied in the medical literature, it is not sufficiently focused on and it is critically important. It is difficult to have one of the neuroimmunologic disorders; it is much harder than difficult to have one

of these disorders without a healthy caregiver. When I first see a patient with transverse myelitis, I spend at least a third of the time talking to their caregiver. I talk to them separately to touch base with them to see how they are doing. This generally doesn't get done in the medical setting despite its importance. I have found that the health of my patients is critically dependent on the wellbeing of their caregivers.

In a number of studies, caregivers report that there are both positive and negative aspects to being a caregiver. Patients generally underestimate the level of distress that their caregivers are having. In other words, and for obvious reasons, the patients tend to focus on their disease, as the doctors do, and not focus on the caregivers. The wellness of the caregiver is often neglected. Caregivers report an increased frequency of loss, loneliness and isolation. Caregivers often offer me a justification for not attending to their personal wellbeing with explanations such as this: "Of course I don't have friends any longer and I don't go out anymore, because I am so busy taking care of my loved one."

While a person has the disease in their body, transverse myelitis and related neuroinflammatory disorders affect the whole family. The family and the patient are all in this together. If the person who has the disorder is going to do well, the caregiver and the rest of the family also have to do well. Caregiver and care recipient coping strategies should be complementary; there is more than one way to adapt together to life under altered circumstances. It helps to have problem-focused coping skills. Both the caregiver and the care recipient have to come to terms with and accept what things they cannot change, to have the courage to change the things they can, and the wisdom to know the difference. If the care recipient or the caregiver becomes increasingly distressed, then something new

has to be tried. It is important to know when and where to intervene and not to get stuck in a failed strategy. I had a patient with transverse myelitis who was a doctor and his wife a nurse. Doctors are, in general, the worst patients in the world. He told me that he felt like he was burdening his wife. She wanted to help; he didn't want to let her help. That was a failed strategy. She felt really hurt. He needed to let her help so that they could be working on the problems together. As soon as he let her do this, they became one another's ally. It is important not to get stuck in failed strategies.

It is critically important that the caregiver realize that they have to take care of themselves in order to be available to take care of their loved ones. Studies indicate that caregivers' health often suffers, because they don't go to their own doctors regularly and don't take as good care of themselves. Taking care of the caregiver's needs does not conflict with the care recipient's needs. It is not taking time away from their loved ones and it is absolutely essential that they take care of themselves.

When you get on an airplane, the flight attendant explains that should the cabin lose pressure and the oxygen masks drop down, parents traveling with small children should put their own mask on first and then take care of their child. I know a caregiver is in trouble when I ask them who they would put the mask on first; themselves or their child and they tell me, of course, their child. I explain to them that when the oxygen gets sucked out of an airplane, you have about 20 seconds before everybody loses consciousness. If you are there fighting to get the mask on the child and you don't succeed in 20 seconds, the kid is not going to make it because you are not going to make it. If you put it on yourself first, you have the opportunity to eventually

put it on the child. After explaining this to the loved ones of my patients, I ask them when they come back for appointments, "Are you getting enough oxygen?" Are they making the time and the effort to take care of themselves? They need to ensure that they have a chance to recharge their energy and do not become burned out.

Major depressive disorder is different from demoralization. I was listening to sessions at the 2004 Neuroimmunologic Symposium and someone called me over to ask me a question. She did not know that I was the neuropsychiatrist at the conference. She had been listening to a day of lectures and she asked me, "When is someone going to get up and explain and talk about how having transverse myelitis is like being dead while you are alive? When are we going to get to that?" I said, "I'll get to that, just hang on."

We have known about depression since Hypocrites. Hypocrites called it melancholia, which literally translated means black bile. As far back as the ancient Greeks, it was considered one of a number of medical conditions. They did not differentiate between melancholia and any of the other possible ailments. It was a medical illness that needed to be diagnosed and treated. There was little stigma associated with it at this time; nothing like what has arisen today.

There are so many myths and misunderstandings about depression. Much of what people think they understand about depression is not correct. People who have had depression and had it treated do understand it. One of my patients told me, "Dr. Kaplin, I'm starting to get depressed again. I've had open heart surgery and I've been depressed and I'd rather have another open heart surgery than go through depression again." If that does not register with you than you probably have not had depression and not had it treated successfully.

The brain has numerous functions. It is not hard for people to understand that the brain controls nerves that wire our muscles and that when people have MS or TM, the muscles may not work as they should. It is not hard for people to understand that you could have troubles with these illnesses that could affect your brain and lead to trouble with memory and concentration. People do have a difficult time understanding that there is a part of the brain that regulates our moods. There is a mood thermostat in the brain and when it gets stuck, people get depressed. If the thermostat in a room got stuck on low, it would get colder, and colder, and colder and nothing would raise the temperature and make it hotter. It is that unresponsiveness that is one of the hallmarks of depression: a fixed, unresponsive low mood. We know that there is a biology to depression. We can actually measure changes in the brain. There are certain regions in the brain of untreated people who are depressed that shrink approximately 20% in size. It turns out that depression is toxic to your brain. The measure of changes in people's rapid eye movement during sleep and the cortisol suppression test demonstrate that there is a real biology involved in depression. One of the best examples of the existence of this mood thermostat was discovered in doing deep brain stimulation to treat patients with Parkinson's disease. There is a very interesting case where they accidentally place the probe in a region that turned out to be wired to this mood thermostat. Every time they turned on the stimulus, this woman would start crying and have this sense of overwhelming doom that would possess her. She would ask them to turn off the electrical stimulation. When they would turn it off, she would suddenly feel fine again. They had placed the electrode right into the central pathway of a mood thermostat, turned it on and she got all of the symptoms of depression.

Lou Gehrig's disease or ALS is arguably one of the worst diseases. In most cases, death occurs from about six months to a year of diagnosis. Death often results from becoming completely paralyzed and on a ventilator and very susceptible to pneumonia. It is a terrible disease. ALS affects the nerves that wire the muscles; they stop working and muscles cannot be controlled. ALS does not directly affect the brain. It is a motor neuron disease. The rate of clinical depression in ALS patients is rare. They do not have depression at any greater rate than anybody else in the medical setting, such as people with colds or the flu. They can become demoralized and have a difficult time with the disease, but they do not get the constellation of symptoms that we call clinical depression. They may feel that, "this is a terrible situation I am in, this is awful," but they do not tend to get the kind of situation where they say, "I am awful, I deserve this and I don't even want to hang in there for six more months."

One of the things that is always interesting and ironic to me is that some-

times people with MS and TM tell us that it took them a long time to convince their doctor that there was really something wrong with them; that the symptoms of weakness, numbness, dizziness are real and should not be dismissed as just something "in your mind." Then I have to convince people who have symptoms of clinical depression after they get MS or TM that these are not just all in your mind, they are in your body, they are in your brain. Depression is not a "state of mind" or a weakness or a character flaw. Depression is part of the disease, part of your multiple sclerosis, part of your TM. You can get spasticity, you can get urinary problems, you can get depression.

There are many conditions that will cause depression, but transverse myelitis and multiple sclerosis are the record holders. There are higher rates of clinical depression in TM and MS than in any other conditions. MS has the highest rates of depression ever described, and that is because this condition attacks the brain in a specific way, and that attack leads to depression.

Medical Causes of Depression:

Neurological disorders: CVA (25-50%), subdural hematoma, epilepsy (45-55%), brain tumors (30%), Parkinson's disease (30-50%), Huntington's disease (40%), syphilis, Alzheimer's disease (15-50%)

Autoimmune disorders: DM (30%), SLE (25-44%), RA (30-50%), **Multiple Sclerosis (37-62%), Transverse Myelitis**

Drug Induced: reserpine (15%), interferon-alpha (10-57%), β -blockers, corticosteroids, estrogens, benzodiazepines, barbiturates, ranitidine, Ca^{2+} -channel blockers

Substance induced (25%): EtOH, sedative-hypnotic, cocaine & psychostimulant withdrawal

Metabolic: hyper/hypothyroidism, Cushing syndrome, hypercalcemia, hyponatremia, diabetes mellitus

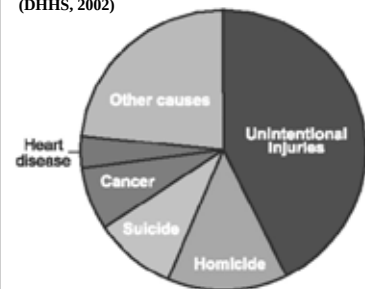
Nutritional: vitamin B12 deficiency

Infections: HIV, HCV, mononucleosis, influenza

Cancer (20-45%): especially pancreatic CA (40-50%)

Figure 22. Percent of deaths due to leading causes of death among persons 1-24 years of age: United States, 1999

(DHHS, 2002)



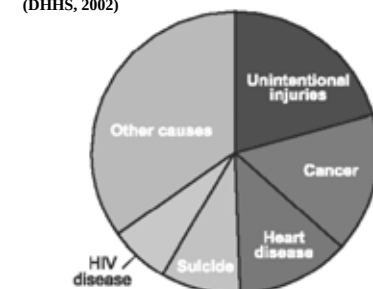
According to former Surgeon General Satcher (1999), "Far more Americans die from suicide than from homicide." Suicide is the 3rd leading cause of death in the general population for ages 1-24. It is the 4th leading cause of death in the general population for ages 25-44. And suicide is the 1st leading cause of death in physicians ages 25-44. Suicide is a major public health issue.

Depression is the single best predictor of cardiac mortality within 12 months following a heart attack. Depression is probably bad for the heart, because it is bad for the neurons that control the autonomic nervous system that controls the heart. Depression is also the second leading cause of chronic disability.

This chart compares hypertension, dia-

Figure 24. Percent of deaths due to leading causes of death among persons 25-44 years of age: United States, 1999

(DHHS, 2002)



betes, heart disease, arthritis, and lung disease to depression. The black cells mean that the medical disease caused less disability when measured in these five different ways, gray means the depression caused more disability and white means that they broke even. Heart disease is the leading cause of chronic disability and depression comes in second. If depression does not kill you, and hopefully it won't, it certainly is the cause of major disability.

There are two simple myths that are used inappropriately to dismiss the diagnosis of depression. What often happens is that a physician will think that a patient is not depressed; they are stressed. They tell me, "You would be stressed, too, if you had their condition. You do not know

when the next attack is going to come. You do not know if you are going to get better from the symptoms." When I persuade the physician that the patient is depressed they say, "Okay, sure they are depressed. They will get over it." The problem is that stress does not prevent you from getting depressed. In fact, stress is a risk factor to getting depressed. Stress does not mean you will not get depressed; it means that you are more likely to get depressed.

In TM and MS there is no correlation between clinical depression and disability. People with more severe physical functional deficits are not more likely to be depressed than people with less severe deficits. Depression correlates, rather, with number of attacks or the severity of the attacks on the nervous system of the immune system.

Depression is not normal sadness. If you are not sad at some point during the course of your life, you are not paying attention to what is going on around you. Sadness is an intermittent and universal experience. That is depression with a small "d"; it is normally responsive to the environment. The degree and duration of the sadness is appropriate to the stressor and it doesn't unduly disrupt work or social function. It is the lack of responsiveness that is critical. Major depression is a syndrome; it is not just severe sadness. Sadness is to major depression what cough is to pneumonia. By way of analogy, I tell my clinical colleagues that a cough can be an indicator of pneumonia and sadness can be an indicator of depression; it is just one symptom. Not every cough is the result of pneumonia. Sometimes pneumonia presents without a cough. You could get depression without sadness, particularly in kids. Instead of sadness, you might see irritability. You have to consider the company the cough keeps. If it is a cough with a set of symptoms (productive sputum,

Depression vs. Chronic Medical Conditions as Cause of Disability in Daily Functioning

(Wells KB, et al, JAMA, 1989)

	Physical	Social	Role	Bed Days	Current Health
Hypertension	Gray	Gray	Gray	Gray	Gray
Diabetes	Gray	Gray	Gray	Gray	Gray
Heart	Black	Gray	Black	Black	White
Arthritis	Gray	Gray	Gray	Gray	Gray
Lung	White	Gray	Gray	White	Gray
None	Gray	Gray	Gray	Gray	Gray

Gray Depression causes more disability
 Black Depression causes less disability
 White No difference

tachypnea, fever, consolidation), then we call it pneumonia.

There is a set of symptoms that we call depression. The acronym SIGEM-CAPS is used in medicine to remember them. For a diagnosis of depression, you need to have at least decreased interest (or pleasure) or decreased mood and then a total of five of these nine symptoms (for more than two weeks): trouble with sleep (either increased or decreased), loss of pleasure (your get-up and go has gotten up and gone), feelings of guilt or worthlessness, low energy or fatigue, low mood, decreased concentration, increased weight (chocolate for women is what they tend to tell me does it when they are depressed), or loss of weight, psychomotor retardation (or agitation) and then suicidal ideation or thoughts of death. The more symptoms you have, the more likely you are to respond to treatment.

If you are not sure whether you are depressed, you can ask your spouse; they will tell you. More often than not, it is the spouse that sends people in to see me. When a person is depressed, they don't want to burden anyone or want other people to know. When they are out in public, they put on their best face and try to mobilize what resources they have. That takes a tremendous amount of energy to do while depressed. To make yourself look happy when you are really depressed takes an immense amount of concentration and effort. Then when they go home, they have to stop trying. It is like having run four-minute miles all day long. They get home and have to just relax. They let their guard down and the family sees what they are, which is depressed. So the family often takes the brunt of it.

Jean-Martin Charcot (1825-1893) is the first person to describe multiple sclerosis. The very first patient that he ever described in lectures that he gave to medical students on the diseases of

the nervous system in 1868 was a 31 year old woman. Mademoiselle V. experienced periods of serious depression accompanied by paranoia that made her think that Charcot was trying to poison her. In fact, her depression was so severe that she stopped eating and had to be fed by a stomach pump to keep her alive. That is the very first patient who was ever clinically described to have multiple sclerosis. We have known about depression associated with these conditions back to the very first patient described, but ironically, it was not until the last 10 or 15 years that depression has been studied in MS.

Burden of Depression in MS Patients (Patten & Metz, Psychother Psychosom, 1997, 66:268-92)

Lifetime Prevalence:
37-62% MS
17% General Population (NCS)

Current Prevalence:
14-27% MS
5% General Population (NCS)

The highest rates of depression follow an MS or transverse myelitis diagnosis. For example, 50% of MS patients will get clinically depressed at some point during the course of their life. It can occur at any time. That is three times the rate of the general population. In cross-section of MS patients at any given time, about 1 in 4 are in a clinical depression. Depression is common in patients with MS and is associated with considerable morbidity and mortality.

The available evidence suggests that depression in MS is caused by the effects of inflammatory insults to the brain. It is just like the other symptoms that you get with MS, like the tingling when you put your chin on

your chest, for those people who get L'Hermitte's sign. It is one of the set of symptoms that happens when your brain is under attack. Depression does not correlate with physical disability. It tends to occur during periods of time of inflammation. Periods of immune activation correlate with increased rates of depression and suicide.

Multiple studies have shown that depression is the primary determining factor in patient's self reported quality of life, with greater impact than other variables investigated, including physical disability, fatigue, and cognitive impairment. Depression also has a significant affect on function. Depression is the primary determining factor in the quality of relationship when rated both by patients and their significant others. Depression is associated with disruption of social support, increased time lost from work, and decreased adherence to neuromedical treatment regimens for MS.

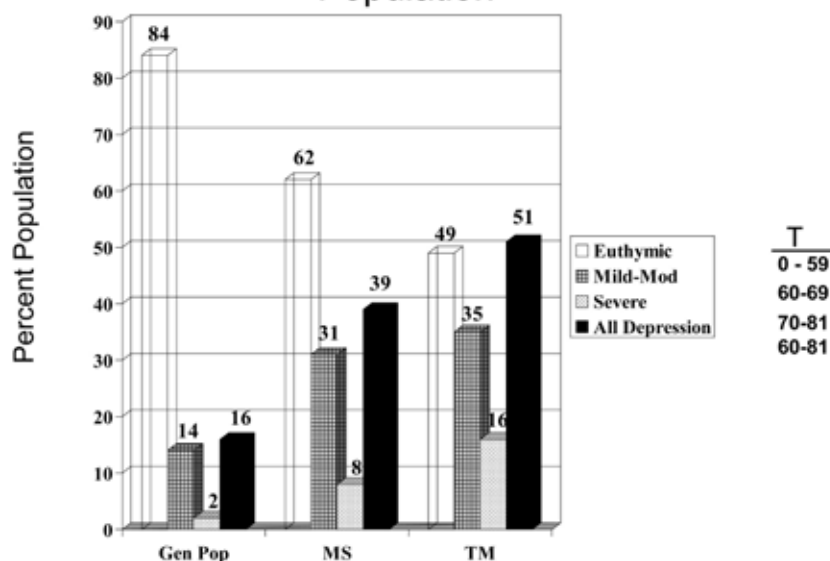
Depression also worsens cognition. Some degree of cognitive impairment occurs in 50% of MS patients. We also find high rates of cognitive impairment in transverse myelitis. This impairment includes memory recall, information processing speed, executive function and working memory. Cognitive deficits are found in moderate to severe depression. Performance in depressed MS patients may be normal for routine tasks but impaired on tasks involving effortful attention. Depression in MS is associated with impairment of complex speeded attention, planning and working memory. Impairment can wax and wane with the type of task and mood. Both MS and depression have overlapping cognitive deficits. The combination of the two is additive in resulting impairment. The important thing to know is that if you have one cause, it does not help to also have another cause. Often patients come in and I tell them, "I understand you're having trouble with your concentration. I don't know if

it's the depression or the MS." You don't know unless you get the depression out of the way by treating it.

Depression is strongly associated with the impact of fatigue on the lives of MS patients. Disabling fatigue almost always interferes with activities (Chwastiak, et al, 2005 JPR). Auto-immune fatigue tends to hit at about 2:00 or 3:00 in the afternoon. In the morning, you wake up feeling better, and as the day goes on, you get more and more fatigued. Then by 2:00 or 3:00 you hit the wall and you feel you cannot take another step. That is classic MS fatigue. Not everyone has classic auto-immune fatigue. MS patients with depression are six times more likely to report disabling fatigue. Fatigue with depression is the reverse of MS fatigue. The fatigue is often worse in the morning and better at night.

There is a 30% lifetime incidence of suicidal intent (thoughts of wanting to kill oneself) in MS. 6% to 12% of patients with MS attempt suicide. Suicide was the 3rd leading cause (15%) of death in 3000 outpatients in Canadian MS clinics from 1972-1988. MS patients dying from suicide were younger and less disabled than patients dying from pneumonia (23%) and cancer (16%). (Sadovnick, et al, 1991,

Depression Scores in TM, MS and the General Population



Neurology). Of 750 transverse myelitis patients at the Johns Hopkins TM Center, 60% of the deaths have been from suicide. It is the number one cause of death in TM. It is like smoking; depression is the most preventable cause of death in transverse myelitis. It is severe.

Suicide is the third leading cause of death; pneumonia and cancer are numbers one and two. Pneumonia and cancer tend to occur in the elderly. If someone is going to die relatively young, it is more likely going to be from suicide.

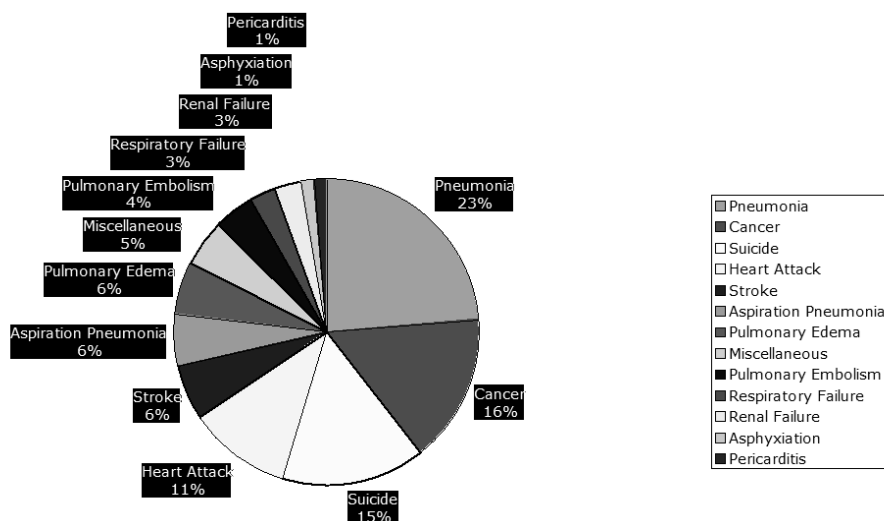
It was commonly accepted that transverse myelitis was a spinal cord injury and had nothing to do with the brain. Dr. Kerr suspected depression in many of his TM patients at the clinic. I had been thinking that what he was seeing was demoralization. He convinced me to come to the clinic to work with his patients and to study the issue.

These are results from the TM Center at Johns Hopkins. The bars with dots are severe depression and the bars with cross hatch are mild depression. Depression in MS is higher as compared to the general population and transverse myelitis had at least equal if not greater rates of depression than MS. We began to suspect that there might be brain involvement in transverse myelitis.

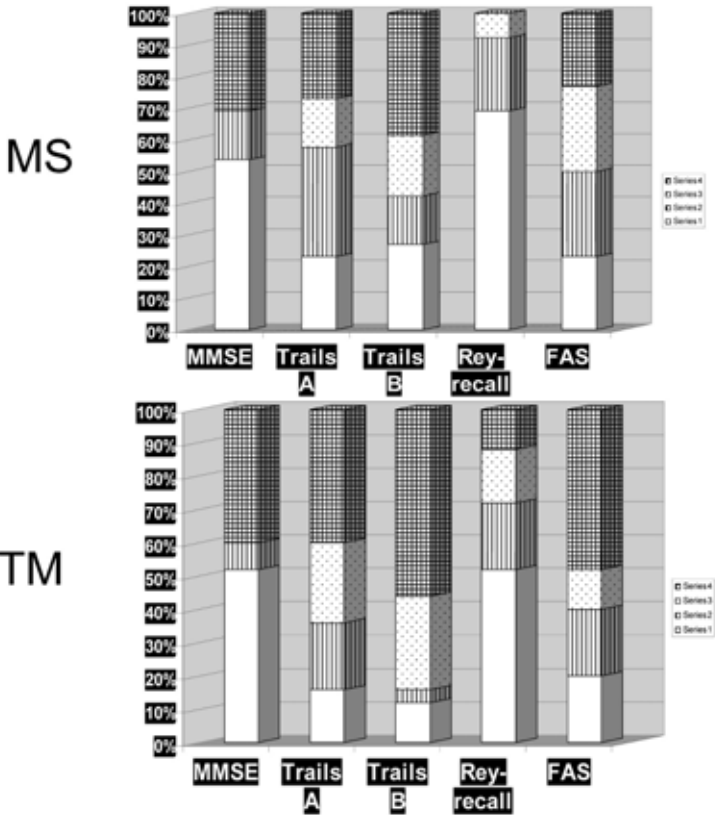
Quartile distribution of test scores in ATM and MS patients (graphic next page)

The white portion of the bar (bottom) signifies a problem; the higher the white portion, the worse the patients scored on these tests of memory and concentration. We saw the exact same pattern in patients with transverse myelitis. They had the same memory

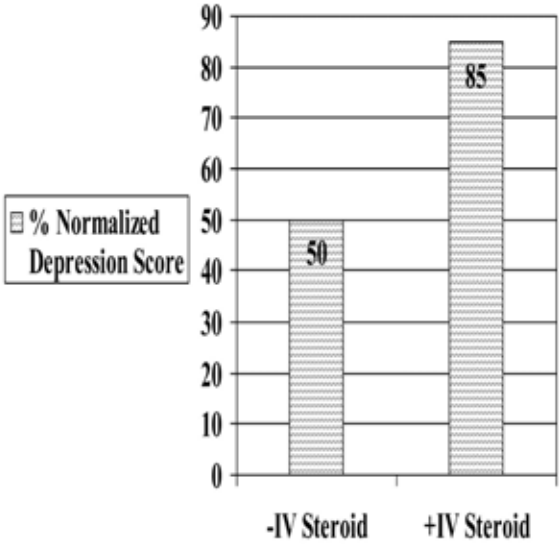
Causes of Death in Patients with MS



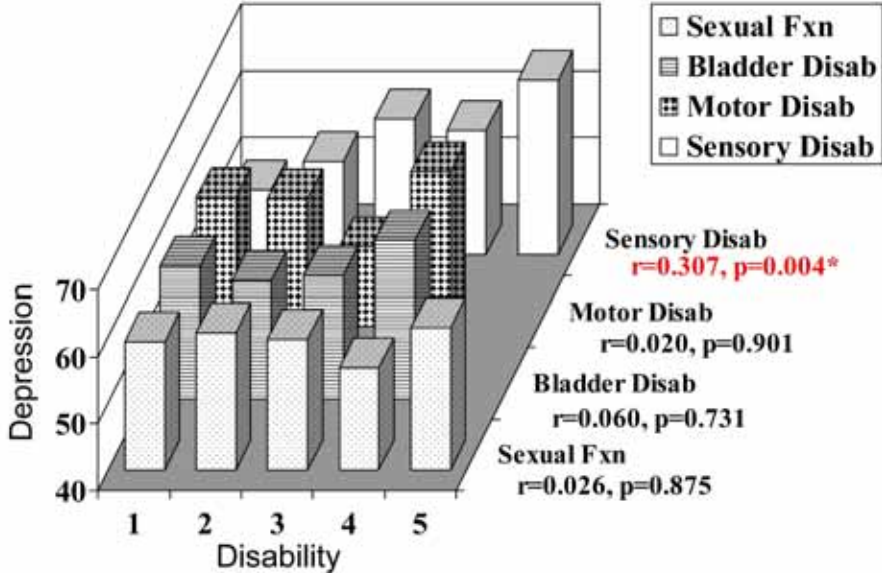
Quartile distribution of test scores in ATM and MS patients



Association Between IV Steroid Treatment and Depression: 70% Increase



Correlation Between Neurological Disability and Depression Scores



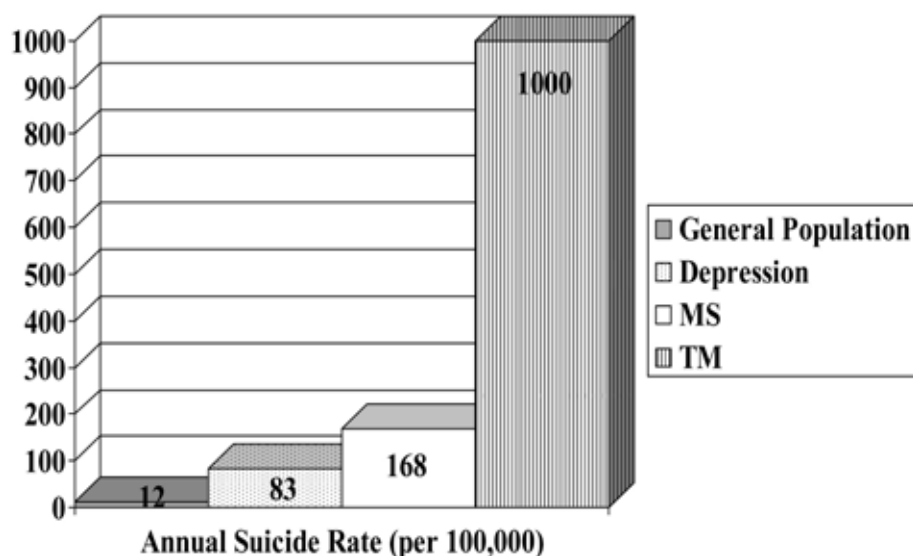
der disability or sexual function in patients with TM. There was a mild correlation that accounted for 10% of the variability in pain; the worse your pain, the worse your depression scores. That may be because people who are depressed have worse pain or maybe the people who have worse pain, have worse depression. The two go hand-in-hand.

Giving steroids during an acute attack of TM involves a risk benefit analysis. The benefit of giving the steroids is that they may arrest the inflammatory attack and spare the nervous system damage. There could also be side effects from taking the steroids. In patients with transverse myelitis, those people who had received IV steroids at the time of their initial presentation were 70% more likely to have depression at some point in the future. It may be that those were the people who were depressed when they came in to their doctors and they looked really bad so they got steroids. We cannot prove this; it wasn't a prospective trial, but it is just worth mentioning that we know from other studies that steroids can increase your chances of getting depressed. If you already know steroids make you depressed, then tell

problems that you see in MS. We now understand that the immune system is attacking the brain in transverse myelitis even though we don't see the lesions on the MRI. Evidence suggests that the activated immune system that has gotten into the brain and spinal

cord is pumping out all of these chemical messengers, and those chemical messengers cause the depression.

We found that depression does not correlate with motor disability, blad-

Suicide Rate: Depression vs MS vs TM

your doctor. They may have great benefits and you should do it, but it may have risks.

This graphic shows the rate of suicide in depression, the rate of suicide in MS and the rate of suicide in transverse myelitis.

Chronic stress has been linked to increased risk for MS exacerbations, as well as accrual of disability (Mohr, et al). A prospective, longitudinal investigation involving serial imaging using MRI with gadolinium enhancement demonstrated that stressful life events (especially family conflict and work-related stress) predicted the development of new and active brain lesions. A meta-analysis of studies examining the effects of stress on MS exacerbations found a significantly elevated risk of exacerbation associated with stressful life events in 13 of the 14 investigations. The degree that stress increased the risk of MS exacerbations in this meta-analysis was on average 60% greater than the degree that IFN-beta treatment has been shown to decrease the risk of MS exacerbations.

Chronic stress, such as that caused by depression, tends to increase your chances of having worsening of your MS or transverse myelitis. Often

when a patient is sent to me, they have been through the process of trying to find a doctor who can figure out a diagnosis of MS and TM. Because they were not sleeping, they were given benzodiazepines, such as valium, to help with the sleep. But because they were also fatigued, they were given Provigil and the Provigil worsens their sleep. So they have to get a higher dose of benzodiazepines. They had concentration problems in part from the MS, and perhaps in part from the depression, and now the benzodiazepines make them feel drunk. If you take enough valium, you will have trouble with your concentration, as well. One of the things I often do is try to detoxify people

from what their doctors have placed them on through the process of treating individual symptoms and missing the diagnosis of the underlying depression. If you try to treat depression symptomatically, you will make people worse.

On the other hand, if you treat the depression, you may actually make the MS better. This was demonstrated in the Mohr study (Mohr et al, 2001, Arch Neurol, UCSF). Patients with depression had biological evidence of worse MS disease severity. In patients who had depression, their immune system, as measured in the laboratory, was twice as active and aggravated as the patients who were not depressed. Treatment of depression in MS patients (with either medication or psychotherapy) correlated with improvement in their autoimmune disease status. This suggests that the treatment of depression may be an important component in the management of MS. As the authors state, "Treatment of depression may provide a novel disease-modifying therapeutic strategy as well as a symptomatic treatment for patients with MS." Stress has been linked to increased risk for MS exacerbations, as well as accrual of disability. You should get treated not just for yourself, not just because your family deserves you to get treated if you are depressed, but you should get treated, because it may very well impact sig-

SIGEMCAPS --> MS & TM

- | | | |
|---|-----|--------------------------------|
| • Sleep (↓ / ↑) | --> | Insomnia |
| • Interest (or pleasure) | --> | Relationship Strain |
| • Guilt (or worthlessness) | --> | Barrier to rehab & Tx |
| • Energy (fatigue) | --> | MS Fatigue |
| • Mood | --> | Sadness |
| • Concentration | --> | MS memory loss |
| • Appetite | --> | Weight loss & decreased energy |
| • Psychomotor retardation
ambulation | --> | MS memory loss, decreased |
| • Suicidal ideation | --> | Hopelessness, Death. |
| • Magnification of suffering | --> | Chronic Pain |

nificantly on the course of your disease.

The good news is that depression is the most treatable syndrome associated with MS. My neurology colleagues sometimes tell me how jealous they are when a patient comes to me who is not working, been in bed for a month, having a horrible time of it, family does not know where they went, this is not the person I married, this is not the mom and dad I remember, they have changed dramatically. I treat the depression and in a month they are back at work, they are doing great. The neurologists are ordinarily not able to be as effective in treating the other symptoms that come with MS and TM, such as fatigue, nerve pain and spasticity. Depression is by contrast very responsive to treatment.

No pill can help me deal with the problem of not wanting to take pills; likewise, no amount of psychotherapy alone can prevent my manias and depression. I need both. It is an odd thing, owing life to pills, one's own quirks and tenacities, and this unique, strange, and ultimately profound relationship called psychotherapy.

This is a quote from one of my mentors, Dr. Kay Redfield Jamison. She dealt with having a terrible illness. She went to her chairman and said, "I know you are going to fire me. I have bipolar disorder. I have a crazy psychotic mania." He told her that he wasn't going to fire her. His advice to her was, "learn from it, write from it, teach from it." She is a better clinician and researcher today, because she has bipolar disorder. Again, you can utilize these things and often turn them into benefits.

Depression and MS is a two-way street. MS causes depression, depression and stress worsens MS. Treating the depression improves the MS. We looked at the data to demonstrate that improvement. Treating the MS im-

proves depression. We do not yet have the studies showing that improvement. I would like to pursue those studies. Depression is a lethal consequence of MS if untreated. Depression is common in these autoimmune diseases, it is caused by the immune system and it is treatable.

Paula Lazzeri is also one of my mentors. Paula got TM as a child and was paralyzed from the chest down. Paula graduated from college with a degree in accounting and works full time. She married a wonderful man who became a physical therapist as a result of being so inspired by his wife. Paula and Myk have a beautiful son. Paula carried and delivered this child with her paralysis. Paula is also an officer in The Transverse Myelitis Association and devotes a significant part of her life helping others.

Paula made the following statements in a speech she gave at the 2004 symposium.

I have to face many challenges in my life. I have had to endure numerous physical and emotional hardships, but my life is good because I will have it no other way. My life is beautiful because I chose to see life this way. We cannot control all of what happens to our bodies and we cannot control what goes on in the world around us, but we do control how we think and feel about ourselves and our families in the world we live in.

Paula is the best example of how you can overcome the demoralizing effects of these illnesses. However, if you are depressed, you cannot follow Paula's example. Hearing about Paula for people who are depressed only makes them feel worse. They think, "I'm a wretch and how did she do all of that? And I can't do that?" The problem is Paula is fabulous and for those of you who are demoral-

ized, talk to Paula. Those of you who are depressed, talk to me, because poor Paula cannot help you. I will tell you that you can become Paula, if you get the depression out of the way.

The deeper sorrow carves into you, the more joy you can hold.
Kahlil Gibran

The one law that does not change is that everything changes, and the hardship I was bearing today was only a breath away from the pleasures I would have tomorrow, and those pleasures would be all the richer because of the memories of this I was enduring.
Louis L'Amour (1908-1988)

Depression is treatable. Your life could be so much better if you get your depression out of the way. Do not settle for **this is the best my life could be** unless you have really excluded all of the possibilities.

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

Unkind Cytokines: A Journey from the Mind to Brain to Mind The Biological Basis of Depression

Adam Kaplin, MD PhD

Johns Hopkins School of Medicine;
Department of Psychiatry and Behavioral Sciences; The Transverse Myelitis Association Medical Advisory Board

Adapted from a presentation at the 2006 Rare Neuroimmunologic Symposium

Though this be madness, yet there is method in it.
Hamlet

The research that I have been doing with Doug Kerr and Chitra Krishnan has begun to shed light on the bad players in Transverse Myelitis, and this work, in turn, has led us to new ways of thinking about developing novel treatments. This work has also led us to new insights into the biology of depression and cognitive impairment. This research has implications for how we think about depression in Transverse Myelitis, Multiple Sclerosis and a number of other autoimmune conditions.

From the clinical perspective, we find depression associated with transverse myelitis and multiple sclerosis. Our preliminary research suggests that there is a 50% rate of clinical depression following the diagnosis of transverse myelitis; the relationship is not random. Fifty percent, or one in every two people, is a dramatic association. There are very few groups of symptoms that one in two people get, for instance, with multiple sclerosis, because it affects so many different parts of the body. What is going on with these disorders that the incidence of depression is so high? Is there some cause for the depression in TM and MS that might help us better under-

Figure 23. Death rates for leading causes of death among persons 25-44 years of age: United States, 1950-99

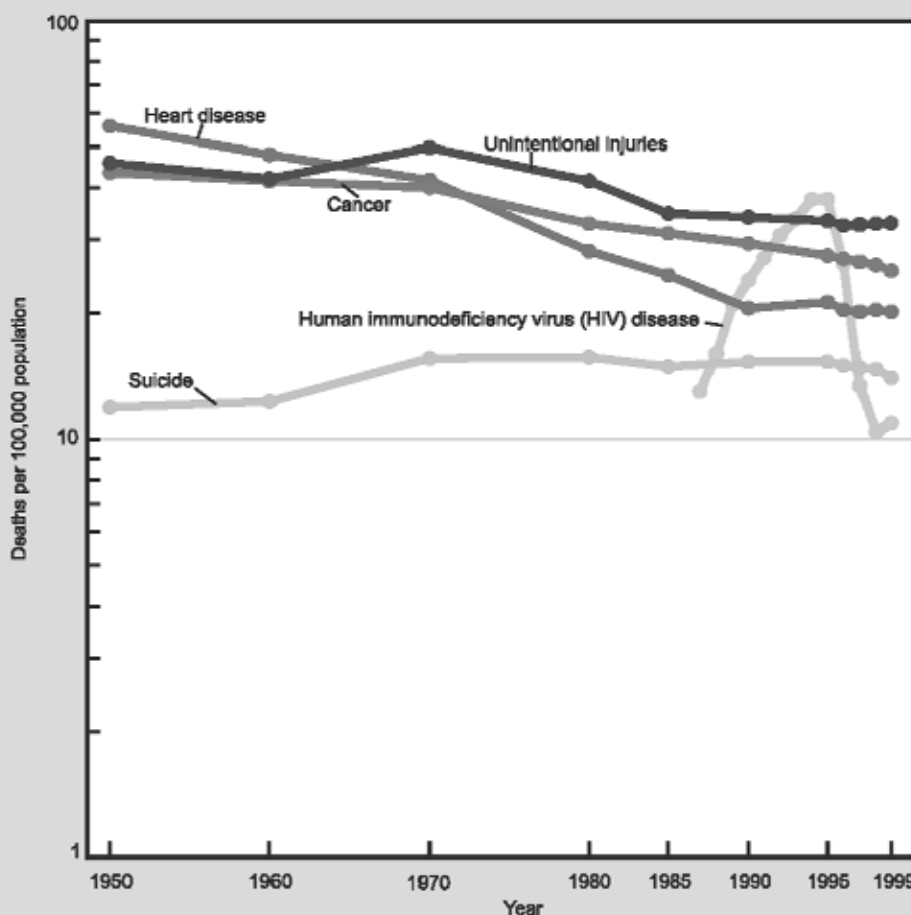


Figure 22. Percent of deaths due to leading causes of death among persons 1-24 years of age: United States, 1999

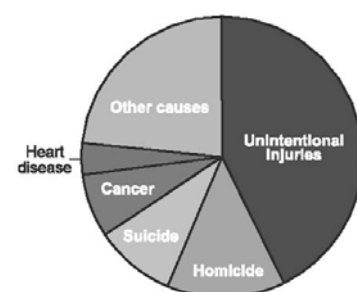
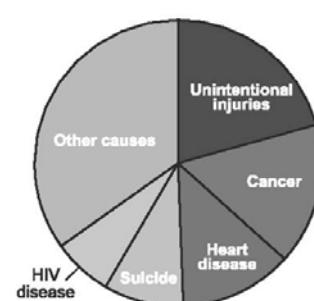


Figure 24. Percent of deaths due to leading causes of death among persons 25-44 years of age: United States, 1999



Health, United States, 2002 (US DHHS)

stand depression, in general?

These charts provide a good background and framework to understand the significance of our research. In a sense, this graphic represents a report card from the Department of Health and Human Services given to the medical practice of the United States

for the past 50 years. It is evident from this log scale that US medical practice has done quite well in some areas. There has been a 60% reduction in death due to heart disease since 1950. We have had a 40% reduction in death due to cancer. It is also important to keep in mind that we have invested billions of dollars in studying

heart disease and cancer. Deaths from unintentional injuries are down, and with the advent of highly active anti-viral treatment (HAART), deaths from HIV have also gone down dramatically. Suicide is the significant problem, the blemish on the medical profession's report card. Suicide is the lethal outcome of depression. Not only has suicide not gone down, since the 1950s, deaths from suicide have increased. Our question has to be why are we so far behind in taking seriously the issue of depression and suicide?

Unfortunately, one of the reasons that depression has not made the strides as some of these other conditions relates to the societal stigma that is attached to it. There are celebrities who have been willing to speak publicly about HIV, such as Magic Johnson, Arthur Ash, and Rock Hudson. There are very few people who have been willing to talk about their experiences with depression. When Brooke Shields discussed her experiences with post-partum depression, she was ridiculed, often with the complicity of the media, by Tom Cruise for doing so. So, stigma has played a role in the lack of focus we have placed on depression. Even though the rate of suicide as a cause of death in the DHHS report was lower than some of the other reported conditions, the numbers are not inconsequential. It is the fourth leading cause of death in people in the 25 to 44 age range in the United States, and it is the third leading cause of death in people up until the age of 24.

The definition and heterogeneous nature of depression makes it difficult to study from a scientific and clinical approach. The diagnosis of depression relies on the Diagnostic and Statistical Manual of Psychiatry (DSM-IV) criteria. A person must have five of nine symptoms for greater than two weeks to receive this diagnosis. The nine symptoms involve deviations in sleep (either increased or decreased), interest

Medical Causes of Depression:

Neurological disorders: CVA (25-50%), subdural hematoma, epilepsy (45-55%), brain tumors (30%), Parkinson's disease (30-50%), Huntington's disease (40%), syphilis, Alzheimer's disease (15-50%).

Autoimmune disorders: DM (30%), SLE (25-44%), RA (30-50%), **Multiple Sclerosis (37-62%), Transverse Myelitis (?)**

Drug induced: reserpine (15%), interferon-alpha (10-57%), β -blockers, corticosteroids, estrogens, benzodiazepines, barbiturates, ranitidine, Ca^{2+} -channel blockers

Substance induced (25%): EtOH, sedative-hypnotic, cocaine and psychostimulant withdrawal

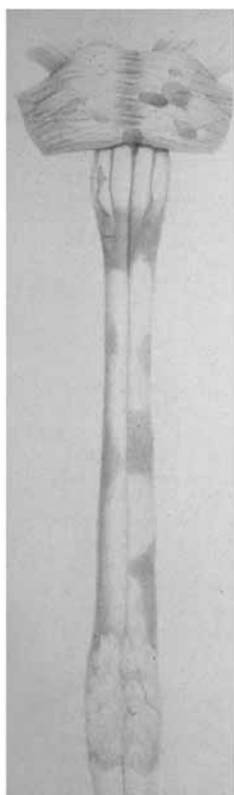
Metabolic: hyper/hypothyroidism, Cushing's syndrome, hypercalcemia, hyponatremia, diabetes mellitus

Nutritional: vitamin B12 deficiency

Infections: HIV, HCV, mononucleosis, influenza

Cancer (20-45): especially pancreatic CA (40-50%)

or pleasure, guilt or worthlessness, energy, mood (either sadness or irritability), concentration, appetite (either increased or decreased), psychomotor retardation, and suicidal ideation or thoughts of death. At least one of the symptoms must be decreased interest or low mood to make the diagnosis of clinical depression. The problem with this approach is that there are over 227 combinations to achieve the criteria of clinical depression using the DSM criteria. This represents a tremendous diversity of possibilities when characterizing depression. When a researcher is enrolling people into a study of depression, this means that we are potentially including 227 different types of patient presentations; presenting with 227 types of symptom combinations. This is a difficult problem for research on depression and for understanding depression. For example, I might enroll a person into my study who has sleep, interest, guilt, energy and mood problems. Another person may have problems with interest, concentration, appetite, psychomotor retardation and suicidal ideation. The only symptom they	share in common is trouble with interest; all of the other symptoms are different. However, they both are diagnosed with depression and they both are enrolled and included in my study. This is analogous to a scenario where I have a great antibiotic that I want to get on to the market for the treatment of pneumonia, and I enroll everybody who has a cough into my study. The problem is that cough is so non-specific a symptom; a person with a cough may or may not have pneumonia. The symptoms of depression are also very non-specific, and consequently, we are enrolling people into our studies with many different types of depression, and perhaps, many different kinds of conditions. To move our understanding and treatment of depression forward we must find a way of dealing with this heterogeneity problem.
	When I began to study auto-immune conditions, I was often asked by people what a psychiatrist with an interest in depression was doing focused on these conditions. My response was, "Why does Willy Sutton rob banks? Because that is where the money is."



Why do I study auto-immune central nervous system diseases? Because that is where the depression is. The frequency of people who have depression with one of these auto-immune conditions and inflammation in the brain is quite high. As a cause of depression, it is more important than a family history of depression and more important than child-rearing practices or experiences.

This is one of the earlier drawings of the lesions you get in the central nervous system of patients with MS. People with MS have the highest rates of comorbid depression compared with any other medical condition. It was with this background and understanding that I was first approached by Dr. Douglas Kerr who had recently initiated the only transverse myelitis treatment center in the world at the Johns Hopkins University School of Medicine. He asked me to get involved in his work. I indicated that I was focused on MS, because of the relationship between MS and depression (Patten & Metz, *Psychother Psychosom*, 1997, 66:286-92). The lifetime



prevalence of depression in MS is 37-62%, while it is 17% in the general population. The lifetime prevalence of cognitive impairment in MS is 45-65%. Depression is common in patients with MS and is associated with considerable morbidity and mortality. The available evidence suggests that depression in MS is caused by the effects of inflammatory insults to the brain. There is no genetic loading, there is no correlation with physical disability and periods of immune activation correlate with increased depression and suicides.

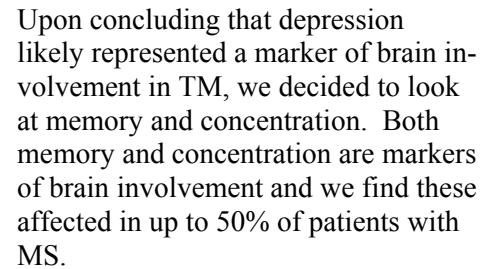
Dr. Kerr acknowledged at the time that there was very little known or understood about TM. He said that TM was sort of like MS of the spine; it is an autoimmune inflammation of the spine and the effect is across both sides of the spinal cord. It is immune mediated and the lesions in the spine lead to disability. It can impact motor and sensory function and it can cause bowel, bladder and sexual dysfunction. A third of the people get better, a third of the people have

some improvement, and a third of the people have a very bad outcome over time. Then he told me that many of the people with TM appeared to him to be depressed. My immediate reaction was that Dr. Kerr was confusing demoralization with depression. I suggested that there shouldn't be depression in TM, because the mood thermostat is located in the brain, not in the spinal cord, and TM was impacting the spinal cord. He pleaded with me to come to the TM clinic, make my own medical observations and lend a hand. I said that if I was going to get involved in evaluating patients for depression that we were also going to have to study transverse myelitis and depression so that we could understand what was going on.

We started screening patients for depression in the clinic; we evaluated consecutive patients who had multiple sclerosis and consecutive patients who had transverse myelitis. We compared these patients to averages that were already known using the SCL-90R depression screening test. The dark bar on the right for each category represents patients who scored in the 98th percentile and above; for example the 2% of the general population were very depressed. The 14% in the general population represents people who had mild-to-moderate severity in their depression scores. The 84% represents people who did not score in the depressed range. The known rate of depression in the general population is 5%. The number is between the 14% and the 2% you see in this bar graph, because some of the people who scored as being in the mild depressed range were demoralized and in distress but not suffering from a clinical depression since the SCL-90R is not specific for depression in this range.

For MS, the number of people who are depressed is between 8% and 31%; it has been reported to be 25% in cross section in numerous studies. What was shocking to us was that the TM

cal study of a person's brain who had had TM. Studies were only focused on the spinal cord, because up until the present time, TM was assumed to be strictly a spinal cord disease.



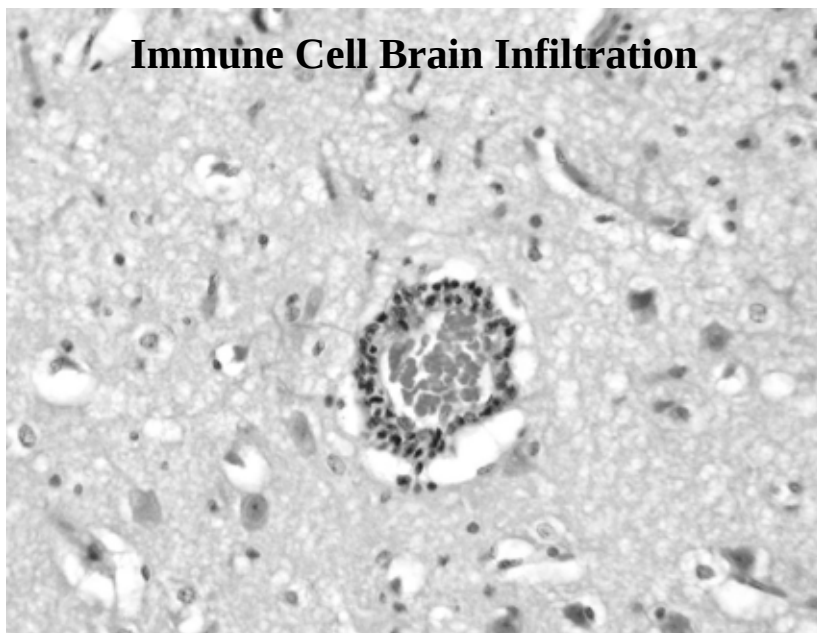
ten across the gate of the blood-brain barrier. If there is inflammation in the central nervous system, it is possible that the depression is really a marker of brain involvement in this condition. Until I became involved in doing this work with Dr. Kerr, no one had ever performed a pathologi-

We measured concentration with, among other modalities, the Rey-recall test. This is one of the most sensitive tests to pick up cognitive impairment in multiple sclerosis. The graph indicates that roughly 75% of patients with MS scored in the lowest quartile (e.g., 3 times the expected rate, indicating a high rate of mild cognitive impairment). In a population without MS, we would expect a distribution of 25% in each quartile. We see the same pat-

MS



Immune Cell Brain Infiltration



tern of concentration and memory problems among people with TM. Again, these results suggested that, like depression, cognitive impairment was a marker of brain involvement in patients with TM.

We asked Dr. Carlos Pardo to study a pathological specimen from someone who had donated their body to science in advance of dying from complications of transverse myelitis. Dr. Pardo reported that there was inflammation in the brain that could be seen under the microscope despite the fact that the individual had a normal MRI of their brain.

This image is a section through the brain, not the spinal cord. This is in the parietal cortex region that controls, among other things, sensory processing. We should only be seeing lots of red blood cells in this image. The red blood cells all clustered in a capillary, a very small blood vessel coursing through the brain. The walls of the capillary should just be one cell layer thick. All of the dark nuclei clustering around are from what is called perivascular cuffing; it forms sort of a cuff around the vessel where there are activated, angry immune cells, white blood cells. This is exactly what you

see early on in multiple sclerosis before a brain lesion or MS plaque forms. They will then go on and develop into a lesion that can be seen on an MRI. You never see these go on to develop into lesions in an MRI with transverse myelitis. By definition, transverse myelitis means that you do not see lesions in the brain. But despite having a normal MRI of their brain, this suggests that there may be activated and aggressive inflammation going on in the brain of patients with TM that is below the level of detection by neuroimaging.

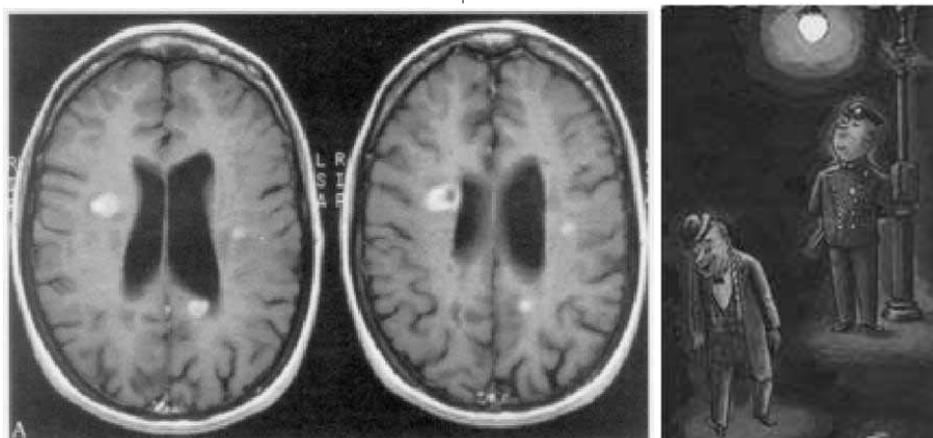
What is the key mediator of depression in MS: have we been looking in the right place?

A drunken man is searching under a

street lamp for a set of keys. A passer-by offers to help. Together they search and search in vain. Finally, the passer-by asks where the keys fell. The man points to the other side of the street. "Why are you looking on this side when you dropped them over there," the incredulous passer-by asks. The reply, "the light is much better here."

This joke effectively describes the problems that we believe have been encountered in research involving depression in multiple sclerosis. When you look at an MRI of the brain of someone who has multiple sclerosis, you see MS lesions or plaques. These are the light spots on the MRI. Everyone reached the same conclusion; depression had to be related to these plaques. Interestingly, however, the plaques do not correlate at all with depression. There is some weak association with the number of plaques, but this has ultimately proved to be a very poor correlation.

We now think that transverse myelitis is a much better model for studying autoimmune depression than MS. There are no plaques visible in the brains of patients with TM. Thus there is no confusion or distraction from these plaques in studying the way inflammation can impact the brain and cause mood dysregulation. People with TM have the same depression and the same cognitive impairment as seen in people with MS without any of the



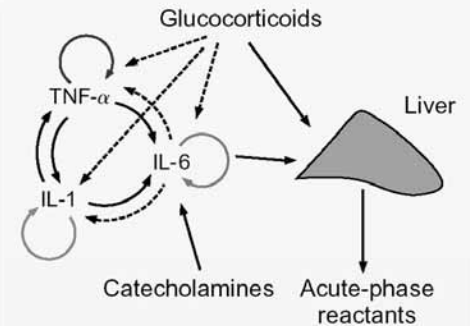
plaques. This suggests that there is something else going on that is causing depression.

When a person with TM has a lumbar puncture done, the spinal fluid is drawn with a needle that is inserted between the L4-L5 vertebrae. Interestingly, the lesion can be up in the neck area, and we still pull off white blood cells way down in the lumbar region that are markers of the immune activation which is occurring. The immune system has already gotten across the blood-brain barrier and is causing trouble. Dr. Kerr and I reasoned that if we are pulling off immune system cells from the lumbar region with a cervical attack, why can't the cells also move up or release something that would diffuse potentially into the brain.

The next step for us was to see what diffuses in the immune system. There

are a number of things diffused in the immune system, and one of the critical things is cytokines.

Cytokines are chemical messengers between cells of the immune system. Cytokines are the way one white blood cell is able to communicate with another white blood cell. This is a representation of a CD4+ T cell, the General Commander of the immune system. It is what it is taken out by HIV and when it goes, the whole immune system collapses and you get AIDS. It is the General, and to rally the troops, it releases all of these chemical messengers that sound the bugle. The bugle is what recruits all the other immune cells to get excited and start coming in and doing their job. Cytokines are the signaling messenger; allowing two white blood cells to communicate, much as neurotransmitters are the



Interactions among the Inflammatory Cytokines and the Effects of Glucocorticoids and Catecholamines (Review from the New England Journal of Medicine, Chrousos, 1995)

messengers for neurons. Cytokines diffuse through the body to call in help, the back-up forces and the reserves.

Amongst the cytokines that have already been implicated in auto-immune diseases, TNF-alpha, IL-1 and IL-6 have already been shown to play a key role in many illnesses, including arthritis. The image represents a joint and the cytokines are produced in response to the General CD4+ T cell getting over-activated. It is recognizing the joint as foreign and it releases these messengers that then cause these other cells to produce the pro-inflammatory cytokines; IL-6 being one of the three early cytokines that get released.

The involvement of IL-6 immediately raised my interest. Catecholamines (that comprise part of the fight or flight response) stimulate the production of IL-6; this means that stress plays a role in this system. Catecholamines include the stress neurotransmitters norepinephrine and epinephrine. That means that stress, which releases catecholamines, increases IL-6. IL-6 also stimulates the production of corticosteroids, which in humans is cortisol. Cortisol is the body's version of an endogenous glucocorticoid, which is in the same family as solumedrol and prednisone which are given to patients to treat immune over-activation. Cortisol is the

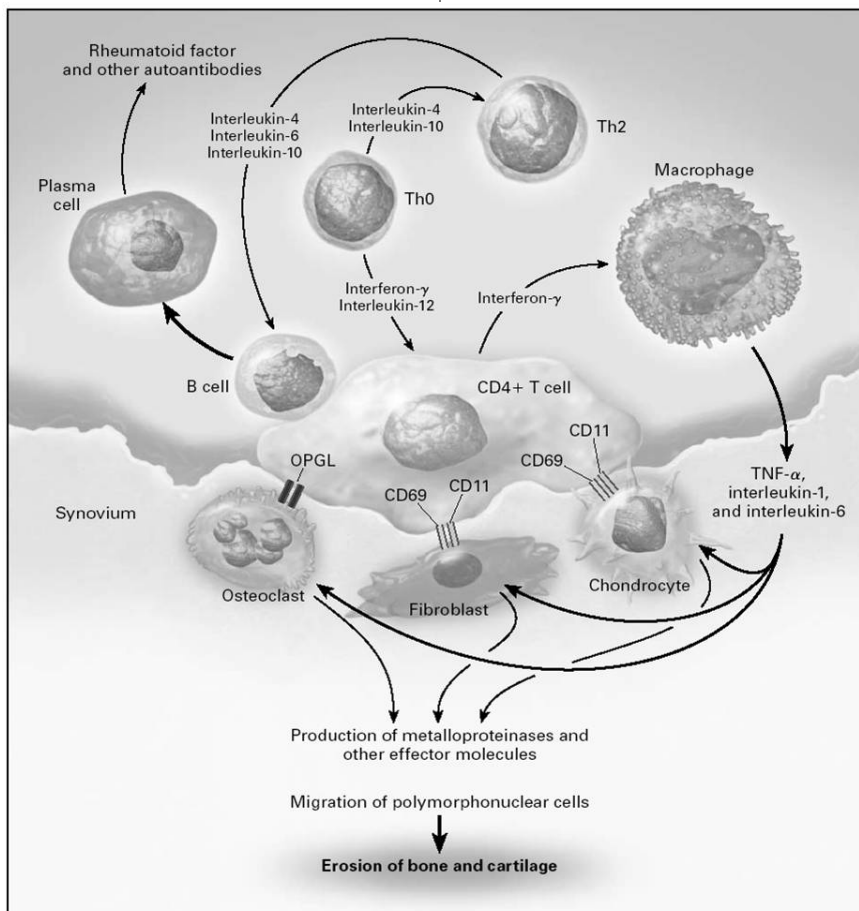


Figure 1. Cytokine Signaling Pathways Involved in Inflammatory Arthritis.

The major cell types and cytokine pathways believed to be involved in joint destruction mediated by TNF-α and interleukin-1 are shown. Th2 denotes type 2 helper T cell, Th0 precursor of type 1 and type 2 helper T cells, and OPGL osteoprotegerin ligand.

human version of an endogenous steroid, the version of the steroids that are produced by our bodies. We already knew that depression involved elevated levels of cortisol in the brain. In patients who are depressed, you can actually measure elevated levels of cortisol in their blood stream through a test called the dexamethasone suppression test. In 80% of people who are depressed, their cortisol levels are elevated compared to normal levels.

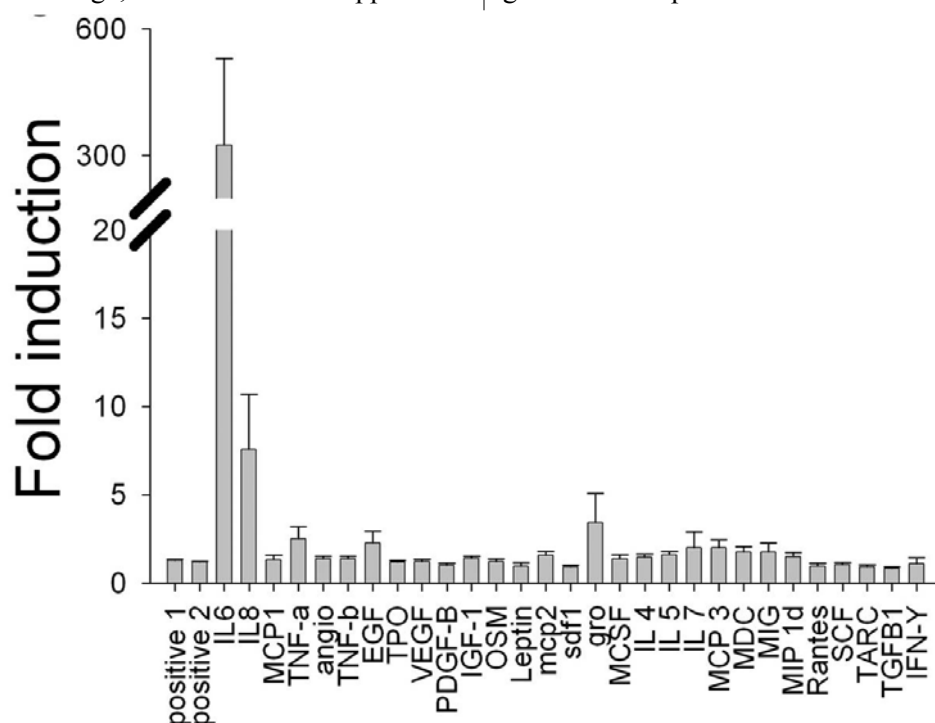
Thus, IL-6 is situated in a key location to permit it to play a key role in coordinating cortisol which is a marker of both stress and depression.

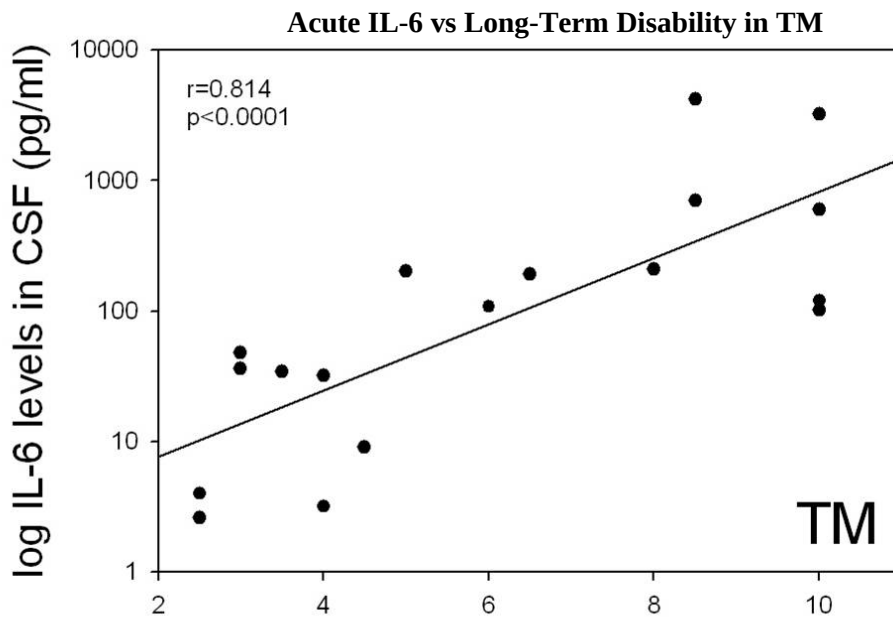
There is also independent evidence supporting the role of cytokines as a cause of depression. If cytokines, including IL-6, are given to animals, they get what is called sickness behavior; it is a syndrome that resembles the symptoms of depression in humans. It is referred to as sickness behavior, because there is no way of defining depression in a rat, for example. A rat with sickness behavior does not have an interest in doing anything. They are not social; they will not approach and socialize with another rat put into their cage; even those of the opposite

sex. Rats love saccharin; rats with sickness behavior are not interested in pressing a lever to get such a reward. They are not interested in feeling good. They get up and move around and they will go feed when they are hungry, but they have a lack of social interest in other rats or even in grooming themselves. They have this set of symptoms that you might imagine would look like depression for a rat. More direct evidence for the role of cytokines in depression comes from the observation that if you give cytokines to humans, they get depressed. Some of the early studies of people with cancer involved giving them cytokines to try and treat their cancers. Lo and behold, they got depressed. Another contemporary example involves the current treatment of hepatitis C. Patients are treated with interferon alpha which then goes on to elicit the production of these other cytokines, IL-6 being one of them, in the brain. Interferon alpha causes depression in 25% of the people being treated for hepatitis. People being treated for hepatitis C need to be monitored for depression, because 2% of them will go on to attempt suicide from this

treatment. Thus, we know that cytokines can cause depression in humans. We also know that IL-6 increases cortisol. Not surprisingly, if you give anti-depressants both to animals as well as to humans, the level of these pro-inflammatory cytokines and of cortisol are decreased, further implicating them in the pathophysiology of depression. There was enough smoke from what we observed and understood about cytokines for us to begin to study the cerebral spinal fluid of patients with transverse myelitis.

The results of this study are reflected on the scale in the graph. While we suspected IL-6 from our knowledge of prior research, we didn't want to bias ourselves in TM by investigating only this single candidate. We began a systematic study of 42 different cytokines in the cerebral spinal fluid of patients with TM. This graph shows 25 of the 42 cytokines that we analyzed. A one on the Y axis of this chart means that the ratio of levels of these cytokines in patients with transverse myelitis was the same as controls who did not have transverse myelitis. Anything above one meant that the TM patients had elevated levels of these cytokines. For instance, the graphic shows elevated levels of the cytokine IL-8 as compared to controls. One could conclude that an 8-fold increase is certainly worthy of following up and investigation. However, our attention was immediately drawn to the IL6 results. First, it is important to notice that this is a broken graph; the scale jumps from 20 to 300. There is not nearly sufficient space on the page to show the relationship between the levels of IL6 and the other cytokines that we analyzed. It is, on average, 300-fold elevated, not 20-fold and that result was absolutely staggering to us. In biology, you have interesting results and can publish a paper, if you see a 30% increase. This is a 300-fold increase, which corresponds to a 30,000% increase. In our wildest dreams, we hadn't anticipated such a staggering result.





We measured the levels of IL-6 in patients with transverse myelitis when they presented to the emergency room or came into the clinic acutely (e.g., shortly after the onset of their symptoms for the first time). We next determined their disability scores at follow-up (roughly 6 months after the onset of their neurologic symptoms) using the EDSS disability scale. Anything below four is still walking independently; ten means death, obviously the most severe outcome. The levels of cytokines and IL-6, in particular, correlated very nicely with the outcomes of these patients; with all of the patients who presented acutely with levels of IL-6 less than 50 pg/ml doing very well and regaining independent ambulation in follow-up.

We conducted a study which demonstrated that IL-6 is both necessary and sufficient for the spinal cord injury found in transverse myelitis (Kaplin, et al. Journal of The Transverse Myelitis Association, Vol. 1, January 2006). If you take the CSF out of a patient presenting with severe transverse myelitis, and you put it on a spinal cord in the laboratory, it kills spinal cord cells. CSF from patients with TM is toxic to spinal cords, which is why it caused

EDSS

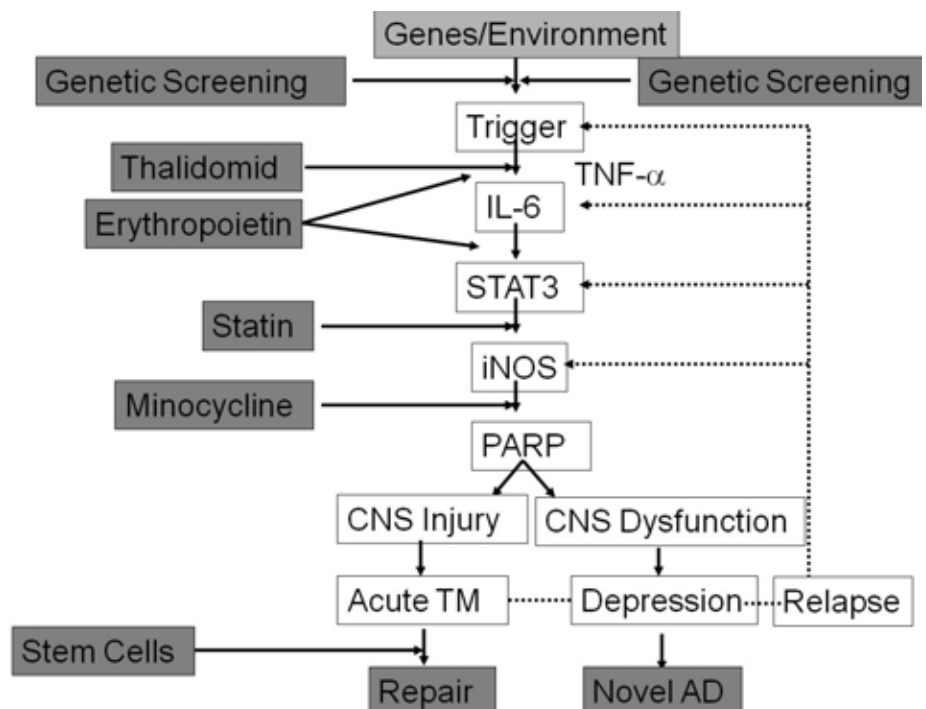
the damage in the person from whom we took it. If you leave all the thousands of other proteins in the CSF alone and pull out only one protein, IL-6, it is no longer dangerous or toxic to spinal cords in the lab. Thus IL-6 is necessary to cause the injury to the spinal cord. IL-6 is also sufficient to cause spinal cord injury. When we infused IL-6 into the spinal

cord of rats, it caused paraplegia over the course of days. When the spinal cords from IL-6 treated rats are examined, they look pathologically like the spinal cords seen in transverse myelitis patients; they had the same kind of microscopic injuries that you see in transverse myelitis patients.

While we were studying depression, we quite accidentally solved one of the central mysteries in transverse myelitis; what causes the injury? What in the final common pathway of damage is the gun that the immune system uses to cause the injury in transverse myelitis?

This was a tremendously important discovery. We then investigated how IL-6 caused damage to the spinal cord; specifically what chain of events or cascade IL-6 initiates that result in neuronal injury and dysfunction. We now know the whole signaling pathway that IL-6 uses to cause the injury in the central nervous system. Now that we know the pathway, we can begin to look for ways to intervene in this triggering pathway to halt the progression of the attack. This chart

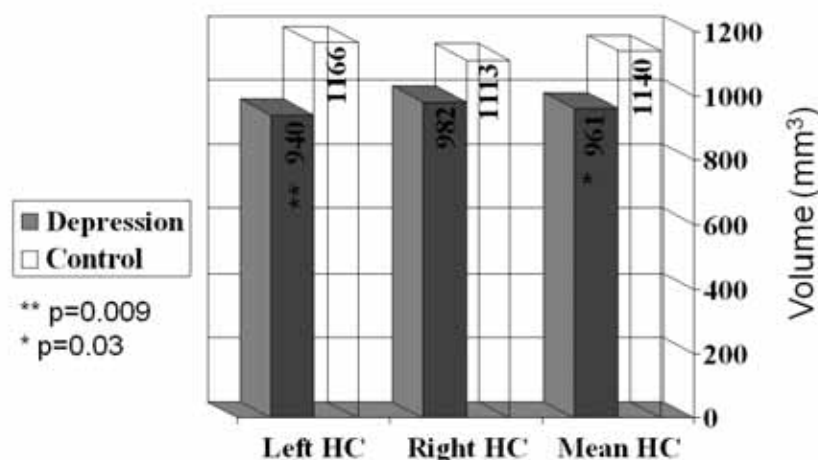
Triggering Pathway and Interventions



shows some of the possible drug interventions and these are already FDA approved drugs for other applications. Minocycline is an antibiotic; it is also being discussed as a drug for multiple sclerosis. Erythropoietin and Statins are already being used in experimental protocols to treat MS, even though we do not know exactly how those drugs are working. Our work on IL-6 and its signaling pathway leads us to think they are blocking this simple pathway. We are starting a trial of Erythropoietin at Johns Hopkins as a neuroprotective agent during an acute attack of TM. The next set of studies might look at erythropoietin for people with recurrent TM. Once you know this triggering pathway for the inflammatory attack, we are off to the races in finding treatments that are already approved and we can begin to develop new treatments.

My chairman said, "That's so great. You did good work over there with Doug Kerr. But what have you done for me lately in Psychiatry?" In our excitement about uncovering the cause of tissue injury in TM, we had strayed from our original reason for starting these investigations. I said, "Oh right, psychiatry, I forgot." So, we returned

20% Hippocampal Volume Loss in Depression
(Bremner JD, et al, Am J Psychiatry 2000)



+No volume loss in amygdala, caudate, frontal or temporal lobe or whole brain.
 +Persisted after controlling for brain size, alcohol exposure, age, and education.

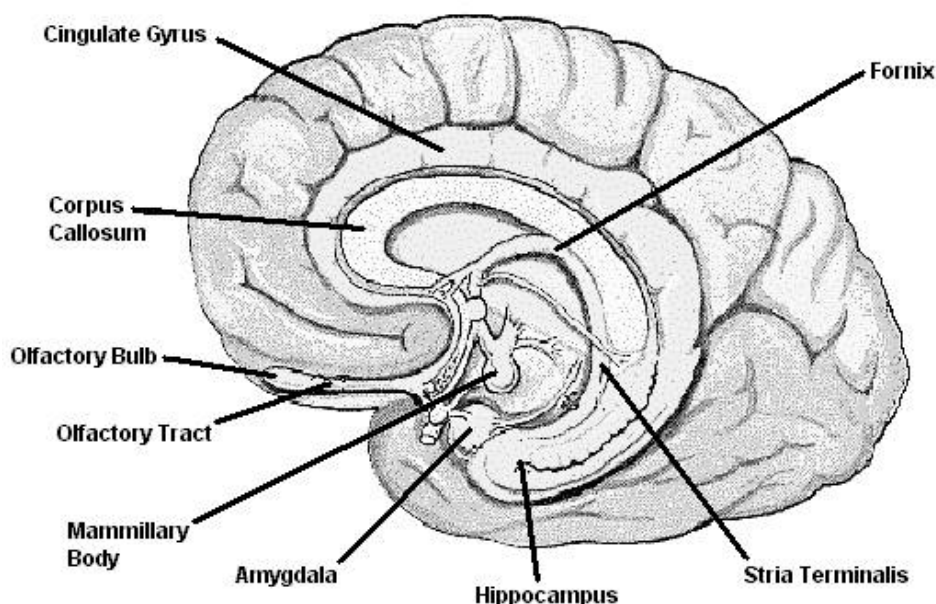
to the question of depression. Our next experiment involved looking at the effects of IL-6 on the brain. We used the same procedure and the same doses that we used on the rat spinal cords that caused injury to their spinal cords, and we infused IL-6 into the center of their brains. The rat's brains were fine. We looked at their brains under the microscope after the experiment and we could not see anything; there was no tissue destruction like we saw in the spine. I

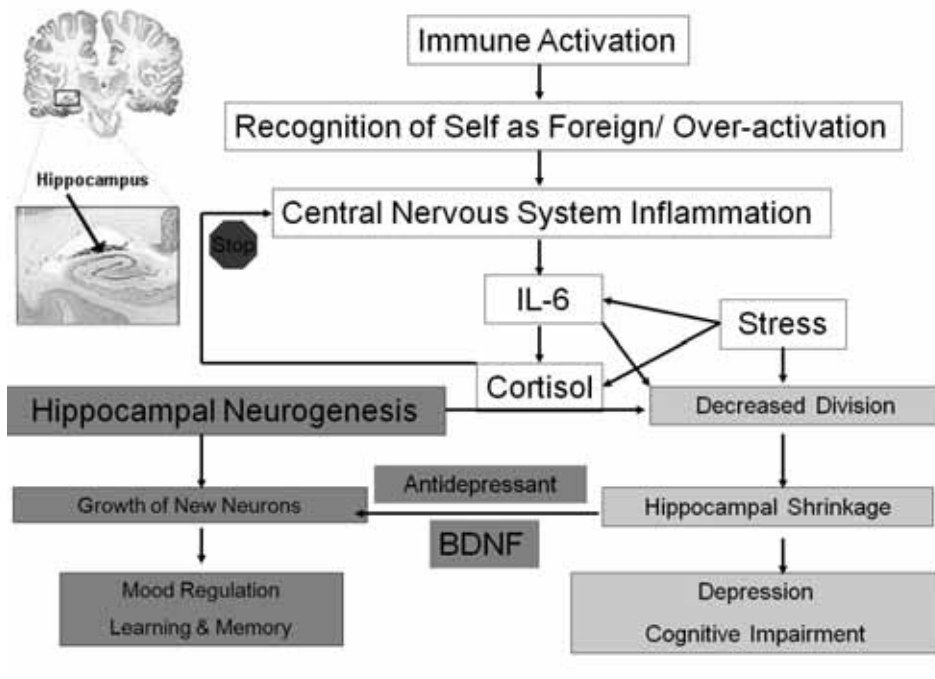
suspected that there had to be some kind of change, so we decided to look more closely to figure out what was going on.

This is the limbic system which starts off with the olfactory system. The limbic system is the seat of emotions. The emotional circuit of the brain starts in the nose. This is the reason the perfume industry is so successful; because our sense of smell really gets emotions going. From the olfactory system, it leads right into the limbic circuit and it goes all the way down to the hippocampus. Interestingly, the hippocampus is not only important in emotions, but it is important in cognition. In TM, just as in MS, as we have discussed, there is the risk of depression, as well as memory and concentration problems.

When reviewing the literature, other researchers have shown that in patients who are depressed, they have 20% decreases in hippocampal volume. The size of this region of the brain (hippocampus) shrinks over time, if the patient is not treated for depression. If the depression is treated, you prevent this shrinkage. The hippocampus is one of only two regions of the

Limbic System: Hippocampus as Seat of Cognition and Emotion





adult brain where new neurons are made throughout one's lifespan. The process is called hippocampal neurogenesis; neuro being neuron and genesis being birth. This is an interesting phenomenon for which there is a Nobel Prize waiting to be had for the person who figures out exactly how this happens and why this happens. There are new neurons being produced in the hippocampus throughout our lives. The function of new neurons in this region is not known. We know that depression and prolonged stress lead to hippocampal shrinkage and that it is prevented by antidepressant treatment, which may correspond to changes in hippocampal neurogenesis.

Interestingly, antidepressant treatment stimulates new hippocampal neuron production, one to two weeks after the initiation of therapy. Antidepressants have been shown to stimulate the production of new neurons in that region in a time frame that looks like it is consistent with the time frame for their onset of action for depression. When you first give them antidepressants, there is no effect in the first few days. Two weeks later, three weeks later, we begin to see the production of new

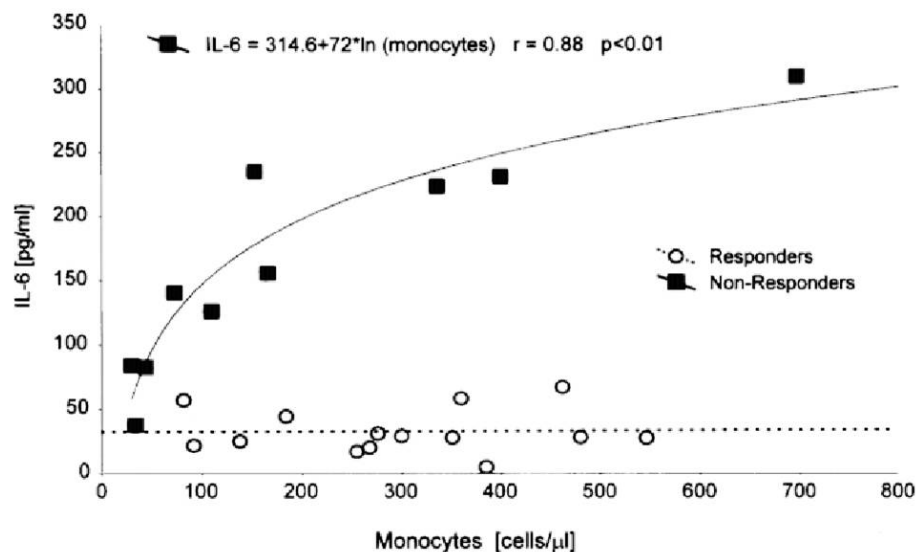
neurons. Coincidentally, it is in this same time frame that we begin to see people's depression improving. Finally, experimenters have recently shown in rats that if you block the production of new neurons in the hippocampus, antidepressants no longer have a behavioral effect on the rats that you can observe in the lab. When you give them antidepressants, it seems to calm them down and they are more relaxed and they will go out and feed in the light. Generally, rats and mice do not like to feed in the light; they like to stay covered. If you block the production of new neurons (hippocampal neurogenesis), antidepressants no longer exert their behavioral effects in animals and the animals will not become more relaxed even with the same treatment.

This research led us to focus on the hippocampus to look at the possible relationship between IL-6 and depression. We can introduce a marker (called BrDU) into the hippocampus that identifies only cells that are dividing; the marker is only taken up by these dividing cells. We introduced phosphate buffered saline into

the hippocampus of rats as a control; they continued to produce new neurons. When we introduced IL-6 into the brains of rats, they had virtually no hippocampal production of new neurons. IL-6 almost completely shut down the production of new neurons.

This graphic represents our current thinking about depression in TM and MS. There is immune activation that leads to the recognition of self as foreign; this is the central problem with all auto-immune diseases. This leads to the central nervous system becoming inflamed, and the activated white blood cells will release a lot of things, including IL-6. IL-6 stimulates cortisol. It is significant that the cortisol stimulation is not just random. Why does IL-6 produce cortisol? Why do we give people steroids when they have an MS attack or a TM attack? We give people steroids, because the body thought of it first; the body naturally produces cortisol to quiet down the immune system. The body has a reason for doing this. The problem is that there is an innocent bystander involved when the body does this under the threat of great or perhaps overwhelming inflammation. The innocent bystander is that the combination of IL-6, cortisol, and stress block the production of new neurons in the brain. We know from other studies that cortisol also blocks the production of new neurons independently of IL-6. Additionally, stress increases IL-6 and cortisol. Next, there is decreased production of new neurons in the hippocampus that leads to the hippocampal shrinkage. This is the model that accounts for what goes on in depression with a hippocampal shrinkage and that leads to depression and cognitive impairment. What happens when you give an antidepressant is that it produces new growth factors like brain-derived neurotrophic factor (BDNF). The antidepressant leads to the growth of new neurons and you can get mood regulation and perhaps some memory and concentration back.

IL-6 Production in Patients with MDD (Lanquillon et al, Neuropsychopharm, 2000)
Consecutive inpatient admissions; Treated with ATP (150-250 mg/day)



What I have just described for you is one of the first testable hypotheses for the biological basis of depression. We are currently in the process of testing this model. If we are able to prove the model, this will lead us to a whole new set of options to try to intervene to block or stop this process with perhaps more than current antidepressants. For

instance, we might consider the use of growth factors.

These investigations are important even for people who do not have transverse myelitis and multiple sclerosis. This graph represents a study done looking at patients who were treated with amitriptyline, which is a

tricyclic antidepressant, who did not have an auto-immune condition. It is interesting that many people got well when they were given this antidepressant, but some did not. What was the difference between those people who got well and those that did not? For those people who got well, their immune cells stopped over-producing IL-6 and those people who did not get well still over-produced IL-6. This may be the same thing going on for TM and MS, and for depression in general.

Researchers in our lab are currently studying Alzheimer's disease. In Alzheimer's disease you have a deposition of plaque which is called amyloid. Amyloid is like a sticky gum that gets into the brain. The graphic also shows microglia. Microglia are the clean-up crew for the brain. When they go in to clean this up, they start producing IL-1, TF alpha, and IL-6.

We are now studying the effects of IL-6 in that process. This graphic shows preliminary work that was done by Jennifer Cheng. This shows the IL-6 production taking white blood cells out of healthy controls (light lines). This is the IL-6 production in patients with Alzheimer's disease (dark lines). The graphic shows a complete separation;

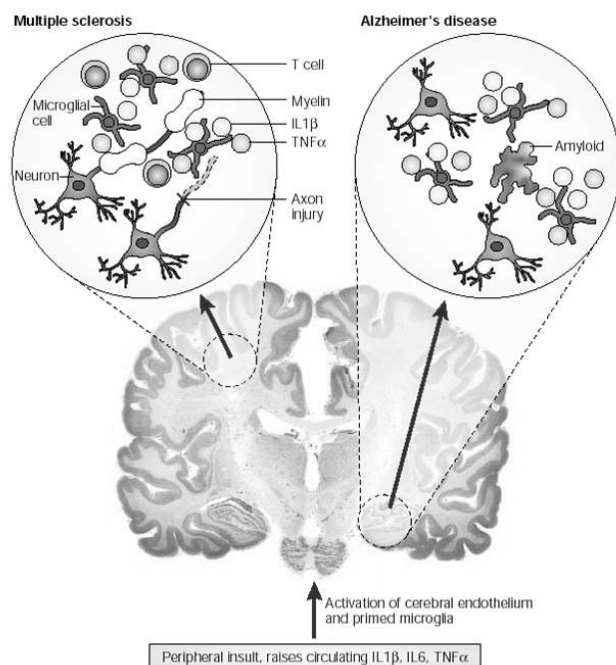
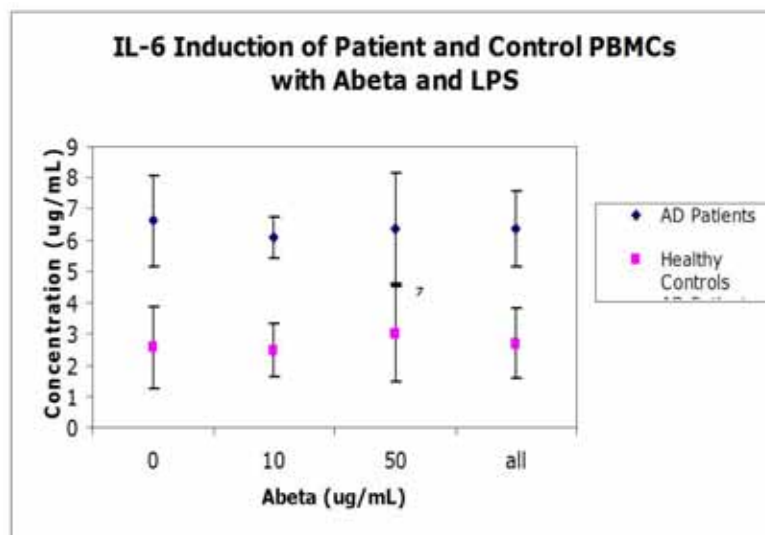


Figure 3 | Impact of systemic infection on the brains of patients with multiple sclerosis or Alzheimer's disease. In chronic neurodegenerative diseases, such as Alzheimer's disease and multiple sclerosis, peripheral insults that result in elevated peripheral cytokine synthesis can cause the activation of already primed microglia and lead to acute central cytokine synthesis with behavioural consequences. These cytokines, or other secretory products of the activated microglia, might cause axonal or neuronal damage and produce a lasting effect on the neurodegenerative process. IL, interleukin; TNF α , tumour necrosis factor- α .

Alzheimer's Disease Preliminary Results



the patients with Alzheimer’s disease made over twice as much IL-6. This means that we now have a potential marker for Alzheimer’s disease, as well.

We now have a testable hypothesis for what causes depression. This new model may lead to novel and more effective diagnostic and treatment methods. Remember, before we had an EEG, which is a novel diagnostic method for seizures, everyone thought that people who had seizures were possessed by the devil. There was a great deal of stigma surrounding seizures and a great deal of discrimination. Even in the 1960s in this country, many states had laws which required the forced sterilization of people who had epilepsy. With the advent of the EEG, the stigma was eradicated. Seizures became understood as a brain-based illness.

Our hope is that we will develop new ways for testing this pathway to help remove the stigma about depression and to help us find novel treatments. TM stands for Transverse Myelitis; but it also now metaphorically stands for Transforming Medicine. It is the only autoimmune CNS disease in which a single molecule is known to be pivotal in the course of the disease. This work has led us to a new way of thinking about depression and concentration and cognitive impairment problems. The development of novel treatments for all aspects of TM might not only improve the lives of patients impacted by this illness, but may help in the treatment of a wide variety of diseases.

COURAGE does not always roar.
Sometimes courage is the quiet voice at the end of the day saying,
“I will try again tomorrow.”

Mary Ann Radmacher
By way of John Craven,
Idaho Support Group Leader

Recruiting for Studies

Recruiting for ACP Study: Help us to Find the Causes and Cures for T M , A D E M , N M O , M S and the other Neuroimmunologic Disorders

Jana Goins

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

Several major academic centers located throughout the country will serve as coordinating project sites, creating a national network of collection sites. Study enrollment is targeted at 10,000 subjects over ten years. Enrolled subjects will be asked to contribute personal data (such as medical history and family information) and biological samples. The personal data collected from all subjects will be combined into a single database while the biological samples will be processed at a central laboratory and stored. The complete anonymity of study participants will be protected. The result will be the creation of a comprehensive information system and specimen repository from which researchers can request samples to conduct in-depth analyses on various disease aspects. This study will play an important role in increasing the current knowledge of demyelinating diseases and therefore aid researchers in the development of better diagnostic techniques and

cures for these diseases.

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

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

In addition to enrolling subjects with one of the specified demyelinating diseases, we are asking participants to refer affected and unaffected relatives as well as unaffected matched “controls” (such as a childhood friend who grew up in the same area as you or a spouse) for participation in the study.

This is a very exciting opportunity for

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

Participating Centers

Johns Hopkins Medical Institution
(Baltimore, MD)

Jana Goins

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

UMass Memorial (Worcester, MA)

Janice Weaver

acp-study-umass@acceleratedcure.org
(508)793-6562

Shepherd Center (Atlanta, GA)

Elizabeth Iski

acp-study-shepherd@acceleratedcure.org
(404)350-3116

University of Texas Southwestern
(Dallas, TX)

Gina Remington

acp-study-utsw@acceleratedcure.org
(214)645-0560

Multiple Sclerosis Research Center of
New York (New York, NY)

Lauren Puccio

acp-study-msrcny@acceleratedcure.org
(212)265-8070

Barrow Neurological Institute
(Phoenix, AZ)

Breanna Bullock

acp-study-barrow@acceleratedcure.org
(602)406-3109

Study Sponsor

Accelerated Cure Project
Sara Loud, Repository Director
300 Fifth Avenue
Waltham, MA 02451

acp-study-director@acceleratedcure.org
(781)487-0032
www.acceleratedcure.org

Neuroimmunologic Disorders Sample Repository:

http://www.acceleratedcure.org/
curemap/tissuebank.php



Risk Factors for Acute Idiopathic Transverse Myelitis

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

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

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

Principal Investigator:

Adam Kaplin, MD/PhD

Registered Protocol Number: 03-07-03-09

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

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

Interested patients should contact the study coordinator, Samantha Bartner, at 410.502.2574 for more information.

Research Volunteers Needed for a Pain Study

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

You may be eligible if you are:

- ◆ 18-55 years old
- ◆ Have been diagnosed with a Spinal Cord Injury or Disease
- ◆ Have had chronic neuropathic pain for at least 3 months

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

TMA California Meeting

Drs. Adam Kaplin, Douglas Kerr, Charles Levy, Frank Pidcock
Saturday, February 23, 2008

A Rare Neuroimmunologic Disorders Education Program will be held on Saturday, February 23, 2008 in Southern California. All TMA members from the west coast are invited to attend. This one-day program was made possible by the efforts of Dr. Charles Levy, a physical and rehabilitative medicine doctor and the physician who established the TMA Medical Advisory Board. Dr. Levy was able to set up a course on the rare neuroimmunologic disorders to be presented to a national meeting of physiatrists. Dr. Adam Kaplin and Dr. Douglas Kerr from the Johns Hopkins TM Center will be teaching this course. Dr. Frank Pidcock, a physiatrist and member of the TMA Medical Advisory Board, will be attending these meetings in Anaheim. Dr. Levy had the wonderful idea that since these physicians would be in Southern California for this meeting, we should try to get a program together for TMA members on the west coast. Drs. Levy, Kerr, Kaplin and Pidcock have graciously volunteered to spend an additional few days in California to make this session possible. Chitra Krishnan will also be attending the meeting from the Johns Hopkins TM Center, Project RESTORE and the TMA Medical Advisory Board.

Debbie Capen and Cindy McLeroy, support group leaders in California, are organizing this event. We owe them an enormous debt of gratitude, as they are doing all of this hard work on very short notice. The Rare Neuroimmunologic Disorders Program will take place all day Saturday. We will post a program agenda on our web site as soon as it is available. A registration fee will be charged for the session

for the purpose of covering the cost of lunch.

If you live in Southern California, please mark the date on your calendar; you have to be there. If you live close enough to drive into the area, you should make every effort to attend. If you live within a short flight from Southern California, you should give this some very serious thought. I have no idea what these physicians are going to present at this meeting, but I know that the information they provide you will be critically important to your understanding what has happened to you and will make you a much more informed and effective advocate for your medical care.

Please do not miss the opportunity to spend a weekend with other members of our community. The emotional power of being together with other people who most intimately understand your experience will energize you in ways that are difficult to describe.

For details, please check our web site regularly or please get in touch with Debbie or Cindy.

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

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

Retreat Weekend for teens and young adults at Victory Junction Gang Camp October 24 – 26, 2008

The next retreat for teens and young adults will be held at Victory Junction Gang Camp (North Carolina) the weekend of October 24 – 26, 2008. Please mark your calendars; you are definitely not going to want to miss this wonderful event. If you attended the retreat weekend in 2006, you know why you need to come back. The retreat weekend is a time to renew friendships and to make new friendships with people your age who have TM, NMO, ADEM and ON. It is an opportunity to spend time with physicians on our medical advisory board to hear about new research and to ask questions. Dr. Douglas Kerr, Dr. Adam Kaplin and Chitra Krishnan attended the last camp, and I am certain that they will try to make it again. We will invite all of the physicians from our medical advisory board, and we are hoping to have even greater participation next year.

The camp is first and foremost about having a fun time; and you will have a really awesome time. VJGC is a fully accessible facility, the camp has an excellent adaptive recreation program, and the medical facilities are excellent. The camp has an exceptional full-time medical staff; your stay at camp will be safe and in an entirely supportive and caring environment.

If you are 16 to 21 years old, please mark the dates on your calendar. If you will be 15 years old during the time of camp or you are 22-25 years old, please apply and the camp will consider applications on a case-by-case basis. If you are older than 21, you might also consider applying to come to camp as a volunteer.

If you are interested in attending the

TMA retreat weekend at Victory Junction, please call or send an email to Paula Lazzeri and ask her to place you on the retreat weekend recruiting list. Give Paula your age, provide her with all of your contact information, and also let her know if you are interested in attending camp as a camper or as a volunteer. If you need traveling assistance or if you are interested in coming to camp with a parent(s) or a sibling, please also give this information to Paula.

PLEASE DO NOT APPLY TO CAMP! VJGC is not prepared to accept our applications. We will let you know when it is time to fill out the application and we will provide you with the details of the application process at that time.

For now, get the dates marked on your calendars and call Paula or send her an email: (425)883-7914
plazzeri@myelitis.org.

The last camp we had was a totally life-changing experience for everyone who attended. Please plan to be a part of this incredible opportunity.

Douglas Kerr Receives Neurological Scholar Award

Douglas Kerr, MD, PhD, Associate Professor of Neurology, was awarded the 2007 Derek Denny-Brown Neurological Scholar Award. This award is given each year to a newly elected member of the American Neurological Society who has achieved a significant stature in neurological research and who has great promise to continue making major contributions to the field. Mazel tov, Dr. Kerr!

Children's Database Help us to provide you with information and support!

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

1. To develop a contact list that will be used by the TMA to notify and recruit families and older teens and young adults for the family camps and the older teen/young adult retreat opportunities, such as those that were held this past year 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 neuro-immunologic 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 and please bear in mind that we will only provide printed copies of the directory to families who are willing to be listed in the directory.

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

NATIONAL FAMILY CAREGIVERS ASSOCIATION



The Transverse Myelitis Association Supports National Family Caregivers Month November 2007



The Transverse Myelitis Association is a member of the National Family Caregivers Association and a proud supporter of National Family Caregivers Month. National Family Caregivers Month is a time to thank, support, educate and celebrate the more than 50 million family caregivers across the country providing an estimated \$306 billion in “free” caregiving services to loved ones every year.

In celebration of National Family Caregivers Month 2007, family caregivers are encouraged to take action to improve their own health and well being by speaking up for their rights. Help support family caregivers to take steps every day to make their lives easier, improve the care they give their loved one and convince others to speak up about the assistance family caregivers need and deserve.

The Transverse Myelitis Association is pleased to be an endorsing organization of NFC Month and a part of this campaign to bring attention to the needs of family caregivers. Here's what you can do to get involved:

- Remind family caregivers to **believe** in themselves, **protect** their health, **reach out** for help, and **speak up** for their rights.

- Encourage family caregivers to identify themselves as a family caregiver in conversations with others, including friends and family as well as healthcare professionals.
- Plan your own local NFC Month Celebration. Contact the National Family Caregivers Association at www.thefamilycaregiver.org or call 800/896-3650 to learn more about how you can obtain family caregiver kits and ideas for celebrating National Family Caregivers Month.

NFC Month is a time to speak up for the rights of family caregivers.

ADEM, NMO, ON, Recurrent TM, TM 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. I only share these lists with people who are willing to be added to the lists.

- Acute Disseminated Encephalomyelitis (ADEM);
- Neuromyelitis Optica (NMO) or Devic's disease;
- Recurrent TM;
- TM or NMO with SLE (Lupus);
- TM or NMO with Sarcoidosis;
- TM or NMO with Sjogren's syndrome
- TM or NMO with HIV; and
- 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
USA
ssiegel@myelitis.org

A Motivator for Young Children to Exercise

During Family Camp this summer at Victory Junction, the parents had the wonderful opportunity to participate in a discussion session with the TMA Medical Advisory Board Physicians and to ask them questions. One of the issues stressed by the doctors was the importance of using exercise bikes to keep the muscles strong and healthy. I described an approach we were using with our son, Riley, and the doctors asked me to share this information with other parents. Riley is seven years old. We use a pediatric-size exercise bike that hooks up to a TV/DVD player. When the child is pedaling, they can watch TV or a movie. If they stop pedaling, the TV goes black. They can still hear the TV; however, they cannot see the picture. Once they start pedaling again, the picture reappears. The name of the bike is "Gamer Cycle" and can be purchased on the following web site:
www.gamercycle.com. You might also try looking for the bike on eBay. This approach works really well for our son, and it might also benefit your child.

Kristi Blee
Lakeville MN

Will White Fund: Support the Accelerated Cure Project and Find the Causes and Cures for the Neuroimmunologic Disorders

Gena White

We are asking you to support a research effort that is incredibly important to our family. This research effort is the Repository Program being led by the Accelerated Cure Project for Multiple Sclerosis and Transverse Myelitis.

When Will was about five months old, I was changing his diaper and noticed that his legs seemed limp. I immediately called his doctor and he told us to go to the emergency room. The ER physician told us that Will had a fever and sometimes a fever can cause a child's body to become limp. We were sent home. We went to see Will's pediatrician the next day and he immediately checked us into the hospital.

He was in the Pediatric ICU for two days while they ran every test possible. They finally concluded that it was Transverse Myelitis. TM is a rare disorder which can sometimes make it difficult to diagnose. The ACP Repository is so important, because it is focused on finding the most effective ways to diagnose TM and the other neuroimmunologic disorders.

Will was put on a high dose of steroids to try to stop and/or reverse the effects of the Myelitis. Fortunately, it did stop the Myelitis from spreading any further up his body, but it did not reverse the effects. Will is paralyzed from the waist down and has to be catheterized every 2 ½ hours to make sure that his bladder is completely emptied and to prevent any kidney damage. He goes to physical therapy and occupational therapy once a week to build up strength in

his stomach and back muscles to help with his stability.

Other than the inability to walk, he is a typical two year old. He does not seem to listen when told to do things and he gets everywhere and into everything. Being on wheels makes catching up with him a bit harder, and he usually gets a head start.

The ACP study was kind enough to include Will, and we feel very strongly about supporting their work and their goals. They could find a cure for TM. Finding this cure would spare other families from going through our experience; what we have been through and the challenges we continue to experience today. We had never heard of Transverse Myelitis until Will was diagnosed. We are committed to a greater awareness of TM in the general public. We are also committed to research which would facilitate the diagnosis of TM and could result in more rapid and effective acute treatments.

The Accelerated Cure Project for Multiple Sclerosis and Transverse Myelitis is a national nonprofit organization whose primary effort is the creation of the world's largest openly accessible collection of bio-samples ever assembled for use in MS and TM research. Through collaboration with The Transverse Myelitis Association, blood samples and data are being collected from individuals with MS, TM, NMO, ON and ADEM, as well as controls across the United States. These samples and data are then being made available to researchers investigating the causes of these diseases. The short-term goal of ACP is to collect samples from 1,000 people. ACP intends to continue enrolling subjects with a long-term goal of recruiting 10,000 participants.

The Repository program gives researchers immediate access to far more samples than they could collect independently and allows them to conduct experiments of a size and scope not

possible otherwise. Through this type of sharing and collaboration, the MS and TM research communities can effectively multiply the value of their important research.

According to Dr. Ben Greenberg, Assistant Professor and Co-Director of the Johns Hopkins Transverse Myelitis Center, "The approach taken by the Accelerated Cure Project is a long overdue effort to collect the vital information and specimens from people necessary for research such as mine to be fruitful. A concerted effort to expand this project will undoubtedly lead to benefits not just for patients with MS and TM, but for science in general."

We believe in the work of the Accelerated Cure Project. The total cost of creating and managing the initial 1,000-subject phase of the repository is \$2.5 million. We need your help! With your support and the support of others who wish to see a cure for MS, TM, and the other neuroimmunologic disorders we can make a real difference.

Please send your contribution to the **Will White Fund** for the Accelerated Cure Project for Multiple Sclerosis and Transverse Myelitis. Please send your check made out to the Accelerated Cure Project and mail it to: "The Will White Fund," Accelerated Cure Project, 300 Fifth Avenue, Waltham, MA 02451. As ACP is a registered not-for-profit, your donations are tax deductible to the extent permitted by law and IRS code.

Should you wish to donate \$1,000 or more, there is currently a special program in place through which this gift can be matched. The Water Cove Charitable Foundation has pledged to match any gifts of \$1,000 or more, up to \$1 million total and to double match any gift of \$1,000 or more that is pledged for three years. These gifts and the matching funds are restricted to the repository program. A gift of

any size is greatly appreciated.

If you would like additional details about Accelerated Cure Project's work and progress, a copy of its annual report can be downloaded from www.acceleratedcure.org or provided to you upon request. Further details about the repository program can also be found at: <http://www.acceleratedcure.org/repository/>

We hope you will join us this year in supporting efforts to accelerate the cure for TM, MS, ADEM, NMO and ON. Our family would greatly appreciate any support you can provide.

Thank 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.

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, is the Executive Director of Project RE-STORE and is the Research Coordinator at the Johns Hopkins TM Center.

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 2006, 2004 and 2001 symposia, from the Southwest Symposium (sponsored by the Cody Unser First Step Foundation), and from the 2002 children's workshop are available under the link 'Symposia Information' or by typing <http://www.myelitis.org/events.htm> into your web browser. Jim has the presentations organized as they appeared in each of these symposia program agendas. You can also find PDF files of most of the handouts and PowerPoint presentations. The video presentations are also available by going through the Multimedia link from our main web page or by typing: www.myelitis.org/multimedia.htm into your web browser.

Support Groups

Devics-Support

The Devics-Support Group was launched in February of 2006 by Tim Mulvihill of Newport News, Virginia. Upon the illness of Tim's partner, Robert Keith Burden in 2005, it was quickly discovered that information regarding this extremely rare disease and its subsequent treatment protocol was sparse. Hoping to remedy this situation, Tim created Devics-Support. Shortly after forming the group, Tim met Grace (Pamala) Mitchell through The Transverse Myelitis Association. Tim and Grace joined forces, determined to make their group a successful support and resource site. The group quickly grew into more than just a support network, drawing the attention of patients, doctors, researchers, and medical institutions from around the world. Recently our members were invited to participate in a clinical trial for Rituxan at UCSF. We were also invited to the 2007 NORDS Conference, held on September 28th through the 30th, in Rockville, Maryland. Our group has now grown to become an informative and beneficial resource for over 200 members from around the world.

Currently, Devics-Support is registered with NORD and NIH, is recognized by the National MS Society, and is referenced by many of the major insurance companies as a resource. We have also been quite successful at getting some of the major internet resources to update their information regarding Devics. We work in tandem with The Transverse Myelitis Association, and members are encouraged to join the Association and to direct all donations there. Our co-director, Grace, diagnosed with Devics in

2005, is a current member of the TMIC list, and has found it to be extremely informative and supportive regarding the issue of spinal myelitis. Sandy Barry, who has been a member of our group since her diagnosis in 2006, recently coming on board as our Manager, is also a current member of the TMA. Tim, Grace, and Sandy, have been very impressed with the resources that The Transverse Myelitis Association has to offer. Please be sure to take advantage of this invaluable information.

Tim, Grace, and Sandy are not strangers to the ravages of Devics-NMO. Tim's partner, Robert Keith Burden, was stricken with total blindness almost over night, subsequently becoming paralyzed from the neck down. At this time, he has made a moderate recovery, is now walking with a cane, has recovered partial black and white vision, and continues to recuperate at home. Grace suffered paralysis twice, first becoming paralyzed from above the waist down, and within weeks of coming home from rehab, suffering another episode of paralysis which began slightly below her shoulders. She has been hospitalized many times since, with repetitive episodes of optic neuritis. She has regained mobility and currently is able to see and read with the aid of glasses. Sandy has been stricken several times with optic neuritis in both eyes and has permanently lost her vision in one eye. She continues to fight to save her remaining eye. She is a valuable asset to us, donating time and effort from her already busy schedule to our group. All three continue to do a wonderful job with Devics-Support.

We encourage anyone who is affected with Devics-NMO to contact us. Our mission is to offer information for patients, caregivers and friends, addressing all with sensitivity and compassion.

Visit Devic's-Support at : <http://groups.google.com/group/Devics-support>

Devics-Support

Timothy Mulvihill
168 North Redwood Ct
Newport News VA 23608
(757)369-8694
tmulvihill@myelitis.org

Pamala (Grace) Mitchell
107 Woodside Manor
Carmichaels PA 15320
(724)966-8157
gmitchell@myelitis.org

Sandy Barry
sbarry@myelitis.org

Arkansas

I am establishing an Arkansas TM Support Group. My husband, Al, got TM five years ago on January 2, 2003.

His attack was sudden and dramatic. Normally quite healthy and never having spent time in a hospital, he had a miserable upper respiratory infection at Christmas. He was getting over the infection, but went to church on Thursday morning to lead his men's cleaning project. He came home feeling very tired and aching all over. He didn't want lunch, and said he was going to build a fire in the basement and "watch it;" i.e., take a nap. He didn't eat much that night. The next morning, he still felt awful and complained of a tightness and odd discomfort across his chest. I called our doctor and said I had a 73

year old man complaining of chest pains, and they had me bring him right in. By the time we got to the doctor's office, he was complaining of hip pain, but managed to walk in under his own steam. Our doctor was in surgery, so he saw his assistant. The assistant did some blood work, determined it wasn't a heart problem, diagnosed it as "flu symptoms and myalgia," and sent him home with some sample meds.

By the time Al got home, his hip hurt terribly. He just wanted to go to bed. He slept and when he woke up in the late afternoon, the pain wasn't as bad, but he couldn't move his legs. He had to go to the bathroom. We managed to get him in there, but then he found he couldn't urinate. He didn't want me to call the doctor; he wanted to sleep. By early morning, he said we had to do something; he couldn't get out of the bed. An ambulance got him to the hospital.

Thus began our introduction to TM. The emergency room doctors did all the appropriate tests for stroke and heart attack. They were stumped. One of the ER doctors said he thought he knew what it was, but he'd never actually seen a case of it. He called in a neurologist. His initial diagnosis was Guillain-Barre Syndrome. As the paralysis seemed to be advancing rapidly, he told me to expect him to be on a respirator before morning. They were very concerned about his breathing, but we passed the critical period and the paralysis stopped at mid-chest. They kept him in ICU and on the fourth day began talking about Transverse Myelitis. They confirmed TM with a spinal tap. That was the good news and the bad news. The good news was that they finally had a diagnosis and the bad news was a poor prognosis for recovery.

He spent 3-1/2 months in the hospital. After ten days in ICU, he was transferred to acute rehabilitation. I became very frustrated. I didn't know

much about hospitals (I was only in the hospital to deliver babies) and I didn't know anything about TM. I didn't even know what questions to ask. My daughter took over. She found information on the internet and she contacted Dr. Kerr's office at Johns Hopkins. Dr. Kerr reviewed his records and found us a neurologist in Springfield who had actually treated TM cases (three in Springfield, Missouri). I got a referral to see him without waiting the normal four to six months for a new patient! I was impressed. He said Al's initial treatment was not only appropriate, it was aggressive. The neurologist was amazed at Al's recovery during follow-up visits, because of the severity of his damage from the attack. He finally said that the rest of his recovery was pretty much up to him.

And this brings me to the reason I feel it is important to become involved in a support group. My daughter got the information from The Transverse Myelitis Association through the website. But we needed to talk to someone who had first-hand knowledge of the disease, not just research material from their computer. The most relevant information we received was from an unusual source, the orthotist. He made braces for Al's leg, which made no recovery, and his right hand, which remains paralyzed. He was struck with TM in Minnesota when he was in college, and had much the same disability that Al initially had. Just talking with him about his personal experiences and his recovery was great. He uses a leg brace and an arm crutch. The major difference was their ages. He was young and strong. Al was 73, strong for his age and too tired for aggressive therapy to gain strength.

He has about 75% use of one leg and none from the other. His right hand

is paralyzed with fingers splayed open. Early on they could manipulate them into a fist, but he couldn't hold it. The left hand is awkward, but he has adapted. He has a catheter all the time, and bowel function is sporadic and unpredictable. He completely lost his sense of taste and smell. He cannot distinguish hot from cold in the paralyzed limbs and his trunk. He has a Jazzy wheelchair for inside; and a big 4-wheel electric cart for the yard. We have a Dodge Van with a ramp, which makes life much more pleasant for both of us. He went through severe depression as did I. But his faith is strong, and he is living proof that G-d gives more Grace. He is full of it! And I mean that as a testimony, and with no sarcasm.

That is our story. We are a team. Al lifts me up so I can carry him around!

We would love for you to get involved in our group. Please call or send me a letter or email. We look forward to hearing from you.

Pat and Al Tolle
246 Queen Lane
Gassville, AR 72635
(870)435-2760
Cell: (870)404-0801
ptolle@gassville.net

Gassville is a small community about eight miles from Mountain Home in north-central Arkansas. Mountain Home has Baxter Regional Medical Hospital, a large and very modern facility, and is a major retirement destination in the heart of the Ozarks, boasting the "World's Best Trout Fishery" and the friendliest people in the world.

Brasil

Busco iniciar um Grupo de Suporte no Brasil, porque eu tenho um filho que teve Mielite transversa aos 7 anos e hoje ele faz uso de uma cadeira de ro-

das motorizada.

Neste período procurei me manter atualizada sobre os avanços em tratamentos, equipamentos, fisioterapias e pesquisas científicas, mesmo sem pertencer a área de saúde.

Neste sentido a Associação de Mielite Transversa muito me ajudou. Soube através do cadastro deles que existem cerca de 90 pessoas no Brasil com TM, mas acredito que seja um número muito maior. Pretendo cadastrar o número real de pessoas que tiveram esta doença e repassar via WEB informações, agenda de eventos e cartas, em português, e o jornal provavelmente será primeiramente repassado via site.

Com estes objetivos nós já estamos trabalhando com a nossa primeira página, a qual pretendemos paulatinamente ir ampliando.

Patrícia Eichler

www.myelitis.org/users/braziltm
pajebbru@yhoo.com.br

Brazil

I am starting a support group in Brazil. I have a son who got Transverse Myelitis in 1994 and he has been using a motorized wheel chair since then.

During this period of time, I have tried to keep myself updated on the new treatments, equipment, therapies and academic research, even though my degree is not from a health area.

In this way, the TM Association has helped me a lot. I knew from their membership directory that there were about 90 people with TM in Brazil. I believe that the numbers of people with TM in Brazil is much larger. My goal is to help find more people with TM, to help them sign up for membership in the TMA, to help them find in-

formation on the web site and to translate information, agenda events and articles into Portuguese. The journal will initially be distributed through the website.

With those objectives before us, we are already working on our Brazilian TM Support Group webpage.

Patrícia Eichler

www.myelitis.org/users/braziltm
pajebbru@yhoo.com.br

California: San Diego

Dear Friends,

I would like to take a moment to introduce myself and encourage you to write if you have an interest in starting up a San Diego TMA Group. Diagnosed in July 2005 myself, I have experienced first-hand the trials and tribulations of this complicated condition. My research led me to the TMA's website and has allowed me to meet and share information with some great people throughout the country. My hope is to have a space available by March 2008 for up to twenty members to gather for regular meetings. If you would like to be kept informed, write me at: DrDavis@SDOptometry.com. Thank you!

Christine Davis

Christine Davis

Canada

The Canadian support group wants to start a live chat, but we need for people to give us suggestions for days/times that would work for them. We ask that people post on the TMA Canada Support Group message board the times and days that would

be best suited for them to participate. We will review all of your responses and then will post the chat dates and times on the Canada support group page on the TMA web site.

Please post your preferred days and times on the message board:

<http://myelitis.org/phpBB2/viewforum.php?f=82>

Please check the Canada Support Group page for scheduled live chats:

<http://www.myelitis.org/local/canada/index.htm>

We look forward to hearing from you and we look forward to talking with you!

Marieke Dufresne
marieke@myelitis.org

Germany

I am Ursula Mauro, the first president of the German Myelitis Society which exists since May 2006. We are pleased with our progress over the past 16 months. Our membership in Germany has increased to 90 people.

The Society's committee members have been meeting to tackle some significant administrative hurdles. As in the past, we have applied for and have received grants from the German insurances. These funds are being used to translate medical articles about TM into German for the TMA and German Support Group web sites, to help subsidize the hotel cost for our members to attend meetings, to send our TMA/German Myelitis Society flyer to neurological rehabilitation centers, to neurological ambulances and other institutions, and to cover the costs of our office materials and postage. As a support group of the TMA, we share the policy of no membership fees. As our members do not support our group in the same way that the US members support the TMA, we depend on these funds to cover almost all of our operat-

ing costs. We are grateful to be able to receive this funding.

Our group has found a webmaster who has created and maintains the German Myelitis Society website. Jim has also installed a chat room to the German message forum, and we are using this communication opportunity on a regular basis.

For the first time, we held a meeting in northern Germany to facilitate support networking in this region of our country. Johann Lienemann, our Society Treasurer, organized the meeting and 13 people attended. It was a great event, people enjoyed meeting each other, and this group plans to get together on an annual basis. Unfortunately, I was not able to attend, because my health condition does not allow long journeys. Our general meeting was held in October in southern Germany. Fifteen of our members attended the meeting. Everyone enjoyed being together and the meeting lasted from 2:00 in the afternoon until midnight!

I am regularly in contact with Lew Grey and Geoff Treglown from the UK TM Society. We collaborate on developing and providing a German information packet for new members. We also work to keep our support group member information accurate and up to date. I am grateful for their help and co-operation! I am also in regular and close contact with Sandy and he helps me in every way he can. And Jim always is there for us to provide support with all of our internet and computer issues. I am very thankful to work with such great people!

If you live in Germany, Austria or Switzerland, please get involved in our support group. We want to get everyone involved and are so pleased with the participation of every new member!

Take care!

Ursula Mauro
The Transverse Myelitis Association
German Myelitis Society
1. Vorsitzende Myelitis e.V.
Neugasse 32
77743 Neuried
Telefon: 07807-3154
mailto:umauro@t-online.de
<http://www.myelitis.de>

India

My name is Abhijit Ganguly. I am 24 years old and from Kolkata, India. One evening in 2003, I was watching a football match on TV while lying on my bed. Suddenly, I felt severe pain in my shoulder and throughout my back, and the pain was rapidly intensifying with every second. I rubbed a balm in the affected area, but it did nothing to relieve the pain. The pain was like a burning sensation and was severe. I was unable to sit and eventually I had to lie on the bed. I skipped eating my dinner. By around 11 PM, I was feeling very strange. First I lost sensation in my hand and then I lost sensation in my legs. Then I was unable to grasp with my hands and I could no longer stand. I was not able to urinate. I did not have any strength and I did not sleep the entire night. I thought I was going to die.

In the morning, our family physician came to our home. He asked me whether I had been hit or experienced some kind of accident. I told him that I hadn't. I told him that I could not pass urine. He had no idea what was happening to me and advised that I be admitted to the hospital.

It was Sunday and it was my good fortune that a neurosurgeon was in the hospital. Most doctors do not stay in the hospital on Sundays. He ordered an MRI. It was very kind of him to call a diagnostic centre and he persuaded them to perform the MRI.

Diagnostics centres are closed on Sundays. I was admitted to the ICCU ward. I was awake the entire night trying to understand what was happening to me. Was I going to die? I had to ask the nurse for a glass of water. I was totally helpless; I had to depend on someone for a glass of water.

The MRI report came back the next day and I was given a TM diagnosis. I was put on high course steroids. After some time, I felt as though a current was passing through my veins. I was able to move my hands and legs. I was having to catheterize myself. After a couple of weeks, I was released from the hospital. I had been begging the doctor to allow me to go home.

I become very weak. The neurologist prescribed me steroids and, unfortunately, I had an allergic reaction. I had eruptions over my entire face and I looked horrible. I went to a skin specialist who explained that the problem was caused by the steroids. He told me that he wanted a photograph of my face because my allergic reaction was so unusual. My face cleared up over a period of about four months, but I still have some scars from the reaction.

I became very depressed; I had so little understanding about TM. What did I do wrong that G-d gave me this disease? It was particularly frustrating for me as the doctors did not clearly explain to me what had happened; what was TM? My friends and relatives each shared their own theories of what had happened. Some said that it was a result of having excessive fast food; some said it was from germs in my body; and someone asked me if I had used drugs! I stopped talking to people. The days in the hospital haunted me. My life was becoming miserable and I was afraid of the recurrence of TM.

Then one day I found the TMA website. It was of great help. Sandy is a wonderful person. The website was an

eye opener for me. I was so surprised to see that there were so many people around the world with TM.

It has been around four years since I got TM. I have come a long way. I have completed my Masters in Economics. I have occasional nerve pain. I have very difficult bowel problems and I have limpness in my right leg. I have become a pessimistic person, but I try to inspire myself when I think about the lives of various people with TM who have been more seriously affected than me.

I am interested in starting a support group in India. I think the best person who can understand a TM affected person is another person who has TM. Through a support group, we can share our feelings and support each other as a family or community. I know that most of you have gone through similar experiences and feelings after being diagnosed with TM. What is TM? Why did this happen to me? How am I going to get my life back? Through a TM Support Group in India, we can offer each other emotional support and we can share information.

Our support group is for people who have TM, ADEM, NMO and ON, their family members, and, hopefully, physicians in India who treat people with these disorders. I would love to hear from you. My contact information is below. And please think about getting involved.

I would also love to hear from other support group leaders from across the United States and from around the world. I would like to learn from your experiences. Please get in touch with me; it would be wonderful to hear from you.

Abhijit Ganguly
15 Elliot Road
Kolkata 700016
India
Phone number: +91 9433702379
Email address: aganguly@myelitis.org

Editor's Note: Words cannot describe how thrilled I am to include Abhijit's article in this newsletter announcing that he is starting a support group in India. I began regularly corresponding with Abhijit shortly after he received his TM diagnosis. We have been writing on a weekly basis for almost four years. Abhijit does not have internet access in his home, so he does his emailing from a cyber café near his home. Having TM and living in Baltimore is difficult. Having TM and living in Kolkata is a different kind of difficult. Abhijit is a very courageous young man. He has worked so hard to make a good life for himself. In getting his master's degree in Economics, Abhijit had an almost two hour train ride to the University every day – one way. Doing this with TM has been a grueling experience for him. Given the incredibly competitive and difficult economy in India, Abhijit is currently working on an MBA to enhance his career opportunities. Societal attitudes about psychological issues and counseling, perceptions of people with disabilities, and social, economic and medical support services for people with disabilities are slowly improving in the United States, but there is a very long way to go before these issues are where they should be. Do you want to venture a guess as to where these things are in India?

Over these last few years I have come to know and to very deeply care about Abhijit and his family. Anushree, Abhijit's 12 year old sister, is my number one pen pal; she manages to find a moment here and there to write to me between studying for her many exams.

Abhijit will greatly benefit in so many different ways from doing this support group work. And he will be able to do so much good for other people in India who have these rare neuroimmunologic disorders and

their family members. Thank you, Abhijit, for taking on this important work. I am so very proud of you!

Italia

Il Gruppo di Supporto per la M T

Circa un anno fa, Jim, il nostro web manager, mise un annuncio su un sito web per il reclutamento di volontari che ci potessero aiutare a tradurre la documentazione associativa pubblicata in inglese sul nostro sito istituzionale (articoli, notiziari, giornali, ecc.). La TMA, è una associazione internazionale con associati residenti in più di 80 paesi diversi, la quale, come tutti sapete riunisce malati affetti da una delle rare patologie neuro-immunitarie; di conseguenza appare evidente che comunicare e fornire informazioni nel maggior numero di lingue possibile, rappresenta uno dei più importanti scopi della nostra associazione.

A rispondere a quel famoso annuncio fu proprio Federica Boiani che da allora ha tradotto una notevole quantità di informazioni e documenti dall'inglese all'italiano. Il contributo di Federica è stato molto utile alla TMA, in quanto sono molti gli italiani, nostri associati che non parlano la lingua inglese. Quello che rende ancor più sorprendente ed unica la collaborazione di Federica è che ne lei ne un suo familiare sono affetti da una malattia neuroimmune; Federica si è proposta come volontaria semplicemente perché cercava una opportunità per poter aiutare gli altri.

La TMA riceve moltissime e-mail da parte di neo-diagnosticati che chiedono informazioni e consigli ma che non parlano la lingua inglese: poter comunicare con queste persone è per noi così importante che siamo costantemente alla ricerca di volontari che possano darci una mano a svolgere questa attività.

Federica si è resa disponibile da subito e ci ha aiutato a comunicare con i nostri associati in Italia. Interagendo regolarmente con noi, con gli associati italiani e soprattutto attraverso il suo lavoro di traduzione, ha gradualmente imparato a conoscere meglio le malattie neuro-immunitarie; di recente ha anche partecipato al Convegno della TMA che si è tenuto a Londra lo scorso ottobre ed ha potuto così incontrare il dott. Kerr e conoscere i nostri associati del Regno Unito.

Da qualche mese, l'attività di spedizione e stampa della documentazione associativa, che in precedenza veniva stampata e spedita ai nostri associati in Italia dal Regno Unito, è stata presa in carico da Federica la quale fa del suo meglio per tradurre quanto più materiale possibile così da poter permettere agli associati italiani, di ricevere ed acquisire notizie ed informazioni nella loro lingua nativa.

Federica non può e non dovrebbe svolgere tutta questa mole di lavoro da sola. Ti chiediamo di aiutarla, soprattutto in vista di una formale fondazione di una associazione per le malattie neuro immunitarie tutta italiana.

Federica, desidera costituire formalmente un Gruppo di Supporto della TMA in Italia e sta attualmente raccogliendo le necessarie informazioni. Ha quindi urgente bisogno che gli associati italiani collaborino attivamente con lei a questo progetto e assumano in ambito associativo ruoli e responsabilità.

Nel futuro, ci auguriamo che il Gruppo di Supporto della TMA in Italia non solo divenga una realtà ma sia anche economicamente autosufficiente e in grado di auto-finanziare, attraverso i contributi degli associati, le spese per la stampa e per la spedizione della documentazione associativa.

A questo proposito, invitiamo cortesemente tutti gli associati della TMA residenti in Italia ad effettuare le loro donazioni direttamente al Gruppo di Supporto della TMA Italiano.

Federica non ha un parente affetto da MT ma ora può contare sull'amicizia sincera di molte persone che fanno parte della nostra comunità! E' meraviglioso che ci siano al mondo persone che come lei si mettono a disposizione del prossimo.

Se sei un nostro associato e risiedi in Italia ti preghiamo di contattare Federica e di partecipare anche tu alle attività comunitarie. Abbiamo bisogno del tuo aiuto!

Grazie Freddie!

Federica Boiani
Via Anapo 29
00199 Roma
Italia
+39 (0)6 8547 829
+39 347 9978295
federica_boiani@yahoo.it

Italy

About one year ago Jim, our IT Director (and our entire IT Department), posted an ad on a web site seeking volunteers to help us translate information from our web site and newsletter and journal articles. As the TMA is an international organization and our members are from more than 80 countries around the world, providing information in as many different languages as possible is an integral part of our association goals.

Federica Boiani responded to our advertisement and has since translated a tremendous amount of information into Italian. Her help has been critically important as we have a growing number of TMA members from Italy

and most of them do not speak or read English. What is unique about Federica is that neither she nor any of her relatives is affected by TM, ADEM, NMO or ON. Federica simply volunteered, because she was seeking an opportunity to do good in the world and to help other people.

The TMA receives numerous emails mostly from newly diagnosed people who do not write in English, seeking advice and guidance about their medical care. We are always looking for translators to help us in providing accurate information and facilitating these communications.

Federica graciously volunteered to help us to communicate with people from Italy. Through these regular interactions with TMA members and her translation work, she was learning more and more about the rare neuro-immunologic disorders. She recently attended the UK TM Society Symposium and met Dr. Kerr. She learned a great deal more about these disorders and had the opportunity to meet many of our UK members.

Recently, Federica took on the responsibility of printing and mailing the TMA materials to our Italian members from the UK TM Society. She is continuing to translate as much information as possible from our website and publications into Italian. Federica cannot and shouldn't have to do this work alone. We need for you to get involved in working with Federica. This participation is even more urgent now as she has initiated the process of formally establishing a TMA Support Group in Italy. She has begun the research and preparations required to accomplish this goal. She will need for all of our Italian TMA members to actively participate and share in the responsibilities.

We hope that the Italian TMA Support Group will become a reality in the near future, and will become self-

supporting. We would like for our Italian member's contributions to be able to cover all of the printing and mailing costs within Italy. To that end, we are asking that all donations made to the TMA by our Italian members be made directly to the Italian Support Group.

Federica doesn't have a family member with TM, but she does have many close friends from the TMA community! We are thrilled and grateful for her willingness to get involved in the TMA, and pleased to have met someone that cares so much for other human beings. If you are a member from Italy, please get in touch with her and please volunteer to get involved. We need your help!

Thank you, Freddie!

Federica Boiani
federica_boiani@yahoo.it

Michigan

Hello fellow TMer's. We recently had a support group meeting at the Old Country Buffett in Jackson, Michigan. There were only five of us in attendance, but we all had a great time getting to know each other and exchanging information.

Prior to the meeting, I attempted to contact as many members as I could either through emails or the message forums. If you were not one of the members that I contacted, please get in touch with me and give me your contact information. Support Group Meetings will be scheduled approximately every six months, the next one being in January 2008. I am currently seeking suggestions for a location for this meeting. If you live in Flint, we are considering having this next meeting in your area, and I would love to have your help in making the arrangements. I also need to hear from people regarding the best times and dates to

schedule this meeting. Please get in touch with me.

I would also like to take this opportunity to thank those of you who responded to my request for members willing to be contacted by area hospitals when the need arises. Over the past year I have received several requests from family members of newly diagnosed people who are still hospitalized and seeking information or just someone to share conversation and support. If you are interested in getting involved in this important project, please let me know and please provide me with your contact information. I hope that you will consider getting involved.

Lynne Myers
lynnemyers1@yahoo.com
(269)420-4144

Montana

Hello. My name is Desiree Van Blaricom and I am the mother of a 21 month old boy, Isaac, who was diagnosed with TM at six months. I am writing to tell everyone that we will be starting a support group in Montana. Sandy has been very kind to help when I had my toughest questions and was able to direct us down the right path. So when he asked if I would be interested in starting a support group here, I was very happy to help.

I am excited to report that we have already had a TM meeting here in Montana, even before we have a "support group" set up. Debbie Capen, the secretary of the TMA, came to Missoula, MT in October and she asked if I would invite the TM members here. I was able to contact people over the phone and through emails and we had a lunch with three adults and two children. That was close to half of all of the TMA membership in Montana! It

was great to sit down and hear each other's stories and what they are going through now. This was especially helpful for me as my little guy doesn't yet talk and can't tell me what he is feeling. So, thank you so much to everyone who attended; we hope to meet with you all again soon.

As for my son, we are fortunate that he is recovering slowly and walking with a little walker. He works very hard at physical therapy and to his benefit (or maybe he doesn't think so), his mother is a physical therapist, so he also works hard with me at home. Isaac's symptoms came on very fast. I was with him at noon and he was fine; when I picked him up at 5 PM, he was not sitting up or moving his legs. Also, his left hand was not opening all the way. We brought him to the ER and they diagnosed him with a sore throat and being lethargic. They told us to take him home and to watch him. I wish I could tell you that we brought him back the next day; but we continued to wait for him to get better, as he still had reflexes and responded to noxious stimuli.

The following day we brought Isaac back to the hospital. They did an MRI and diagnosed him with TM. And at that time, we had no idea what we were going to be dealing with 15 months later. Even as a PT, I had never heard of TM and I did not understand how devastating it can be. He did receive his six month shots one week prior to being diagnosed. Other than the sore throat, he had not been sick before he got TM, so we are concerned about giving him his immunizations due to fear of a set-back. At this time, we are working on him standing alone, one handed walking, and hip, knee and ankle control. Please pray for Isaac as he has shown great gains with prayer.

My goal with starting this support group is to help even one person find direction and answers in a very con-

fusing and hard time in their lives.

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

New Jersey

My name is Robert Pall and I live in Central New Jersey. I was diagnosed with TM a little over ten years ago. I found it startling that a state as large as New Jersey does not have a support group. Therefore, I am volunteering to start one.

The onset of TM hit me one week after my 50th birthday. It started with a slight tingle in my right thigh and within several hours I was totally paralyzed from the waist down. I had zero feeling in my legs, but nevertheless, I thought I must have pinched a nerve or something else quite treatable. How wrong I was! First of all, I never heard of TM nor did I understand what it had done to me. Living in the New York area, I was lucky to have access to premium medical care. That being said, I was immediately put on 1000 mg per day of steroids, which I imagine prevented my condition from being worse. I was transferred after a week from my hospital in New Jersey to Columbia Presbyterian Hospital in New York City, and was finally diagnosed with TM. The diagnosis was made after two spinal taps and three MRI's. The third MRI showed the lesion on my spine.

After two weeks at this hospital, I was transferred to Kessler Rehabilitation in New Jersey (the same rehab hospital that cared for Christopher Reeves). I remember asking the doctor if I would ever walk again. She told me that she thought that I would, but didn't know if I would need some assistive device (e.g., walker or crutches) to do so. While at Kessler, I developed a clot behind my right knee which broke and

caused me to have a pulmonary embolism. After a week of being treated at a nearby hospital, I returned to Kessler. I remember thinking how great it would be if I could just use a walker to be able to make it to the bathroom by myself!

After a few weeks, I was using a walker, and by the time I left Kessler (after ten weeks), I was able to get around with a quad cane. I was very excited that I had started to see some improvement almost everyday. I was convinced that if I worked real hard, I would become "all better." Well, as most of us realize, we do not get all better. We simply become better adapted to dealing with the condition.

After one year, no matter how hard I tried (physical therapy, exercise); I could no longer see improvement. This caused me to become extremely depressed to the point of needing medication (Paxil). I was having a difficult time coping with the realization that I was not going to get "all better." I found it so frustrating that nobody understood what had happened to me, nor had anyone heard of TM. Consequently, as my walking improved, everyone thought I was cured. They thought that my just having a limp was not that terrible. What they did not understand was that as my walking got better, I was now experiencing pain, numbness, pins and needles and excessive banding. I did not see this coming! I never realized that when some feeling returned that this feeling would be horrible; and it remains so to this day.

After six months I returned to work. I am an accountant and have a desk job. I would not have been able to perform physical labor. I also re-dedicated myself to exercise and getting myself into the best shape I possibly could. Probably the best thing I did after one year was to see Dr. Kerr

at John Hopkins Hospital. First, he was able to confirm that I do indeed have TM. He also prescribed various medications which he has adjusted or changed every year I see him. I do make sure to see him once a year and Dr. Kerr is the only neurologist I see.

I consider myself one of the lucky ones with TM. I am still able to work and drive; I am on the road more than two hours per day. I walk with a limp, but use no cane or other device. As many of us understand, the pain or discomfort is with us 24/7. Until a cure is found, I basically try to stay in shape and treat my condition with medications that either reduce the discomfort or aid my walking.

I try to maintain a positive attitude. I never (well almost never) ask "why me?" I am often embarrassed by my condition, even though I know it is silly to feel this way. Regardless of whether it is real or imagined, it bothers me that I might be seen by others as disabled. So I try to walk and act normally. Walking "normally" takes a great deal of effort, and I fatigue very quickly. Fatigue has been one of my most difficult problems. It frustrates me that no one, including my wife and family, understands how much more difficult all of our lives have become. They may say they understand, but unless you walk in my shoes, you cannot truly understand.

The TMA website has been an enormous help for me in understanding the condition and how best to deal with it. Many members have helped me with advice and understanding. After ten years, I hope I can share my experience, help and hope with other members, especially the new members, as other TM'rs have helped me!

Robert "Rob" Pall
4 Victoria Court
Morganville NJ 07751
(732)536-5308
robthecfo@aol.com

South Africa

Jenny Moss

I've been a member of the South Africa TM Support Group for a number of years. I was only able to find out about TM and the support groups after I got onto the internet. Receiving that first TMA Newsletter from the States and being able to read about TM and other members' stories was such a thrill! Prior to getting the internet, I really had no idea if there was anyone else in South Africa who had TM and I really felt that no one understood me and what it was that I had gone through.

I got TM when I was nine years old and for me it happened overnight. I went to bed with a fever and my body feeling sore all over. No matter what position I lay in, with my head on the pillow or off the pillow, I was just uncomfortable and sore! I eventually fell asleep. I woke up that Saturday morning feeling fine and ready for the day, as you do as a nine year old. I swung my legs off the bed and thought it strange that I couldn't feel the carpet. I tried to stand up, but I couldn't! And that's where my love-hate relationship started with hospitals and doctors.

It was nearly four or five weeks before they came up with a TM diagnosis and by then the damage was done. I was simply taught how to look after myself and sent home to get on with life. 1980's - good times I tell you. I was at the time completely paralysed from the waist down and really feeling all alone. I am, however, very thankful for some of the movement and sensation which did return all on its own during the following years and without ever receiving any kind of medication.

Once I got that all important internet and was able to search for the mystery illness called Transverse Myelitis, and

actually finding out that there are thousands of other people from all over the world who have had similar experiences as myself, I just somehow felt better and not so alone. And that feeling I had when I found out about TM and the support that is available is what has kept me motivated and then willing to take over as a support group leader from Tanishka. Tanishka started the South Africa TM Support Group and single handedly arranged the very first TM SA get together! Now that was an awesome weekend! Meeting other members, exchanging war stories and talking medication was a real trip.

I'm just so thankful that Mart Uys has been willing to take on this challenge with me. Mart and I share the responsibilities of being support group leaders in South Africa. Her knowledge and willingness to help others has impressed me time and again. Mart knows more about TM than I do! (Mart's daughter has TM). I just live life as someone who has TM. I would not have been able to continue without Mart's help; that's for sure! Every new member that finds their way to us is to me such a blessing and sending off those new member packs is such a satisfying feeling. And, hopefully, that member pack will make that new member feel a lot less alone.

Jenny Moss
PO Box 3865
Tygervally
Cape Town, 7536
South Africa
082 928 3000
moss25@mweb.co.za

Mart Uys
397 Central Park Ave.
Lynnwood, 0081
South Africa
012-361-7671
martuys@iburst.co.za

Sri Lanka

I am announcing the initiation of a TM Support Group in Sri Lanka. My name is Ivan S. Fernando. I got TM on 29th April 1993. I had just turned fourteen years old and was in the tenth grade at school. My health was fine.

It was a Sunday morning. I had the strongest headache that I had ever experienced. I could barely open my eyes. So I slept on the floor and I felt that my left leg was becoming paralyzed. I stopped urinating and couldn't walk at all. That Sunday totally changed the meaning of my life. I had the worst pain ever in my back. From that morning onwards, I couldn't get up on my own for nearly one and a half years.

I was rushed to the hospital emergency room. The doctors performed a number of tests and finally diagnosed me with TM. They then transferred me to a rehabilitation hospital where I received physical therapy for about seven months. I was doing pretty well with my leg then. I returned home from the rehabilitation hospital in 1995.

I returned to my studies. I am currently working as a Customer Service Assistant in a world-recognized INGO. I am married, I am happy and I have a good life. My family members who were so worried about me in those early days of getting TM are now very proud of the way that I am living my life.

Today, I have a full and normal life. I work, travel and do things I once thought I would never do again. While I was searching for information on my symptoms, I came across the TMA. I was thrilled to read about it and to discover that there were others like me.

Today, I am very happy to announce

that Sri Lanka will have a TM support group.

I really hope that we can make a difference in the lives of those patients affected with TM, ADEM, NMO and ON. I encourage all those SRI LANKENS to reach out and contact me. We can all learn from each other. Please feel free to contact me anytime. **I would love to see SRI LANKA have a very active support group!**

G-d bless you all.

Ivan S. Fernando

ivan_s_fernando@wvi.org

+94773451279

Virginia

TM Awareness Day

Mark Warner was the governor of The Commonwealth of Virginia when I first began my quest to write a resolution for a TM Awareness Day. I began my research into establishing a Virginia awareness day with a conversation with Pam Schecter, the TM Support Group Leader in New York. Pam was able to get a New York resolution passed through their state legislature. My work began with the New York awareness resolution. Pam and I had numerous conversations and she offered me excellent guidance through the process.

After I started working on the resolution, I had two brain surgeries, Tim Kaine became the new Governor of Virginia, and Ohio and Australia passed TM awareness days. Finally, after many drafts and many years of hard work, Governor Tim Kaine signed the Virginia TM Awareness Day resolution. (A copy of the resolution appears on following page). TM Awareness day was established as June 6, 2006 to coincide with the date previously set in New York, Ohio and Australia. We must now move for-

ward and demand the recognition we have worked so hard for through education and fundraising.

Three Virginia Support Group Chapters

The Virginia TM Support Group now has three chapters! We are very excited to be able to provide more local contacts for people across the state. We have a SW Virginia Chapter, which covers west of Charlottesville. Drema O'Dell leads this group. We also have an Eastern Shore Chapter, which is led by Agnes Killough. Agnes does a wonderful job working with Dr. Paschal, a physician from a small rural community on the Eastern Shore. Dr. Paschal asked Agnes to start this support group! Agnes has been extremely helpful and a very important part of *my* life as I recover from my brain surgery and stroke. She has stepped in and taken responsibility for the Virginia TM Support Group when I needed time to focus on my own rehab and recovery. Agnes has offered me a great deal of support through my difficult times; thank you my dear friend. I don't think I tell you enough how important you are to me and to all of us.

Virginia Bowls Over TM!

The Virginia TM Support Group is planning an awareness and fundraising event. We hope that we can get many of our members involved in this important activity. You will hear more about it at upcoming meetings.

And if you live in Virginia and have not yet participated in our support group activities, please get in touch with Drema, Agnes or myself. We would love to hear from you.

Please keep all of your contact information current! If you change your

address, phone number or email address, please send those changes to Sandy Siegel and please also send the changes to me at pnew@myelitis.org. G-d Bless.

The TMA Equipment Exchange

Darian Vietzke

Please get involved in the TMA Equipment Exchange. You will see the link to the Equipment Exchange on the column of links on the main page of the TMA web site. The program is intended to assist our community in exchanging surplus equipment with each other for the cost of shipping only. 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. If you have any comments or questions regarding the TMA Equipment Exchange, please send an e-mail to exchange@myelitis.org. Thank you for your support!

Please Keep Your Membership Information Current

Please keep us informed of any changes to your mailing address, your phone number and your email address. To let us know about any changes, please fill out a change of information form on the TMA web site: <http://www.myelitis.org/memberform.htm> – just click on the box indicating that you are changing existing information.



CERTIFICATE of RECOGNITION

By virtue of the authority vested by the Constitution in the Governor of the Commonwealth of Virginia, there is hereby officially recognized:

TRANSVERSE MYELITIS AWARENESS DAY

WHEREAS, Transverse Myelitis, a disease affecting some 34,000 Americans, is not widely recognized by the medical profession or the general public as being a serious spinal cord condition; and

WHEREAS, Transverse Myelitis can affect a person in a variety of different ways, affecting the neurological system as the spinal cord may become inflamed, a condition that can occur as a single condition or in the presence of an existing illness; and

WHEREAS, symptoms can often be physically exhausting and often include back pain, numbness of the lower extremities, and headache; and

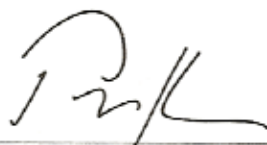
WHEREAS, recent findings have indicated that the incidence of Transverse Myelitis has risen nearly four hundred percent, with 1200 to 1400 new cases being diagnosed each year;

WHEREAS, the Transverse Myelitis Association (TMA) is a not-for-profit organization that advocates for people with immunologic diseases of the central nervous system and has continued to grow in membership over the years;

WHEREAS, it is important that citizens across the Commonwealth become more informed about this disease in order to help better educate the public, physicians, and other members of the medical community on the specific needs of Transverse Myelitis patients;

NOW, THEREFORE, I, Timothy M. Kaine, do hereby recognize June 6, 2006 as **TRANSVERSE MYELITIS AWARENESS DAY** in the **COMMONWEALTH OF VIRGINIA**, and I call this observance to the attention of all our citizens.




GOVERNOR


Secretary of the Commonwealth

The TMA Newsletter and Journal Archives

The TMA announced a new publication schedule and format for our newsletters and journals. A newsletter will be published each fall and spring, and a more extensive journal will be published in January of each year. When people sign up for membership in the TMA, they receive a packet of information which contains the most recently published TMA Journal. The newsletters are not included in the new membership packets.

We encourage people to read the previously published newsletters and journals. They are an excellent source of information about the neuroimmunologic disorders, both through articles written by medical professionals and by people with these disorders and their family members, which describe their personal experiences. Through these publications, you can also learn about research and clinical trials, the TMA, awareness and fundraising efforts, and the support groups around the country and around the world.

All of the newsletters and journals are archived on our web site; you can find them under the link 'newsletters' on the main page of our web site or you can type www.myelitis.org/newsletters/index.html 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

Contacting the T M A 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!

Purchase Seasonal or Anytime Cards from Café Press and Support the T M A

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

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

Honor the Children in Our Community and Support the T M A

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

The workshop offered the children an opportunity to have a fun weekend. One of the many activities they participated in during this special weekend involved working with an art therapist from Chicago, Lori Stralow Harris. With the help of Ms. Harris, the children created beautiful

paintings which were constructed into a quilt of courage and hope. The original artwork currently hangs in the Johns Hopkins Transverse Myelitis Center where it is appreciated by the hundreds of patients every year who are cared for at the Center.

We are very pleased and proud to be able to offer you the children's artwork through Café Press. The proceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. We hope you will take the opportunity to enjoy the children's work and to support the TMA.

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

Helping to Fund the Work of Your T M A

The TMA does not charge membership fees. We operate exclusively on the basis of the generous and voluntary support of our members. There are numerous ways for everyone to help support the TMA, even if you are not in a position to make a financial contribution. Please consider getting involved in one of our fundraising efforts.

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>

Inkjet Recycling

The Transverse Myelitis Association has partnered with a recycling company to collect and recycle empty inkjet printer cartridges, and empty toner cartridges from laser printers and copiers. All you have to do is visit the TMA inkjet recycling page at: <http://recycle.myelitis.org>

Awareness Wristbands

You can show your support for The Transverse Myelitis Association and help raise awareness by ordering wristbands. To order using PayPal or by credit card, please log on to the web page at: <http://www.myelitis.org/wristbands.htm> You can also order the wristbands by sending an email to: wristbands@myelitis.org or call (951) 658-2689.

Online Shopping

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

iGive.com

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

Café Press

You can purchase TMA logo items through Café Press.

Amazon.com

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

eBay

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



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

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

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!

Medical Advisory Board

Gregory N. Barnes, M.D., Ph.D.

Vanderbilt University
Nashville, TN

James D. Bowen, M.D.

MS Center at Evergreen
Kirkland, WA

Benjamin M. Greenberg, MD, MHS

Johns Hopkins Hospital
Baltimore, MD

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Johns Hopkins Hospital
Baltimore, MD

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Johns Hopkins Hospital
Baltimore, MD

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The Ohio State University
Columbus, OH

Frank S. Pidcock, M.D.

Kennedy Krieger Institute
Baltimore MD

Officers and Board of Directors of The Transverse Myelitis Association

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

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

Honorary Board of Directors

Deanne Gilmur
Founder

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

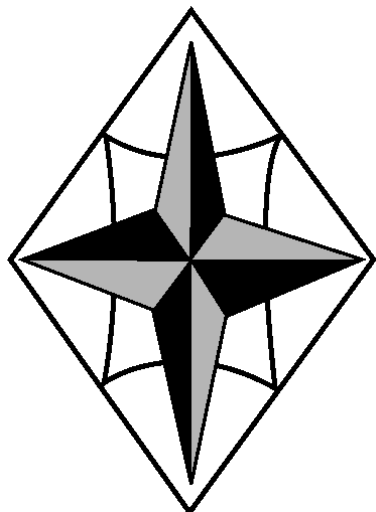
Jim Lubin
Information Technology
Director
jlubin@myelitis.org

www.myelitis.org

The Transverse Myelitis Association

Powell Ohio
43065

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



TMA California Meeting, Saturday, February 23, 2008
Drs. Adam Kaplin, Douglas Kerr, Charles Levy, Frank Pidcock

2008 Rare Neuroimmunologic Disorders Symposium,
Seattle, July 16-19

Young Adult's Autumn Retreat: October 24-26, 2008,
Victory Junction Gang Camp, Greensboro, NC
