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From the Editor
Sandy Siegel

Pauline was placed with a Service Dog from Canine Companions for Independence.® CCI is a wonderful organization headquartered in Santa Rosa, California. Pauline and Kazu went through extensive training and passed their public access testing in August. Kazu was born in California; he is a mixed lab and golden retriever. A wonderful family from California cares for Kazu's Mom; the breeder caretakers are volunteers. When the puppies are old enough, they are sent across the country to another group of amazing volunteers, the puppy raisers. The puppy raisers care for the puppies until they are old enough for advanced training, which is done at one of CCI's five regional centers. The puppy raisers carry out a regimented program with the dogs which includes socialization, teaching the dogs more than 30 different commands and offering lots of care and love. There is a regional center located in Delaware, Ohio. Through the efforts of a compassionate and remarkable woman who works for the Ross Correctional Institution, there are inmates at the prison who have the opportunity to be puppy raisers for CCI. Kazu was raised at RCI. I wrote to Kazu's puppy raiser just before Christmas and we received a letter from Doug shortly thereafter.

December 12, 2007

Dear Doug:

My wife, Pauline, was placed with Kazu, a Service Dog from CCI. We live in Columbus, Ohio. Pauline began the application process in 2006. Pauline was placed with a truly astounding dog and Kazu has been placed with a person who has significant need and will provide Kazu with the home he so much deserves. Pauline and I met your Mom and Dad at the graduation in August; and we met Denise. It was a thrill and very emotional for us to meet them. There were lots of hugs and tears. We have talked about writing to you from that Saturday afternoon when we graduated and met your family. I am glad that I waited until now to write to you. In August, I would have been able to say thank you. After watching Kazu and Pauline work together over the past four months, I can say so much more about the incredible foundation you provided for this really wonderful, loving and sweet dog. Pauline and I think of you often, Doug, because we know that what Kazu is today derives in very large part from the love, care, devotion and training that you provided to this truly remarkable creature.

Pauline was totally paralyzed from the waist down on Sunday, July 29th 1994 at 5:30 in the evening. Pauline was a healthy 35 year old woman. That instant was the last time Pauline was able to feel normal sensation in her lower body and the last moment she was able to move her muscles in a normal way below her waist. Pauline was given a diagnosis of transverse myelitis.

Over a period of two years, Pauline had some recovery. She lost most of the muscle function down her lower back and down through the back of her legs. So, Pauline can bend over, but she can't get back up. Pauline is able to walk with canes, and if we go to a mall or museum or some other place that involves a lot of walking, she uses her wheelchair. Pauline has adjusted to her physical limitations and manages to lead a very good and productive life.

But there is much that Pauline can't do, and she had pretty much accepted that these limitations were just a fact of life. We never even thought about a Service Dog. We had a dog for many years that died when she was 16 years old. Losing her was so difficult for us that we really didn't give much thought to having another dog. Then one of our friends got a Service Dog. It was really fascinating to see what these dogs were able to do.

I urged Pauline to think about applying to CCI for a Service Dog. She thought about it for almost a year before she decided that she would look into applying. We made an appointment with one of the trainers in Delaware and I went with Pauline to meet her and to discuss the process. It was a great meeting, and Pauline decided to begin the application process. After many months of filling out applications, getting physicians to provide medical information, after a phone interview and an in-person interview at CCI that included working with some of the dogs along with other prospective candidates, Pauline began the months of waiting to hear back from CCI as to whether she was accepted into the program. CCI wants to ensure that they are making the right placement – that the Service Dog can enhance a person's quality of life, and that the person will be able to provide proper care for the dog. Finally, last October, Pauline received the wonderful letter from CCI notifying her that she had been accepted and that she would be

placed on the waiting list. We were very excited, but we also knew that the wait for a dog could be up to two years. So, we dried our tears of happiness and went into the wait mode.

There are four training classes during the year. One of those classes is in August. The CCI folks knew that Pauline was a school teacher and that she wouldn't have to take off from work if they had her in this class. The people at CCI are just the most sensitive, kind, compassionate people. I just had a sense that they weren't going to ignore Pauline's teaching schedule and that they would do what they could to accommodate her, if it was possible. Sure enough, at the end of the school year, Pauline received notice from CCI that she was going to be accepted into the training class that would begin on August 6th. Pauline told me that she wanted for me to attend the class with her – to support her efforts and also so that I would know how to behave with or care for the dog, should the need arise. I was more than glad to do this. CCI sent Pauline a large packet of materials. She spent the entire summer learning this material and memorizing much of it.

Finally, August 6th arrived. Pauline was very excited and very nervous. The training classes are Monday through Saturday for two weeks and the classes last from about 8:00 in the morning until late in the afternoon. There is a great deal of lecturing, covering a lot of information about behavior, training, and health and care issues. And then there is a lot of working with the dogs. There were ten people in the class who were being placed with Service Dogs. A few of the people were receiving successor dogs. There were children and adults. It was a wonderful group of people, and everyone became very close over the two week period. There is a lot of mutual support during the Team Training. And the instructors are just amazing. They are such caring people. They are totally committed to everyone succeeding – the people and the dogs. All of the Service Dogs in the class were lab-golden mixes except for one who was a pure bred lab. All of the dogs were males and they were all black. It was very difficult to tell them apart except for Kazu! You could always identify Kazu from the scar on his nose.

Monday started with a lecture and then later that day we were introduced to the training room. When we arrived, the dogs were in the down command in the middle of the floor. The students made a large circle around the room and the dogs were "handed out" one at a time to the students. For the first two days of training all of the students worked with all of the dogs. The CCI trainers spent the first two days observing everything and marking comments on a clip board. There were four trainers involved in this process. They were keeping track to ensure that every student was working with every dog and they were also making close observations about how each student was working with a particular dog. We didn't know this at the time, but they have an idea about placements before the class begins. The trainers know the dogs intimately from the many months of advanced training. They know students well from the application and interview process. They are totally committed to making the right match.

The first dog Pauline was given to work with on that Monday morning was Kazu! The first thing they did with the dogs was to say their names and make sure that the dogs gave them their full attention. Once they got the hang of this, they started giving them the "let's go" command. The students moved in a circle around the room with the dogs. Pauline walked with her canes. The rest of the students were in manual and motorized chairs. The dogs walked along side each person. Some people worked alone and some people had a spouse or a parent working with them. Pauline was working alone – I always observed and stayed away from the dogs. Every once in a while, they would have the dogs go into the "sit" command or the "down" command. Kazu listened to Pauline so obediently from the very first time they were together. He looked at her when she said his name, and he complied in every way. He never forged ahead of her and Pauline moves very slowly with her canes. His head was always on her hip. On those very first trips around the circle, Pauline looked at me and mouthed, "I want this one." I just smiled and thought, "Yikes; they are going to place Pauline with any one of these ten dogs and she's getting emotionally attached to the dog she's just spent five minutes with."

The next thing they did was to teach the students how to do a correction. That was difficult for Pauline, but she learned when and how to use it. On Tuesday there were lectures, they introduced the students to a new set of commands and then the students worked with the dogs. Each student would work with a dog for about 15 minutes or so and then they would switch all of the dogs. This must have been an incredibly stressful experience for the dogs. Some people spoke very softly, some people weren't giving the commands – a parent was doing this. Some dogs had two sets of leashes on them (for a parent or spouse). Pauline walked with canes very slowly, the people in manual chairs were a little faster, and the motorized chairs were faster still. Each student had their own way to correct and their own way to praise. And yet the dogs did their thing. It was just amazing to watch these incredible animals totally adjust to their new circumstances every 15 minutes.

We were told that the placements were going to be made at a ceremony on

Wednesday morning. Before we went home on Tuesday night, the trainers gave each student a piece of paper and were asked to write down the names of three dogs – their first, second and third choice. During the course of the first two days, Pauline had worked with Kazu many times; probably more than any of the other dogs. I think Kazu might have actually been the last dog Pauline worked with on Tuesday before she was given this assignment. She sat with the paper in front of her, looked at me, and said, "My first choice would be Kazu." She then wrote down two other choices. There would have been no bad placements from this group. I had no doubt at all why Pauline put Kazu at the top of her list. In addition to doing everything she ever asked of him, he was such a sweet animal. He was so eager to please and he did everything he was told as he was taught to do it. If he wasn't doing it, it had much more to do with being confused than with being obstinate. He was a great dog and he would have been a perfect match for Pauline.

We went to training on Wednesday morning and the room was filled with anticipation. After going through so much effort to apply and the long waiting period, it was going to be only a matter of minutes before being placed with the companion with whom each person would form the most intimate and emotional relationship. There was a lecture to start the day, and then we were told to go into the training room. Everyone filed in and formed a circle around the room. The dogs were lying down in the middle of the floor. The placement ceremony was conducted by the two primary trainers in our session. The other trainers stood behind the circle of students and joined in the proceedings. One of the trainers started the process. She went over to the first dog and took the leash. She made a short statement about who the dog was and where he was going to be placed. She walked the dog over to the person and handed them the leash. One by one, each of the dogs was led over to the person in the circle and was handed the leash. Each placement was announced and followed by lots of applause and hugs. About midway through the ceremony, the trainer went over to Kazu and picked up his leash from the floor. He walked out of the circle, said that this was Kazu, and that he would be staying in central Ohio with Pauline Siegel. Pauline was sitting in a chair, and he handed her the leash. She immediately burst into tears and hugged Kazu around his thick neck. She held onto him and cried through at least one of the next placements. I went over to Pauline and gave her a big hug; and then I gave Kazu a big hug.

The rest of the week continued using the same structure of training. There were lectures, new commands would be introduced and then the students would go into the training room with the dogs and practice the new series of commands, as well as work with ones previously learned. Sit, down, heal, side, jump, up, get, hold, give, under, dress, get the leash, tug, kennel …. It is amazing how much these dogs know how to do and how well they do each of their commands. The light and switch command is totally amazing. I don't know if you were involved in teaching these commands. If you weren't, the dogs turn on the light by jumping up on the wall and straddling the switch plate with their paws. Then they turn the light on by moving it up with their nose or mouth. That is the light command. The switch command is done with their paws; they paw down the light switch. Kazu is a champ at this.

During the two week session, they also spent a lot of time making sure that when the dogs were with their person, they would not be distracted by anything. There is a rabbit in the training facility and the dogs have to ignore it. Then they sprinkle food all over the place and the dogs have to ignore the food. Can you imagine Kazu ignoring food? He does! They ran all sorts of toys and noise makers around the dogs and they had to ignore all of it!

On the Friday at the end of the first week, they sent us home with the dogs for the first time. Each person would take their dog home each evening and on the weekends for the rest of Team Training. That morning, they worked on the "car" command; getting the dogs in and out of the cars and getting their leashes tethered onto the seat belts. So, we borrowed a crate from CCI and went home with Kazu. Over the weekend, we went to a pet store and we got Kazu two nice crates; one for home and one for Pauline at work. Pauline also bought him great beds. She spent more money on Kazu's bedding than we spent on our mattress and box springs. He has one of these beds in the bottom of his crate and he also has a very large bed in our living room.

He loves his crate and he sleeps in it every night. CCI told us to have Kazu sleeping in his crate with the door closed when we first brought him home. Pauline follows all of the CCI instructions carefully. After about a month, when Pauline was certain that Kazu was acclimated, she decided to leave Kazu's crate door open and to let him come and go as he wished. He sleeps every night in his crate. It is in a very safe and warm place in the winter and cool in the summer. It is enclosed in the corner of two walls, so he feels very much like he is in a den which must make him very comfortable. While he could go anywhere, almost every morning when I come to get him, he is in his crate and he doesn't leave it until I am tying my shoes and he knows he's going out. He gets up, shakes out, stretches and puts his head into my lap. Even during the

day, if he is really tired and wants to sleep and be left alone (and Pauline doesn't need him for something), he goes into the crate. When he was living at CCI during advanced training, he was in a kennel with a cement floor and he was fine. So the bedding Pauline got him was a very serious upgrade in sleep surface.

It was really interesting how Kazu handled being in the house for the first time. He didn't seem interested in the second floor and he's never been in the basement. He didn't check out the house. Kazu has never chewed on anything that didn't belong to him. He has been absolutely wonderful from day one.
There were more commands and more field trips the second week. On Thursday of the second week, they took everyone to the mall for a public access test. Pauline was so nervous. She and Kazu were great and they passed the test. It was amazing how well Kazu responded for as stressed out as Pauline was. You would have been so proud of him, Doug. He did all of his commands so well.

During the second week of training, we observed something amazing. We had just heard a lecture about dominance, submissiveness and the natural order in a pack. They brought us into the training room and all of the dogs were lying on the floor in the middle of the room – there were no leashes on the dogs. They told us they were going to let the dogs play and they wanted for us to observe their play behavior and how the dogs related to each other. They told the dogs "release." What happened next was absolutely astounding to us. This collection of totally well behaved, docile, responsive dogs went totally berserk. It was sheer mayhem and they all ran wild with each other – except for Kazu. Kazu backed his way out of this mayhem and stood behind the trainers who were outside of the circle. A trainer would find Kazu and would try to coax him into the play. Kazu would just move his way behind another trainer. Pauline and I felt horrible. We were so concerned that Kazu wasn't interested in playing.

On the last day of class, Pauline was told that she passed the public access test with Kazu and was given a temporary license. Pauline has a liaison with CCI who she is in regular contact with; this person is there to help Pauline, to answer questions, to assist with training new behaviors. She does follow up interviews with Pauline and checks on Kazu's weight, general health, and any behavioral or routine issues. The support Pauline receives from this person and from CCI is outstanding!

Pauline and Kazu graduated from CCI on Saturday, August 18th. The graduation was at a community recreation center. We brought Kazu to the center early Saturday morning. They had a really nice breakfast and it was arranged so that we could spend this time with the puppy raisers. But before the breakfast, they took Kazu from Pauline out to your Mom and Dad and to Denise to spend time with him before the breakfast and the graduation ceremony. After your Mom and Dad and Denise had their special visit with Kazu, they met us for the breakfast. There was a photograph of Pauline and Kazu on the table. I hope you have this, Doug, or have seen it. Pauline and I both hugged your Mom and we all cried … a lot. We have a sense about how emotional this moment was for her and it was for us, as well. Denise shared some photographs of you and Kazu with us – it was really great to see you with Kazu! We spent about an hour with your Mom and Dad and Denise during breakfast. We talked about you and we talked about your experiences with Kazu and thanked your Mom and Dad for the miracle that you brought into our lives, Doug. We tried to share with your Mom and Dad as best we could how grateful we were for your selfless gift of Kazu to Pauline!

After breakfast, we went into the auditorium. The ceremony started with the next group of puppy raisers bringing their dogs to CCI to be given over to the trainers to begin their advanced training. The CCI staff presented each of the puppy raisers with a bouquet of flowers and a big hug and the dogs were handed over to the staff. I just cried my eyes out during this entire part of the ceremony. I'm sitting here crying while I write about this. It just so totally blows me away what a selfless and incredible act of kindness people such as you participate in to make a better life for someone else.

After the puppy raiser ceremony was completed, they began the graduation of the August training class. One at a time, the person (who is receiving the Service Dog) was introduced and then the puppy raiser brought their dog down from the audience and presented their dog to them. When it came time for Pauline's turn, she walked her way to the middle of the stage while the trainer introduced her. Then they announced his puppy raiser and your Mom and Denise walked Kazu down from the audience onto the stage. Your Mom handed Kazu's leash to Pauline and she gave Pauline a big hug. Denise also hugged Pauline and they went back to their seats. After all of the people were matched with their companions, Pauline came up to the podium to give a speech. Her classmates selected her to talk about their experience in Team Training, which she did. She gave a wonderful and very emotional speech while Kazu lay by her side.

When the ceremony was over, your Mom and Dad and Denise came down onto the stage and we took some photographs together. It was really wonderful to meet your parents, Doug.

Pauline and I were so grateful to be able to share this incredible moment with them. And we were most grateful that in your absence they were able to bring a part of you into this experience.

We did not walk out of the ceremony and take Kazu home to live happily ever after. We walked out of the recreation center and handed Kazu to one of the CCI staff for them to take Kazu back to the training center in Delaware. After spending two weeks bonding with him, it was really difficult for Pauline to say good-bye. But there wasn't much choice. Pauline and I headed to the airport to fly to Victory Junction Gang Camp. We had a family camp beginning on Sunday that would last the entire next week. We had families with kids with TM come from all over the world. By the end of the week, from the combination of our experience with Team Training and then our week at camp with the families, we were emotionally spent. We were more than ready to be home and start our new life with Kazu.

Pauline picked up Kazu from CCI on Monday after we came back from North Carolina. He was very happy to see Pauline. I was instructed by CCI to totally ignore Kazu. Their instruction was for me to stay away from him for 3 months to a year so that he and Pauline could thoroughly bond. For the first month Kazu was at our house, I totally ignored him. I never said a word to him, I never made eye contact with him, and I never touched him. It was so hard, but I understood why I was doing it, and it was working really well, because Pauline was getting his undivided attention. I was certain that Kazu thought that I had some kind of personality disorder.

Over time I have developed a relationship with Kazu. I try to keep it fairly structured and I try not to give him too much affection (which isn't easy) so that he gets most of his loving from Pauline. I take him out for a walk first thing in the morning and then I walk him again when I get home in the evening. If the weather allows, I try to make this a long walk so that he is getting some exercise. He doesn't get much exercise with Pauline. He loves these walks. I had never seen a dog empty their bladder all at one time. The hurry command still totally blows my mind. And I never feed Kazu; only Pauline gives him his food. So, I'm basically the maid – for Pauline and Kazu.

I do give Kazu affection – he loves to lie under my feet while I am working at my desk on Saturday and Sunday mornings while Pauline is sleeping. I love this quiet time with Kazu. I'm not asking him to do anything, he has a full belly, an empty bladder and bowel, and he can just sleep – which is one of his favorite activities, after eating. They just don't come any sweeter than Kazu.

Pauline's school began the same week we returned from camp. CCI gave Pauline a video presentation and some materials to help her "teach" the children and the teachers and staff about Service Dogs and their responsibility to Pauline and Kazu, which can pretty much be summarized as "ignore the dog." So, from the very beginning, Pauline taught her second graders to not say his name, don't make eye contact with him and don't touch him. It is an amazing proposition, but her students totally ignore Kazu and Kazu ignores them! The teachers and staff are also great. The teachers have all worked with their students to ignore Kazu, since Pauline has lunch and recess duty and is around all of the students in the school throughout the day. Kazu is awesome; he does what Pauline tells him to do and he remains focused on Pauline in school (when he isn't sleeping). We set up a crate in her classroom and he spends a lot of time in his crate. Pauline also put a bed under her desk and Kazu will lie on this bed, as well. He spends the day with Pauline carrying things for her and I got a small wagon for him to use at school to "tug" things around the room. Pauline taught Kazu to tug this wagon for her all the way to the library to return books. Pauline's class photo came back and Kazu is in the class picture sitting next to Pauline. It is wonderful for Pauline to have Kazu with her all day long in her classroom. The other teachers and staff love having him in the school.

Kazu also picks things up off of the floor for Pauline. This is probably the most important thing he does. She is incapable of bending down to pick something up that falls. He can pick up anything! He is able to pick up a credit card! He can pick up paper. While this is the most important thing he does for Pauline, Kazu is rather particular about what goes into his mouth. I've owned dogs all of my life and I've seen dogs eat just about everything. The idea that Kazu might find some objects as too yucky to go into his mouth was a puzzling concept. So, we are working to both accommodate Kazu's issues with Pauline's needs. When she drops something, Pauline expects Kazu to follow the "get" and "hold" command immediately and then the "give" command. We've also figured out that he specifically dislikes metal in his mouth. Pauline's canes are metal and that is probably the number one item that falls and needs to be picked up during the day. I went to the hardware store and bought insulation material and duct tape. We wrapped Pauline's canes so that Kazu has something to grab that was not metal and was soft in his mouth. He seems more comfortable getting the canes. And Pauline is working with Kazu to be more responsive to picking things up ... without hesitating.

Obviously, we figured out that Kazu knows how to play and has a very fun

personality! Pauline first saw his playfulness and excitement around food. She feeds Kazu first thing in the morning. She would excitedly announce to Kazu that he was going to eat, and he would immediately go into a play bow and then spin around in circles and then would take off running like a crazed maniac. He would go sliding down the hallway until he got to his food bowl. We've seen this crazed and frenetic behavior in other situations. He loves to play; he loves to run and to fetch his toys. We found a football field near our house that is totally fenced in. I throw a Frisbee for him and a ball and he goes wildly chasing after it. He loves to pick it up on a dead run and then to run around the field. Kazu just gets this crazed look in his eye when he is running like this, and his ears and legs go flopping around in every direction at once. He is so big and fast. And, Doug, he walks in such a regal way – he prances. When we are out on a walk, I have had more than one person remark at what a beautiful dog he is.

We have tied ropes onto all of the drawers and doors that Pauline uses for Kazu to tug. Kazu opens and closes the doors in the bedroom every night for Pauline. She washed all of the throw rugs in the house yesterday, and Kazu tugged all of them for Pauline to the washer. Kazu is great at getting the laundry. I got them a plastic wagon for them to use at home like the one I got them for school. He tugs the laundry from the dryer into the living room so that Pauline can sit on the couch and fold it. If she drops any of the laundry onto the floor, Kazu is right there to pick it up. He also very quickly learned to retrieve Pauline's shoes. That was amazing. She gave him the command a couple of times and he seemed to know exactly what she wanted and brought her the shoes.

We have season's tickets with our sons for the Cleveland Browns. Pauline and I go to one game together. They have accessible seating in the stadium. Before the game, we went into a restaurant for breakfast. Kazu is awesome in restaurants. He lies under the table by Pauline's feet and he doesn't move or make any noise at all. He is so incredibly well behaved when we have him out everywhere! When he gets out from under the table, he always shakes and Pauline tries to get him to do this in a discrete way away from people. When we got to the stadium, they took us up an elevator to our seats which are out on a platform. We brought a blanket for Kazu to lie on and that was a good thing, because the floor was metal and it was cold. We also brought a bowl for water. The ushers were great; they brought Kazu his water and they kept asking us if we needed anything. People came down and wanted to pet Kazu and the ushers kept telling them that the dog was working and he needed to be left alone. Pauline and I just smiled at each other. Kazu ignored **everything**. 70,000 fans were screaming and going nuts. There was a speaker behind us that blasted incredibly loud rock music. The dog pound was directly below us; Kazu was definitely much better behaved than any of those dogs! And there was a football game being played directly in front of his face. Kazu totally ignored all of it. It was our first major adventure with Kazu and he made it so easy for Pauline.

Our next big adventure with Kazu was a trip to Boston. We went to a meeting the weekend before Thanksgiving. We booked the flight and told them we were flying with a Service Dog. They reserved bulkhead seating for us. I have to say that I was nervous about doing this travel. Our flight to Boston was at 7 am on Saturday. We got up at 3:30 and Pauline gave Kazu his breakfast. At 4:30 I took him outside to "hurry." We got to the airport and made our way to the ticket counter. Then Pauline got into a wheelchair and we headed to the gate. Going through security was interesting as they wanted everything off of Kazu – his service jacket, his collar and his leash. He listened to everything Pauline told him to do and he helped her by picking up her things and bringing them to her. The airline botched our getting onto the plane and didn't have us pre-board. We were in line with all of the other passengers; that was chaos. It was a small jet and there was no jet ramp, so we had to get Pauline up a flight of stairs to the plane – and Kazu. The stairs were horrible because they were steep and narrow – more like a ladder. Kazu was reticent to go up and the engines were on so it was very loud and he was confused. We finally got him up. Then when we got into the bulkhead, it was only two seats wide and the outer wall of the plane was angled in so there was not very much room for Kazu to lie down at Pauline's feet.

We got settled in and the jet taxied to the runway. Kazu was fine until the jet accelerated down the runway; the floor shook and then when the floor began to tilt at more than a 45 degree angle, Kazu sat up. He put his head in Pauline's lap and she reassured Kazu. He was fine. The landing also went fine, but Kazu was most definitely stressed. We let everyone get off of the plane before we left. He was fine getting down off of the plane, but the woman who had Pauline's wheelchair (who did not speak English) communicated that she was afraid of the dog and that if she was going to push Pauline in the chair, I was going to have to take the dog and not walk next to Pauline. So, I took Kazu's leash and walked in front of Pauline in the wheelchair. Kazu was so excited to be off of the airplane and on the ground that his entire back end wagged up in the air back and forth. One short flight, many important travel lessons.

Our event in Boston was at the faculty club at MIT. Kazu was awesome.

There were many automatic doors and the push pads were located everywhere; some were high and some were low. Kazu opened all of them for Pauline; he either pushed with his nose or he would jump up on the wall and push with his paw or nose. Doug, it is so impressive to see Kazu do this. There was a reception with more than 200 people and there was a lot of activity around him. Kazu ignored everyone and really listened to Pauline or he slept on the floor because it was way past his bedtime. We go to bed really early and Kazu is often in his crate and sleeping by 7:30 pm.

Our flight home was much better than our flight to Boston. The Boston airport was a great deal more crowded and more chaotic than Columbus had been; this was Sunday afternoon and the weekend before Thanksgiving. When Pauline got into her wheelchair after leaving the ticket counter, she dropped everything she had in her hands, including her canes. She told Kazu to pick everything up, one item at a time and to bring it to her. He went about doing his tasks. The entire line at the airport stood by and watched Kazu and Pauline do their thing. I could tell that people were astounded by what they were watching. I thought they were going to applaud. Finally, the guy standing closest to Pauline said, "Wow, now that was really impressive." Pauline thanked him.

When we got to the security area, they asked Pauline to get out of her chair and to take Kazu's service jacket, collar and leash off. Then the guard standing at the security screening called for Kazu to come through. Pauline stopped the guard and said to her, "I give the dog his commands." I was really impressed that Pauline did this; and it was definitely the right thing to do. So, Pauline said "front" and Kazu got in front of her, facing Pauline. Then she said "back" and Kazu backed up through the machine in front of Pauline while Pauline also walked through. The guard watched this incredulously and then said to Pauline, "I see dogs in here all of the time, and I have never seen a dog do that!" Kazu then helped Pauline gather all of her things. He was awesome.

We told an airline employee at the gate what our experience had been coming to Boston and she was very sympathetic. When our plane arrived at the gate, she took us down to the plane before any other passengers. We had plenty of time to get Kazu onto the plane and situated before the first passenger arrived. It was a very tight fit for Kazu, but he did find a way to lie down in front of Pauline. We also asked that they block the seat next to her so that Kazu had more room. I sat across the aisle from them. The take off, the flight and the landing were much easier for Kazu. He seemed a great deal less stressed. After going to the Browns game and after traveling with him, Pauline got the confidence that she could manage Kazu in about any situation. He is just wonderful. He pays attention, he does what he is told, and he's bonded with Pauline really well in just four months.

It is so important that Pauline manage Kazu well; there is little room for error in a school classroom. Pauline wants having Kazu at work (school) to be a totally positive experience for her and also for the children. She wants for the parents to be supportive. It is hard to describe just how well it has all worked out for Pauline and Kazu. The children ignore Kazu unless Pauline is doing some work with Kazu, and then the children are totally fascinated, just like everyone else who is watching him work.

We have heard Kazu bark twice, and both times were from Pauline giving the "speak" command and both times were during training at CCI. The only time we hear anything from Kazu is when he yawns or when he "quietly" complains about something (and we're certain he's not complaining about his bedding).

On the Thursday of the second week of advanced training, a veterinarian came to class to do a presentation about canine health and caring for the dogs. This vet was on the CCI board and cares for all of the dogs while they are at the advanced training center. When he came into the room, Pauline and I were so surprised; this was the vet who cared for our dog for most of her 16 years. He also takes care of our children's dog and cats. The vet looked over and saw Pauline and gave her a great big smile and was coming over to say hello. And then he saw Kazu. And now it was his turn to be shocked. This is the vet that did the surgery on Kazu for the infection on his nose. He absolutely adores Kazu! When he saw that Pauline was placed with Kazu, he was excited beyond words. So, now Kazu's vet has a long history with Pauline and with Kazu. He takes such good care of him.

And through this relationship and because of Kazu's surgery, we were let in on a wonderful set of circumstances. Kazu was supposed to be placed in the spring class at CCI. Then he had the troubles with the infection healing and they decided to do the surgery. CCI did not want to place Kazu until his infection had completely resolved. As soon as Kazu's trainer knew that he was being held back, perhaps until the summer class, she thought that he would be an excellent placement with Pauline. She knew that Pauline was going to be in the summer Team Training, because she was out of school (as I had suspected they would do for her). This trainer had been involved with Pauline's application process and she knew Pauline's personality very well. She also knew Kazu's personality really well, because she was the person primarily responsi-

ble for Kazu's advanced training. As we learned through the Team Training experience, the dogs work best when they are working for the leader of their pack – the alpha. They are reassured by their leader, they are directed by their leader, the world is defined for them by their leader. So, Pauline has to be the alpha. Pauline is very mild mannered, very soft spoken and doesn't do alpha very easily (except with me). Kazu doesn't need much alpha out of Pauline to get the point; he's fine with Pauline's level of alpha. And Kazu does really well with responding to "no." Pauline's physical corrections are delivered infrequently. He responds well to her commands. He responds really well to the praise he gets from Pauline. Pauline is the perfect leader for Kazu – and it is hard to imagine a better follower than Kazu. If they needed to find a dog to be responsive to a very gentle and quiet leader, Kazu was most definitely the guy! They so got this placement right – and they knew that they did many months even before the class began. Kazu and Pauline were just meant to be together.

Pauline works on her commands with Kazu to be sure that he is doing everything as he should. She has been teaching him the "go to" command so that she can send him to me if she has an emergency (e.g., she falls) and needs for Kazu to bring me to her. So, we are practicing "go to Sandy" and "go to Pauline." Pauline has been teaching Kazu to carry things to the recycling bin for her and then drop it. He definitely picks up patterning really fast. He is really smart and so eager to please. His tail wags the fastest and the hardest when he is doing something for Pauline. It is just so amazing to watch.

If I have used the words amazing and incredible 500 times in this letter, it is only because Kazu is so amazing and incredible. Pauline had her permanent public access testing a few weeks ago. It was a Saturday and the CCI staff asked Pauline to bring Kazu to the shopping mall at 11:00 in the morning. They observed Pauline go through all of the commands with Kazu in the middle of Saturday morning chaos in the mall. They did great. In fact, they were perfect! Kazu and Pauline passed their permanent public access test with flying colors. I was so proud of both Pauline and Kazu.

Kazu has totally transformed Pauline's life. There is absolutely nothing else in her life that has caused this kind of positive change – nothing – not the accessible home, not any of her medications, not all of her favorite foods, not me! This incredible dog has brought more smiles to her face than I have seen in many years. He gives Pauline a reason to get out of bed every day. He has really given Pauline's life meaning and purpose. Kazu's reason for being is to take care of Pauline – we see this in him. And it is, in part, this purpose that provides so much positive response from Pauline. She feels the responsibility she has for Kazu and she is totally immersed in the emotional connection she has to this dog. When she hugs Kazu or strokes his belly, the pleasure and contentment on his face can only be matched by the pleasure, contentment and peace that I see on Pauline's face. When Kazu goes into his play bow and gets ready to speed down the hallway to his food bowl, his excitement and enthusiasm are only matched by the squeals of laughter that are coming from Pauline. They feed off of each other in so many ways – after just four months!!!! And this exchange of energy and emotions is all positive.

And none of what I am describing to you has anything to do with what he does for Pauline to improve the physical aspects to her quality of life. Every step Kazu takes for Pauline is one additional step she will be able to take later in life. Every time he retrieves something for her or picks something up off of the floor is one more avoided reminder of what she is no longer able to do for herself or the reminder that she is dependent on others for the most routine of activities. Every time Kazu opens a door for Pauline is one less chance of stumbling or falling. For all of the physical help he provides, it does not reach the level of positive impact Kazu has had on her mood, her attitude about life, and her self-esteem. Kazu's companionship with Pauline has completely changed her life. I couldn't get Pauline out of bed on a Saturday or Sunday morning at 6:00 with a stick of dynamite. She gets out of bed seven days a week to feed Kazu. And what Kazu hears out of her at 6:00 am while she is dragging herself out of bed (which is so difficult for her because what muscles that still work take some time to get moving) is not – geeeeze, I need to feed the dog. What he hears is, "I love my Kazu." It all totally blows my mind, Doug. You would have to see all of this to believe it, and you would have had to know Pauline before this big, beautiful, black dog appeared in her life.

And a day does not go by that I do not think of you! I don't pet Kazu without thinking about you. I don't watch his interactions with Pauline without thinking about you. For me, you are a part of everything that **is** this incredible dog. I raised two kids – I know what impact we have on our children – I completely understand what parenting and education and modeling are about. While socializing children is not exactly like raising an animal – there is much about it that is the same. What Kazu learned from you has made this dog such a special creature. What personality influence you had on Kazu made him one of the kindest, sweetest, gentlest creatures I have ever seen. What modeling you did with Kazu made him into one of the most respon-

sive and disciplined creatures one could imagine. I don't ever separate what you did from who Kazu is; they are one in the same for me.

I have a sense of the meaning and purpose that Kazu brought to your life, because I see what he has brought into Pauline's life. In the same way that my tears flow so intensely from thinking about the sacrifice puppy raisers experience from having to say good-bye to their dogs, I am saddened for you, Doug. I know there must be an incredible sense of pride and accomplishment in what you have done. How could there not be. But there must also be a sense of sadness from having said good-bye to Kazu. Words will never be able to describe our gratitude to you and our sense of your personal sacrifice in having had to say good-bye. What you did for Pauline – for us – was both a miracle and a blessing. You have given Pauline the miracle and blessing of independence. You have given Pauline the miracle and blessing of a positive spirit.

I want for you to know that Kazu is happy and he has a great home. Kazu is so loved and receives wonderful care. He is the focus of Pauline's attention. And Kazu is doing the work he was trained so well to do. He delivers independence to Pauline 24 hours a day, seven days a week. And he brings her independence packaged in warmth, kindness, companionship, devotion, loyalty and love!

We are forever grateful for your hard work with Kazu. We are forever grateful for the affection and care you gave to Kazu. And we are so grateful for your willingness to offer such a generous and kind effort to someone in need. This was such an amazing and wonderful gesture, Doug. Thank you. Thank you from the bottom of our hearts!

Take care and be well,
Pauline and Sandy

January 20th 2008

Dear Pauline and Sandy,

Let me start by saying thank you so much for the wonderful letter and pictures. To receive that really meant a lot to me. I would have written sooner, but to be honest, I really didn't know where to start. So much information and so many thoughts of my own about each and every thing you wrote. I just had to mentally sort it all out.

I would like to share with you how I got started in this program at RCI. I arrived here in October of 1999. At that time the dog program had just started and there were only a couple of inmates with dogs. They weren't CCI dogs, but a "pound puppy" program. Needless to say, I was immediately interested. I couldn't believe that inmates had dogs that lived with them in their cells. I took every opportunity to interact with the dogs that I could. The thing is, so did 1000 other inmates; so my interest didn't stand out in the least.

In 2000 they started raising CCI puppies here; three or four of the cutest little bundles of fur romping around out in the yard. I found out that they weren't planning on getting any more puppies, so I knew my chances were slim. I chose to only watch it from a distance. In 2001 I noticed that there was a high turnover rate of the inmates that were raising the puppies. I saw this as an opportunity to get a dog. I started sending in request after request to be accepted into the program and I never got one reply.

In 2003 I moved into the merit housing for "honor" inmates. This is the unit that Denise works in, so I knew I was getting closer. I continued to show interest and I was accepted into the program in September of 2004. At that time I was only a secondary which is another name for babysitter. I would get a dog when one of the primaries had a visit, doctor's appointment or was sick. That was fine though. My foot was finally in the door.

On December 2nd one of the primaries got an early release and went home. His dog's name was Lockett. Denise asked me if I wanted him. I don't even think I let her finish the question. She knew I wanted him. Lockett was already six months old, and to put it mildly, he was a challenge. He was very head strong and responded poorly to any type of correction. I had my work cut out for me. It turned out to be a blessing. Lockett taught me as much as I taught him. I kept Lockett until July of 2005. I'd learned that those first six months of a dog's life are the most important and if they don't know what's expected of them by then that it's almost too late. We sent five dogs to CCI that July and all five did not graduate for various reasons. Lockett didn't graduate because he refused to respond to correction. I was still confident that the work I did with Lockett gave him a good chance to succeed.

Here is the good part. On July 18, 2005, the day we turned Lockett in, I received Kazu. He was exactly two months old that day and he was so cute. We got four puppies that day: Kazu, Kashi, Lilac and Lassen. Lilac and Kashi were female breeders and were already spoken for. So, it was down to the two males. Being the low man on the totem pole, so to speak, I deferred and let the other guy choose which one he wanted. He had just turned in a yellow lab and wanted another, so he chose Lassen. That left me with Kazu. To be honest, I didn't know how his name should be pronounced. I wanted it to sound as far away from Kashi to avoid confusion.

I was so happy to have this sweet little puppy to love, teach and spend time with. For the first three or four days, I

spent one on one time with him. I talked and talked to him so he could identify my voice. I said his name to him hundreds of times and introduced him to the "hurry" command. The best I can remember, he only had a few accidents inside, but only when he was that young. He did so well with that. We take them out at 8:00 PM and they have to hold it until 6:00 AM. Also, it was the middle of July and all he wanted to do is drink and drink.

The next big hurdle was to leash break him. Here he was only nine weeks old and I put this little halter on him and tried to get him to walk where I wanted to walk and not let him go anywhere he wanted to go. He fought it for about two weeks and then he gave in. I strongly believe that early leash breaking is the foundation for everything else. It definitely establishes who is the alpha. It was when he gave up trying to fight the leash that he started walking so proudly. He was twelve weeks old and prancing and walking perfectly with me step for step. How you described him walking is how he walked then. Next, through the endless miles, we walked. I taught him to walk with his head next to my knee no matter how fast or slow I walked. I would start out walking about as slow as possible and then would take off walking as fast as I could; then almost stopped once again. He was so focused that he would never pull the leash tight in either direction. He was perfect.

Throughout this time, I was introducing commands to him. I had this great idea to try to teach him one a week or so. That is when I discovered how smart Kazu was. I would show him something once or twice, and he would know it proficiently. I was blown away. By the time he was four and a half months old, he knew all 32 commands. I was so scared that I had pushed him too hard, but there was really no "pushing" involved. I really was waiting for something negative to arise, but it never did.

Kazu was always trained and treated with love. Sandy, I agree with you 100% on the similarities between dogs and children. I praise the positives rather than punish and focus on the negatives. Kazu was trained letting him know what I expected from him and rewarding when he did it. When he would do something wrong (eating grass, sniffing garbage cans), I would redirect him to something positive and praise and reward when he did it. He caught on really quickly; especially when treats were involved. Kazu really wasn't treat-driven as some of the other dogs here are. He loved the pets, hugs and kisses. And he got plenty. Everyone here loved him so much. He amazed people when he was here, so I know he is amazing people now.

I cried so many times through reading your letter. It was so pleasing to see that every single thing he and I worked so hard on is being used to help Pauline. I can't deny it. I am so proud. Not because of what I did, but because of what Kazu is doing. It feels like I've turned my son out into the world and he is doing great things.

One of Kazu's innate strengths was retrieving. He loved to pick things up and bring them to me. We really aren't supposed to teach them this. I never really did; I only encouraged it. We are told specifically to never use the words "get" "give" or "hold." We are told that these are advanced commands. We use the words "find" and "bring." We would say, "find the toy; bring it here." He was so good at it that I would say, "find my shoes" and he would bring them and place them right in my hands. He would specifically bring boots, shoes or slippers and knew what each item was by name. He amazed me by how quickly he learned all of this. I'd show him once or twice and he'd know.

I also taught and made Kazu perform the switch command while he was here. It was mainly for my benefit. Our cell doors here are regular hinged doors. If I'm outside of the cell and I push the door shut, the door locks and I have to wait for an officer to come and open my door with a key, which they are not too enthused about. If I'm in my cell and pull the door shut, there is a button that I can push and the door will unlock and I can get out. I made an apparatus that I put over the switch that ended up being a square of about the same size as an automatic handicap door push plate. That way if I was locked out of the cell and Kazu was in it, I would simply tell him "switch" through the door window, and he would come over, reach up, and push the button with his two front paws and let me in. This saved me countless hours of waiting outside for an officer to come over to let me in. No wonder he is so proficient at this. He's had plenty of practice.

Kazu was always so eager to please. Kazu seems to be going to bed at night about the same as he did here. Around 8:30 or so, he was in his crate and fast asleep. His crate was set up so that the back of it was right next to the head of my bed. I elevated the frame of my bed up to about 3 ½ feet high so my dogs could crawl up under my bed and lay down, if they wanted; just to have more room to move around. One night I was up pretty late watching tv and doing crossword puzzles. It was about 11:30 so he had been asleep for a good three hours. About that time, my tired eyes told me that I'd had enough. I reached over and turned off my bed lamp, put my pen on my clipboard, and reached over to put it on the shelf. When I did this, the pen rolled off and hit the floor. I decided I'd get it when I was going to get up in a few minutes and finish getting ready for bed. I laid there for about 30 seconds or so with my eyes closed resting them. I opened

my eyes to get up and there was Kazu about eight inches from my facing doing an "up" on the side of the bed with my pen in his mouth and his tail wagging. I was blown away. I never heard him leave his crate or felt him do an up on my bed. But for him to be lying there asleep and hear the pen hit the floor and feel as though it was his job to bring it to me, I'm still amazed. I praised him and got down on the floor and gave him a bunch of lov'n and he just laid there and took it all.

There is an elderly man here that walks with a cane. Every once in a while, he would come over while Kazu was out and drop his cane on the floor. He would tell Kazu to bring it to him and Kazu would go over and pick it up for him. The man really liked that. It was a wooden cane and for some reason, Kazu wasn't too thrilled about that either. So we took a piece of denim cloth towards the upper part of the cane. After that, there was no hesitation from Kazu. To this day, this man still has that strip of cloth tied to his cane and asks about Kazu all the time.

I am so proud of my boy and I miss him so much.

The day I had to say good-bye to Kazu was so rough. I have a hard time thinking about it as I write this. We spend the whole year with them knowing that day will come, but there is really no way to prepare for it. Our biggest wish is that we will never see them again. That means that they have succeeded. Only when they don't graduate do they come back to be given to one of the staff members here. The day they leave, Denise has us bring them up to the front gate at 8:00 AM. She waits out in the parking lot with the van and has another staff member to come and get the dogs from us. She doesn't even want to see us on that day, because she knows what we are going through. She gets as attached and emotional about everything as we do. The way I like to do it is to say all of my goodbyes before I go up to the front gate. That way when they come and take the leash from my hand, I can just turn around and walk as quickly as possible before the flood gates open. Well, with Kazu I almost made it back to my cell which is about a half mile walk. I got to the front door of my housing unit and I realized that I'd never be walking in and out with Kazu and then the levee broke. I went in my cell and pulled the door shut and had a real good cry for about 15 minutes. As I was sitting there drying my eyes and blowing my nose, I was struck with a great feeling. After all of those years of being in this cold and hard place, I was so happy that I could still have all of those feelings and emotions. And all of this began with this little romping ball of black fur. Kazu made me better in so many ways.

After he left here, CCI did a really good job of keeping me abreast of his progress. I knew everything about his surgery and his training. Everyone who turns a dog in gets a monthly progress report at the least. With his nose, they called here a lot more often to let us know what was happening. I could tell that they really loved him up there. The monthly reports usually are filled with various problems that the dogs are showing. With Kazu, they were always about how good he was. I was thrilled. Adrena, one of the trainers, would call and say, "Kazu is being Kazu. Everything's fine." I was happy.

The day before Team Training was to start in May, they called to say that he was being pulled out of training but would be kept for the August class. I was a little worried. I didn't like the idea that he would be up there for nine months on that hard concrete. He had a mattress cut down to fit his crate while he was here. I just had to have faith that there was something great waiting for Kazu. I was so happy that such a wonderful match was made between Pauline and Kazu. It's perfect. I don't think that the staff of CCI could have done a better job with the match. I have to say that I shed a tear or two when I read in your letter that Pauline wanted Kazu after five minutes with him. I really see G-d's hand in all of this.

Pauline, I am so happy that Kazu has helped you in so many ways. It was definitely an answered prayer that he was matched with the perfect person that could love him like you do. No words could ever be spoken to explain how grateful I am that he has you and that you have him. In the sixteen months that I had Kazu, I knew that he changed me in ways that would last the rest of my life. I know that he has already made a difference in your life and I can't wait to see what waits for the two of you in the years to come.

When I turned in Kazu in November 2006 and I started receiving his first couple of progress reports, I had a pretty good idea that he might graduate. At that time, I asked my parents if they would like to attend the May graduation ceremonies. They were very excited to go. Then he got held out of the May class, because of his nose. So, I told them that it would be some time in August. I wanted for them to share in the graduation; and to see firsthand why I was participating in this program. Then Denise asked my Mom to help her since we had three dogs from RCI graduating that day. I called Mom Saturday evening after the ceremony to see how everything went. Through tears over the phone, she told me all about it. She spoke so highly about the both of you. I was so pleased with everything. After a long pause, Mom said, "You know, that was one of the best experiences of my life." If nothing else good came out of all of this, just to hear my Mom say that made it all worth it.

Kazu is such a special boy.

Kazu has already been able to do something I've always wanted to do. He got to fly in a plane. I love the stories about him going through security. I can visualize every step you described. We do a little work here with wheelchairs just to introduce them. I would always approach doorways with Kazu while I was sitting in the chair. I would tell him "front" and then have him "back" up through the door. He's an old pro at that stuff.

The story you shared with me about Kazu not playing with the other dogs when they were "released" at CCI let me know that Kazu was the same old Kazu. He played so much here and so vigorously and he was so used to playing with a bunch of dogs that it probably just wasn't that exciting for him anymore. I've always thought that Kazu thought he was a person. When he was here and all of the other dogs started getting over excited, he would come over and sit next to me and just watch the other dogs. When they would settle down, he'd go back and pick a toy up and play. He was here beyond his year. Also the fact that he had already been up there for nine months probably was getting old for him.

Kazu has always been excited at feeding time. We are let out of our cells at 6:00 am every morning. Before the doors unlocked, I would pour his cup and a half of food in his bowl and set it on the edge of the sink. Then when the doors opened, I'd take him outside to do all of his hurry business. He knew his food was waiting, so he did it quickly. All the way back in I would say, "din din, din din, din din." He would be high stepping the whole way. Then I'd take his collar off and he would put himself into a sit. He'd watch me set the bowl on the floor and then as I straightened up, his eyes would lock on mine. He'd wait, and then I'd say, "Release!" He'd pounce on the floor to his bowl and got busy. Sometimes just to test him, I'd make him sit there for about a minute before I'd release him. He would be perfectly still, but the drool would start dripping from the corners of his mouth. He was great.

The whole time Kazu was here, he never barked without being told to speak. The way I always worked on it with Kazu was to have his butt firmly planted in a sit position and tell him to "speak." I'd tell him once and expected the command to be followed by many barks until I said "quiet," which he always did perfectly. I had always imagined that this could be used by someone who had fallen down or fell ill. Believe me, if this happened in your house, it would definitely bring others running. I just thought that this might be useful to try, if the "go to Sandy" or "go to Pauline" isn't working well.

Denise got a DVD of the CCI graduation ceremony. It was as good as I imagined it to be. Pauline, your speech was great. I tried to hide the fact that I was tearing up while watching it. The thing is, I wasn't the only one. You might not be able to imagine it; ten guys in prison, sitting in a small tv room watching a DVD and crying like babies. All of us in this dog program know exactly why we do this. I have shared your letter with everyone else in this program and it has made an impact. One of the guys that has been a puppy raiser since early 2003 said that he was "re-inspired and re-motivated" after reading your letter.

I truly appreciate your taking the time to write me such a wonderful letter to let me know all about how Kazu is doing. More than that, I thank you very much for opening your hearts and your home and letting Kazu in. I could have never dreamed that such a perfect match could be made. Thank you so much for loving Kazu the way you do. I know he can't say it, but I know Kazu, and I know he loves you unconditionally.

I look forward to receiving updates in the future and I hope to get to meet both of you one day.

Sincerely,
With love and caring,
Doug

Doug has a gift. The more I learn about Kazu, the more I appreciate the discipline, focus, and nurturing that goes into the work that Doug does with these dogs. I greatly respect and admire Doug as I do all of the people who work and volunteer in the CCI program. Only 40% of the dogs in the CCI program are able to graduate. Having the right temperament, being physically able to do the work, learning all of the commands, adhering to the correct behaviors, and being able to bond with and serve as a companion for a person represents an incredibly high level of expectations. To achieve these goals requires the expertise and experience surrounding the breeding program, the devotion and selflessness of all of the breeder caretakers, the legions of exceptional puppy raisers, like Doug, and the skills, dedication, experience, knowledge and sensitivity of the advanced trainers who work at the five regional CCI centers. Underlying all of these efforts are the many volunteers who support this program and help to raise the resources that make all of these miracles possible. CCI estimates that their investment in each of these dogs is about $40,000. There was no cost for Pauline to be placed with Kazu. As a president of a not-for-profit organization who has a very clear understanding of the resources and leadership that are required to possess a vision and a mission and to construct it into a reality, I can only be in awe of the quality of this program and the incredible

achievements of Canine Companions for Independence.

We have stayed in touch with some of our fellow graduates, with the breeder caretakers who care for Kazu's Mom and Dad, and, of course, with the wonderful CCI folks from the North Central Regional Center in Ohio. And we are in regular contact with Doug. Pauline, Kazu and I will be making a trip early this summer to the Ross Correctional Institution for a visit with Doug and Denise. We are so looking forward to meeting Doug and to sharing in the Doug and Kazu reunion!

Next Generation Molecular Diagnostic Assays for MS and Other Demyelinating Diseases

Eric M. Eastman, Chief Science Officer, and Douglas Bigwood, SVP of Biostatistics and Analysis, DioGenix, Inc.

Introduction

This article will discuss new approaches to the diagnosis of demyelinating diseases such as Multiple Sclerosis (MS) and Transverse Myelitis (TM). I will introduce you to some concepts that will be new to many of you, although you may have read about them in recent newspaper or magazine articles or heard stories about them on NPR (see references below). Although some of these concepts may seem complicated, I will do my best to define each concept as we go and put them into the proper context.

As you are well aware, MS and TM are very difficult diseases to accurately diagnose and treat effectively. Many of you have dealt with this problem personally. This unfortunate situation is, to a great extent, due to the fact that these diseases are biologically very complex and heterogeneous, and the lack of accurate and predictive diagnostic tests.

Although I will focus on issues relating primarily to MS, many of the issues discussed here are relevant to other demyelination diseases including TM, neuromyelitis optica (NMO), optic neuritis (ON), and acute disseminated encephalomyelitis (ADEM) – see disease descriptions at the TMA website, www.myelitis.org. All of these diseases result from damage to the central nervous system (**"CNS"** – brain and spinal cord) resulting from malfunctions in the body's own immune system.

The immune system is the body's major defense system and is made up of a large number of specialized cells that circulate in our blood and reside in other tissues. These cells act as sentinels and are responsible for our ability to fight infections by recognizing specific proteins from invading microbes (bacteria or viruses) as foreign and potentially harmful. When a foreign invader is detected, the immune system produces **"antibodies"**, proteins that selectively bind to these foreign proteins and target the microbes for destruction. At the same time, other cells are deployed to hunt down the microbes, wherever they are, and destroy them. These cells are also involved in healing wounds and response to other types of tissue injury. This process is called **"inflammation"**.

All the demyelinating diseases listed above involve inflammation of the CNS. MS is further complicated by the fact that it is also an autoimmune disease. In autoimmune diseases like MS and systemic lupus erythematosus (SLE or lupus), the immune system malfunctions and wrongly thinks certain normal proteins produced in healthy tissues are foreign proteins and they become the target.

In MS, the immune system attacks proteins contained in the myelin sheath, which is the protective coating on the nerves in the CNS. Normally, the myelin sheath acts like the insulation around electrical wires and is important for the proper transmission of nerve signals from the brain to other parts of the body. In MS, anti-myelin antibodies direct a "friendly-fire" inflammatory attack on the myelin sheath, leading to demyelination. This can lead to permanent nerve damage slowing or blocking critical nerve transmissions that control muscle co-

ordination, tactile and vision sensation, bladder function and strength. Even in the absence of anti-myelin antibodies, certain cells from the immune system will invade the brain and spinal cord and cause direct tissue damage.

Since all the demyelination diseases listed above involve changes in the immune system and the inflammatory response is a major driver of the disease process, the information we generate studying MS should help elucidate the underlying causes of TM and other demyelinating diseases. Furthermore, this information will provide the framework for the development of diagnostic tests for all these diseases.

Diagnosis of Multiple Sclerosis

MS is a debilitating autoimmune disease that attacks the central nervous system causing demyelination of nerves. There are 25,000 to 30,000 new cases of MS diagnosed each year in the United States while estimates of patients presenting with clinical symptoms that could be MS are 5 to 10 times that number per annum. At present, effective treatment of this disease is hampered by the lack of **"clinical assays"** (diagnostic tests) capable of providing actionable information about diagnosis, prognosis, disease segmentation and response to treatment. Unfortunately, the diagnosis of MS is somewhat subjective, based on the experience of the practitioner and the severity of disease at the time of presentation. Many patients suffer for months, if not years, before they get a definitive diagnosis.

Figure 1 illustrates the current process used to diagnose patients presenting with symptoms of MS.

Patients with symptoms of MS are often subjected to a battery of tests that must both support the diagnosis of MS and exclude common mimics of the disease. These tests are expensive, require multiple visits to the clinic and some are invasive and painful, such as spinal taps for CSF testing. Patients with early signs of demyelination undergo this sequence of testing in order to stratify their risk of having MS. The risk of MS is usually expressed in rough percentages ranging between 20 and 80% depending on symptoms and MRI results. Worse yet, the outcome of this diagnostic workup results in a significant healthcare dilemma: given the benefits of treating MS at an early stage (Kappos et al., 2007), patients must decide whether they will start costly, invasive treatments even when uncertain about the diagnosis.

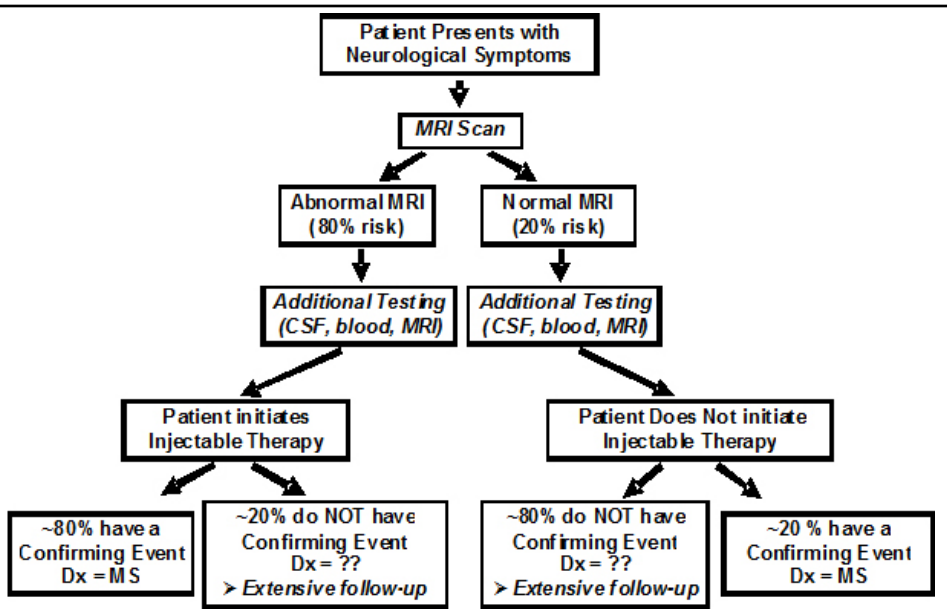

Figure 1: Current MS Diagnostic Process

Patients must elect to either:

Start therapy, even if the diagnosis is uncertain, knowing that early treatment may reduce the severity of the disease and minimize long-term disability. Unfortunately, some of these patients will be exposed to an expensive therapy unnecessarily **AND** remain in diagnostic limbo for years to come. In addition, many of these patients will have to endure at least annual MRIs and other tests in an attempt to confirm the diagnosis and monitor to determine if the therapy is effective.

OR

Forego therapy given the uncertainty of the diagnosis. In this scenario patients will usually undergo as many as four MRIs per year for up to five years as part of a program to screen for changes consistent with definitive MS. This strategy carries the risk that, in the interim, the patient may suffer continuing demyelination leading to additional permanent disability.

Why is MS hard to diagnose and treat?

Here are a few issues that make MS (and other demyelination diseases) so difficult to diagnose and treat:

- The symptoms of MS vary from patient to patient.
- There are different subtypes of MS – most patients have relapsing-remitting MS (RRMS) but other common subtypes include primary progressive MS (PPMS) or secondary progressive MS (SPMS).
- Many other diseases may look like

MS, particularly in the early stages of the disease. These include other demyelinating diseases such as TM, neuromyelitis optica (NMO), optic neuritis (ON), and acute disseminated encephalomyelitis (ADEM); and other autoimmune diseases, including Systemic Lupus Erythematosus (SLE or lupus), Sjogren's Syndrome, etc.

Symptoms commonly shared among these diseases include blurred or double vision, slurred speech, muscle weakness and fatigue, partial paralysis, numbness, unexplained pain, incontinence, etc.

- Some patients who start out as being diagnosed with TM, ON, NMO or ADEM actually have MS that has not been diagnosed yet.
- Some patients diagnosed with MS have more severe symptoms than other patients or their disease may progress faster than for other patients.
- The disease can progress along different courses for different patients and can even change course over time. For example, approximately half of patients initially diagnosed with RRMS will later develop SPMS, which is a more aggressive form of the disease.
- Patients with different forms of MS, i.e., RRMS, SPMS or PPMS, require different therapies.
- Not all patients diagnosed with a given subtype of MS respond to the same therapies and some do not respond at all.

These facts present serious challenges for both patients and their physicians. Thus, there is a critical need for better methods to diagnose, prognose, and monitor patients with MS and other demyelination diseases.

Most existing diagnostic tests measure only one biomarker. As used here, a biomarker is any biological analyte found in the blood, other body fluid, or tissue of a patient that can be objectively measured and correlates with specific biological processes. These simple, single-analyte tests tend to be inaccurate and are seldom definitive. Good examples are the PSA test for prostate cancer and anti-nuclear antibody (ANA) tests for autoimmune disease. The current PSA test has a very low specificity. Only about 25% of individuals with a positive PSA test actually have prostate cancer based on biopsy results and about 15% of individuals with a negative test do have cancer (Paul et al., 2005). Almost everyone has some ANA in their blood. Of those with high levels of ANA, only about half actually have some type of autoimmune disease, such as SLE, Sjogren's syndrome or rheumatoid arthritis. High ANA levels can also result from viral infections; certain liver, lung, intestinal and skin diseases; and can even result from taking certain drugs, including some blood pressure and anti-convulsant drugs. Thus, the ANA test alone is not an accurate diagnostic test for autoimmune disease.

An emerging trend in human healthcare is to use panels of biomarkers (typically tens of markers) at the same time. Individual biomarkers in these panels are often associated with distinct biological processes involved in the disease. In these types of assays, subtle but characteristic changes in the pattern of biomarker expression are more important than changes in any single biomarker. Recent scientific advances in the fields of genomics (the identification of all genes in an organism's genome and their function) and proteomics (the identification of all proteins that are encoded in an organism's genome and their function) now make it possible to development next-generation **"molecular diagnostic"** (**"MDx"**) tests, as discussed in more detail below.

Another emerging healthcare trend involves pairing specific diagnostic tests with specific therapies to help insure that patients receive the drug(s) most likely to provide relief. This approach is often referred to as **"companion diagnostics"** or "**theranostics**" (**thera***py* plus *diag***nostics)**.

Together, these trends make possible the dream of **"personalized medicine"**, also referred to as **"individualized medicine"** or "**molecular medicine"**. According to the Personalized Medicine Coalition (www.personalizedmedicinecoalition.org); "*By employing new methods of molecular analysis to better manage a patient's disease or predisposition towards a disease, personalized medicine aims to achieve optimal medical outcomes by helping physicians and patients choose the disease management approaches likely to work best in the context of a patient's genetic and environmental profile"*. As a result, healthcare professionals are now gaining access to new diagnostic tools to better deal with hard-to-diagnose and hard-to-treat diseases like MS and TM. Exemplifying the attention personalized medicine is getting, Senator Barack Obama (Illinois) introduced a bill titled "*To improve access to and appropriate utilization of valid, reliable and accurate molecular genetic tests by all populations thus helping to secure the promise of personalized medicine for all Americans"* (Bill S.3822, 109th Congress 2nd Session).

How will Personalized Medicine change how MS is diagnosed and treated?

It is generally accepted that MS results from the interplay of both environmental and genetic factors. Environmental factors include such things as 1) exposure to toxins that are ingested, inhaled or absorbed through the skin; 2) infectious disease agents such as bacteria and viruses; 3) radiation exposure; and 4) stress, etc. Genetic factors

include both changes at the DNA or gene level, including gene mutations and the duplication or deletion of gene sequences; as well as the abnormal expression of genes (mutated or normal) involved in many complex biological processes such as DNA repair, cell replication, cell metabolism, inflammation and immune response. Anything that disrupts the normal functioning of one or more of these biological processes can lead to disease.

The human genome – *the genetic blueprint* – contains an estimated 20,000 to 30,000 individual genes. Genes contain the information needed to make proteins, which are the main functional constituents of all cells. Proteins act as enzymes, hormones, signaling molecules and antibodies required for the proper function of each cell and, in turn, each organ in the body. Although we used to think that each gene produced a single protein with one function, we now know that most genes actually can produce multiple versions of a protein and each version can have a different function. In this manner, the genome can actually produce hundreds of thousands of different proteins. Each of the roughly 50 trillion – yes trillion!! – cells in your body contains virtually all the same genes. So, what makes a liver cell different from a kidney cell or a muscle cell, brain cell, blood cell, etc. is determined by which genes are turned on (**"expressed"**) and to what level they are turned on in each type of cell. For example, red blood cells need to express the gene that makes hemoglobin, the protein that carries oxygen throughout the body. Other cells do not need to make hemoglobin to function so they do not turn this gene on. B cells, which are the cells in the immune system responsible for making antibodies to fight infections, express the genes that code for the various bacteria- and virus-specific antibody proteins – other cells do not.

What determines which genes are expressed in a given cell? One can think of the regulation of **"gene expression"** like having 20,000 to 30,000 molecular rheostats, similar to rheostats that might control lights or fans in your home. Each gene can be turned off but, if it is turned on, it can be continuously adjusted from low to high. It also can be turned up or down at any time. Each gene in the genome is controlled by a molecular rheostat. The sum total of the expression of all genes in a cell represents that cell's **"whole-genome expression profile"** and determines which proteins are produced by the cell and, therefore, the function of that cell. This also determines whether that cell functions normally or abnormally.

Furthermore, individual proteins do not work in isolation, but rather they interact with other proteins in complex biological networks similar to intricate electrical circuits in computers. The complex system of biological networks must be carefully controlled for each cell, organ, and ultimately the entire body to operate normally. Damage to key genes or the improper regulation of key genes involved in these biological networks can result in the development of serious disease. When these changes can be reliably measured and shown to be specifically associated with a disease like MS, they may be useful as a **"biomarker"** in a diagnostic test.

In general, each biomarker will be associated with a specific biological network. Thus, a given biomarker will only be informative as a diagnostic biomarker if this biological network is affected in that patient. It will not be informative if the patient's disease is a result of changes in other biological networks. Thus, the best way to diagnose these complex diseases is to measure multiple biomarkers, each associated with different biological systems that are known to be involved in the disease in question.

MS is difficult to diagnose because it can be caused by aberrant regulation of multiple biological networks. What is diagnosed as the same disease in different patients can involve different biological networks. As mentioned earlier, MS is actually a class of related diseases comprised of various disease subtypes. In addition, other diseases can look like MS (**"MS mimics"**) including other demyelinating diseases, such as TM, NMO, ON and ADEM. Unfortunately, the best diagnostic tests currently available are unable to readily differentiate MS from these MS mimics or differentiate MS subtypes. This is particularly true during the early stages of disease progression. Thus, patients with different diseases or disease subtypes are often diagnosed as having the same disease and treated the same way when, in fact, they have very different diseases and require different treatments.

All these factors seriously complicate the diagnosis and proper treatment of these diseases since patients with the various subtypes of MS and the confounding diseases respond to different treatment approaches – **Proper treatment depends on accurate diagnosis.**

A number of different drugs are available for the treatment of MS patients. Although there are fairly good drugs available for patients with RRMS, the drugs available for treating PPMS and SPMS are not as effective and often involve the use of chemotherapy drugs, which were developed to treat cancer patients.

In general, response rates for many commonly prescribed drugs range from as low as 25% to 80% (Spear et al., 2001). This means that, in some cases, up to 75% of patients given a specific drug will not benefit from the treatment. Many MS patients respond well to current therapies. Unfortu-

nately, it is estimated that up to 50% of MS patients on Interferon-beta therapy will continue to experience significant relapses and disease progression leading to severe disability (Byun et al., 2008). This highlights the added need for new MDx tests to predict which drug is most likely to work for each patient and to check whether the drug is working after therapy starts.

Thus, as suggested above, there is a critical unmet need for better methods to diagnose, prognose, and monitor patients with these complex diseases.

DioGenix

DioGenix is an early-stage diagnostics company that has developed a novel strategy for the development of next-generation MDx assays using panels of biomarkers to improve the diagnosis of difficult-to-diagnose diseases. DioGenix is currently focused on developing MDx assays for neurologically-based autoimmune and inflammatory diseases. We are currently focused on developing MDx assays for MS.

DioGenix uses state-of-the-art genomics technologies and sophisticated biostatistics to quickly identify and validate novel panels of genomic biomarkers that represent **"gene signatures"**. A gene signature is a panel of genomic biomarkers whose pattern of gene expression correlates with disease status. They can be used to 1) provide disease diagnosis and prognosis; 2) predict disease progression and regression; and 3) predict and monitor a patient's response to therapy. Optimally, the biomarkers included in a gene signature will be associated with multiple biological networks that are affected in the disease being studied. One can think of a gene signature as a unique molecular fingerprint. Since genomic biomarkers measure changes in biological processes at the molecular level, they can more accurately identify and differentiate similar diseases and disease subtypes, even when patients display very similar clinical symptoms. Gene signatures form the groundwork for the development of critically needed MDx assays and improve patient management for difficult-to-manage diseases like MS and TM. They also may be used as key components in future theranostic applications to facilitate the delivery of the right drug to individual patients, based on the individual patient's own genomic profile.

DioGenix evolved out of Gene Logic, a leading Genomics Service company with more than 10 years experience generating high-quality genomics data and building comprehensive genomics databases including BioExpress®. BioExpress® is a comprehensive database of human genomic and clinical information. It contains **"whole-genome"** expression profiles for more than 12,000 clinical samples covering more than 400 different disease types. DioGenix maintains a close working relationship with Gene Logic with preferred access to BioExpress®, in addition to their extensive clinical network, biorepository and genomics data production lab.

DioGenix is leveraging this relationship and has established new relationships with clinical experts and prominent organizations in the MS and TM research communities, including Dr. Benjamin Greenberg, Director of the Johns Hopkins Encephalitis Center and Co-Director of the Johns Hopkins Transverse Myelitis Center; The Accelerated Cure Project for Multiple Sclerosis (ACP) and The Transverse Myelitis Association (TMA).

How is DioGenix developing Next-generation MDx assays for MS?

DioGenix has developed a Research and Product Development strategy that consists of three major phases:

1. Gene Signature Discovery
2. Gene Signature Validation
3. Product Development

Gene Signature Discovery involves the following steps:

- Analyze data in existing public and proprietary (BioExpress®) genomic databases to test a clinical hypothesis. DioGenix has exclusive access to BioExpress® for the development of diagnostic assays. This provides us with a unique advantage.
- Perform clinical studies to accrue well-characterized clinical samples from patients confirmed to have the target disease; patients with related diseases and other confounding diseases; and matched healthy controls.
- Measure gene expression profiles using DNA microarrays that measure the expression level of virtually all genes in the human genome to generate whole-genome expression profiles.
- Identify genes that are differentially expressed with high statistical significance between patients with the target disease, related diseases, confounding diseases and controls using sophisticated bioinformatics and biostatistics tools.
- Identify a prototype panel of molecular biomarkers (**"gene signature"**) capable of differentiating patients with the target disease, from patients with related or confounding diseases and controls.

Gene Signature Discovery is typically performed using DNA microarrays. DNA microarrays can measure the expression of thousands of genes in a single assay and are used for large-scale gene expression studies capable of determining the gene expression profiles of virtually all known human genes simultaneously.

Gene Signature Validation involves the following steps:

- Qualify (test) and refine the prototype gene signature by performing clinical studies with larger numbers of patients.
- Validate the gene signature using a low-density assay platform that is more sensitive and quantitative than DNA microarrays. Ideally, this assay platform could be used to commercialize the final diagnostic assay, when ready.

Product Development involves the following steps:

- Develop diagnostic or screening assays based on the validated gene signature using a low-density assay platform appropriate for commercial clinical use.
- Validate the commercial MDx assay in a blinded prospective Clinical Trial.

Clinical gene expression analysis for MDx testing requires the analysis of a small number of genes (10's to 100's) compared to Gene Signature Discovery. This is partially due to the high cost of running high-density microarrays in a clinical setting and economic pressure to keep healthcare costs low. Therefore, a critical factor in developing a genomics-based MDx assay is to identify the smallest number of biomarkers possible that provide the requisite clinical utility.

A critically important aspect of this entire process, particularly during the early phases of Signature Discovery and Validation is gaining access to large numbers of well-characterized patient and control samples. Although Gene Logic's extensive biorepository contains more than 45,000 human and animal tissue samples, each with detailed clinical and experimental study information, this is insufficient for the development of commercial MDx assays requiring FDA approval. This repository was created to include a broad range of tissue types and diseases. As such, it does not have a comprehensive collection of samples for each disease. Even though it contains more than 3,500 samples from patients with immunological diseases, there are a relatively small number of MS samples, most of which are represented in BioExpress®. To supplement this repository, we have established a strategic collaboration with The Accelerated Cure Project. This gives us access to their extensive repository of biological samples from patients with MS and other demyelinating diseases.

The Accelerated Cure Project is a nonprofit organization with the stated mission of "curing MS by determining its causes". They have created a comprehensive biorepository of blood samples and clinical data from patients with MS; other demyelination diseases including TM, NMO, ON and ADEM; and matched controls. They make these samples available to researchers investigating the causes of MS. Although they are focused on aiding research to understand the causes of MS, they recognize the importance of these other diseases to the study of MS. For more information on the Accelerated Cure Project go to their website – www.acceleratedcure.com – and see the article by Jana Goins in the Spring 2007 issue of The Transverse Myelitis Association Newsletter (Volume 7 Issue 2, page 21). Jana is the Study Coordinator for ACP at Johns Hopkins School of Medicine.

As of February 14, 2008, the ACP biorepository contained blood samples from a total of 970 subjects including:

- 631 MS samples
- 55 TM samples
- 10 NMO samples
- 4 ON samples
- 5 ADEM samples

Molecular Diagnostic Assay for Multiple Sclerosis

DioGenix has strategically chosen MS as its lead program given:

- The ability to improve clinical management at multiple intervention points in the patient's healthcare: from initial presentation through monitoring therapeutic response;

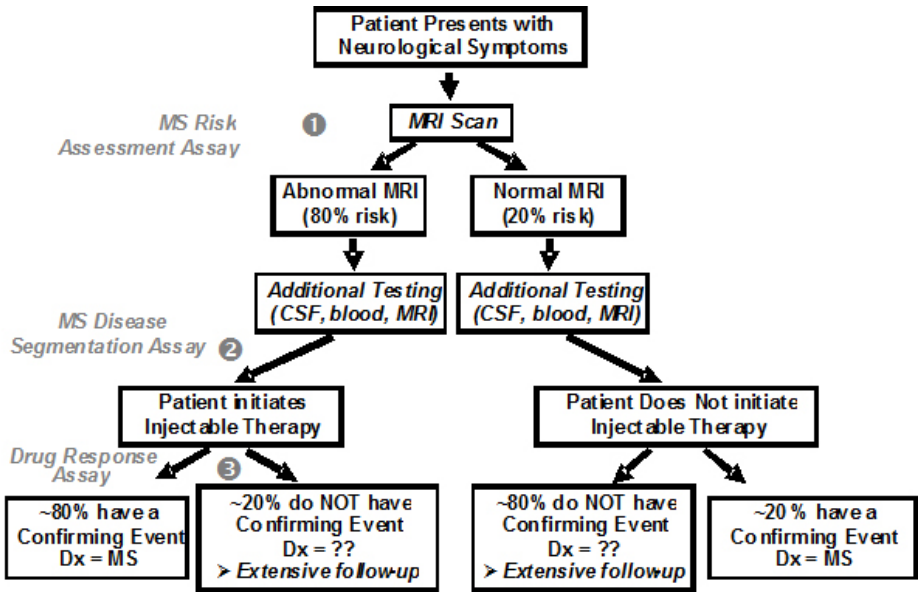

Figure 2: Points of intervention in Current MS Diagnostic Process where MDx assays are most likely to change how patients are treated.

- The current invasive, time-consuming and inaccurate diagnostic process;
- The costs of ineffective diagnosis and treatment;
- **The presence of whole-genome gene expression data for appropriate samples in BioExpress®**.

Figure 2 indicates where new MDx assays are most likely to make a significant difference in the current diagnostic process to improve healthcare for MS patients.

A simple, highly-accurate, blood-based MS Risk Assessment Assay (assay ❶ in figure 2) would significantly reduce the number of spinal taps for CSF tests and MRIs for patients presenting with symptoms of MS. Likewise, a highly-sensitive blood test capable of confirming the diagnosis of MS and differentially diagnosing patients with MS versus patients with related demyelinating diseases, such as TM, NMO, ON, and ADEM (assay ❷ in figure 2) would reduce the costs and uncertainty associated with this complicated disease.

MDx assays also are needed to both predict and monitor therapeutic efficacy (assay ❸ in figure 2). As mentioned above, up to 50% of MS patients on Interferon-beta therapy will continue to experience significant relapses and worsening disability (Byun et al., 2008). The availability of MDx assays capable of predicting which patient will respond to a given drug will help ensure that each patient gets the most appropriate therapy available. Up to 40% of patients on Interferon-beta therapy will develop interferon resistance and no longer respond to this drug. This type of assay, along with an assay that can assess how well a patient is responding to therapy, would provide tremendous benefit to MS patients and forever change how MS patients are treated.

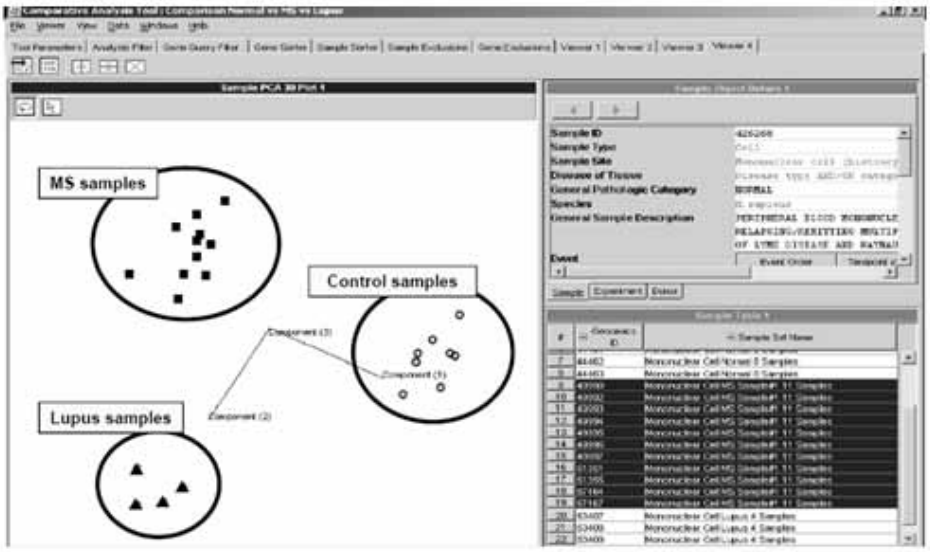

Figure 3: Initial gene signature differentiates between blood samples collected from MS patients, lupus patients and healthy controls

Initial DioGenix MS Study Results

We hypothesized that some number of genes should be differentially expressed in the blood of patients with MS compared to patients with inflammatory demyelination diseases that are difficult to differentiate from MS and healthy individuals. Furthermore, these dysregulated genes would represent the initial set of biomarkers for the development of a blood-based MDx assay that would provide a definitive diagnosis of MS for patients in the early stages of disease progression.

Statistical analysis of data contained in the BioExpress® database identified an initial gene signature comprised of more than 250 genes that are differentially expressed between MS patients, non-MS patients and controls. This preliminary study involved analysis of whole-genome expression data from 19 blood samples including 11 confirmed MS patients and 8 healthy control subjects accrued from a single clinical site (Figure 3).

Figure 3 presents the data from this experiment in graphical form using Principal Components Analysis (PCA). PCA is a mathematical method used to visualize the potential usefulness of a particular gene signature. Tight, well-separated clusters of related samples indicate that the initial gene signature may have clinical utility. Figure 3 demonstrates that one of our initial gene signatures can identify all 11 MS samples within a group of 23 samples that also includes 8 healthy controls and 4 patients with lupus.

Using more rigorous statistical analyses we were able to derive a number of smaller gene signatures with varying assay performance characteristics. These results give confirmation of our original hypothesis and provide us with a large set of candidate diagnostic markers to work with.

To further assess the utility of these biomarkers in a clinical assay, we challenged our gene signatures using additional data residing in the BioExpress® database. We added in data from additional blood samples that were collected from 24 independent MS patients and 2 asthma patients (Figure 4).

We were still able to clearly identify all 35 MS samples. Interesting, the 2

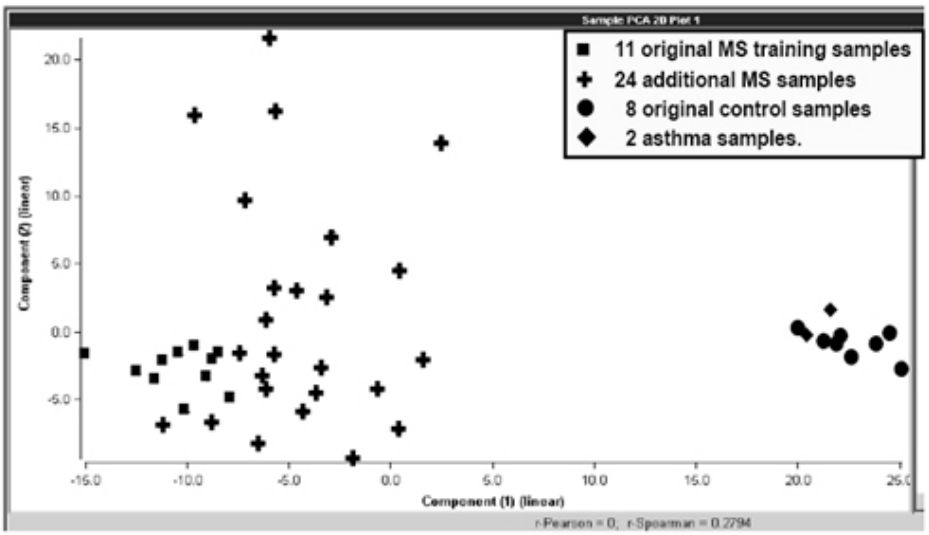

Figure 4: Additional MS samples confirm utility of candidate markers. The original 11 MS samples are represented by squares (■) and the 24 additional MS samples are represented by crosses (✚). Asthma and control samples are represented by (◆) and circles (●), respectively.

asthma samples clustered with the control samples.

Realizing that a commercial diagnostic assay would require use of a smaller set of genes, an attempt was made to develop a "minimal" MS gene signature. We compared the ability of multiple sets of genes (two or more) from the original MS gene signature to properly identify MS samples in a mix of MS, lupus, asthma and control samples. We found that as few as two genes from the original gene signature were able to accurately identify virtually all 35 MS samples (Figure 5).

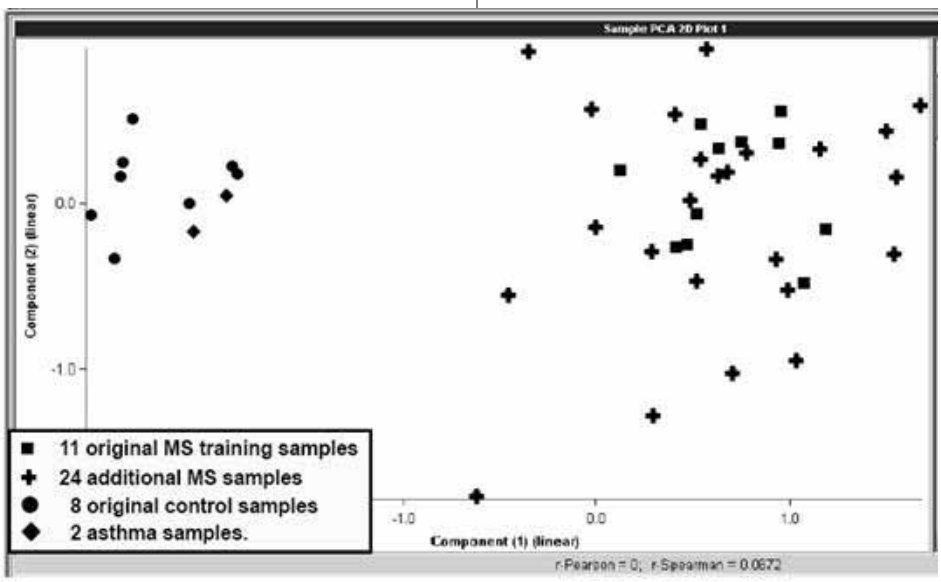

Figure 5: As few as 2 genes are effective in differentiating MS samples from lupus, asthma and control samples. The original 11 MS samples are represented by squares (■) and the 24 additional MS samples are represented by crosses (✚). Asthma and control samples are represented by (◆) and circles (●), respectively.

Again, the two asthma samples clustered with the controls. The 4 lupus samples were clearly distinct from the asthma and control samples but clustered closer to the MS samples. In fact, one lupus sample overlapped with one of the MS samples at the edge of the MS cluster. This is not altogether surprising since MS and SLE are both autoimmune-based diseases.

Although lupus is not really a confounding disease for MS in the clinic, they are related since both are autoimmune diseases. Furthermore, patients with SLE and other autoimmune diseases can display early symptoms similar to MS – and TM. A good discussion of the diagnostic challenges these diseases pose can be found in the article by Julius Birnbaum in the Spring, 2007 issue of The Transverse Myelitis Association Newsletter (Volume 7 Issue 2, page 18). The data presented here demonstrates the potential of this approach.

Asthma is an inflammatory disease of the respiratory system and does not affect the central nervous system. Taken together this data suggests that our signature does not detect patients with miscellaneous autoimmune and inflammatory diseases. This signature appears to be specific for MS, although we do not have access to enough samples from patients with related diseases such as TM, NMO, ON, and ADEM to test whether this signature or one of the smaller signatures derived from this signature is capable of differentiating MS from these other diseases. This is one of the challenges we now face. We need access to blood samples from large numbers of patients with each of these diseases to test this hypothesis. This is critically important for us to determine the sensitivity and specificity of our signatures and complete the clinical validation phase of product development. We hope that we will be able to get these samples from the ACP biorepository in the near future.

Summary

In summary, MS is a complex disease that results from the interplay of both environmental and genetic factors. It is clear that there is a critical need for improved methods to diagnose, prognose, and monitor patients with MS and other demyelination diseases. DioGenix is developing a series of next-generation molecular diagnostic assays that will facilitate 1) the early diagnosis of MS; 2) differentiate MS from other demyelination diseases; 3) predict which patients are most likely to respond to specific drugs; and 4) monitor drug response and resistance in patients receiving therapy.

As discussed above, MS shares many common features with other demyelinating diseases, including TM, NMO, ON and ADEM. For example, inflammation plays a critical role in causing nerve damage, a hallmark of all these diseases. As such, the information we generate studying MS should help elucidate the underlying causes of TM and other demyelinating diseases. Furthermore, this information will provide the framework for the development of diagnostic tests for all these diseases.

However, to accomplish these goals we need access to hundreds of patients diagnosed with MS and patients with TM, NMO, ON and ADEM, as well as healthy controls. We encourage patients with these diseases and family members to get involved and donate blood to The Accelerated Cure Project for MS. This will benefit efforts by DioGenix and others to develop both molecular diagnostic assays and improved therapies for patients with these devastating diseases. Hopefully, some day in the near future, patients presenting with TM, ON or ADEM will be able to undergo a simple blood test and find out whether or not they have experienced a first attack of MS or a one time only demyelinating event. This information with be critically important for deciding on the best short and long term treatment strategies. This can only happen with your help.

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The Transverse Myelitis Association

The membership of The Transverse Myelitis Association includes persons with the rare neuroimmunologic disorders of the central nervous system, their family members and caregivers and the medical professionals who treat people with these disorders. The Transverse Myelitis Association was established in 1994 as an organization dedicated to advocacy for those who have these disorders.

The TMA was incorporated on November 25, 1996 in the state of Washington and became a 501(c)(3) organization on December 9, 1996. The TMA has more than 6,500 members from every state in the United States and from more than 80 countries around the world. There are no membership fees. The TMA is registered with the California Department of Justice, the Maryland Secretary of State, the Ohio Attorney General's Office, and the Washington Secretary of State. The TMA has also been registered with the National Organization of Rare Disorders since 1994.

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A primary care guide to transverse myelitis

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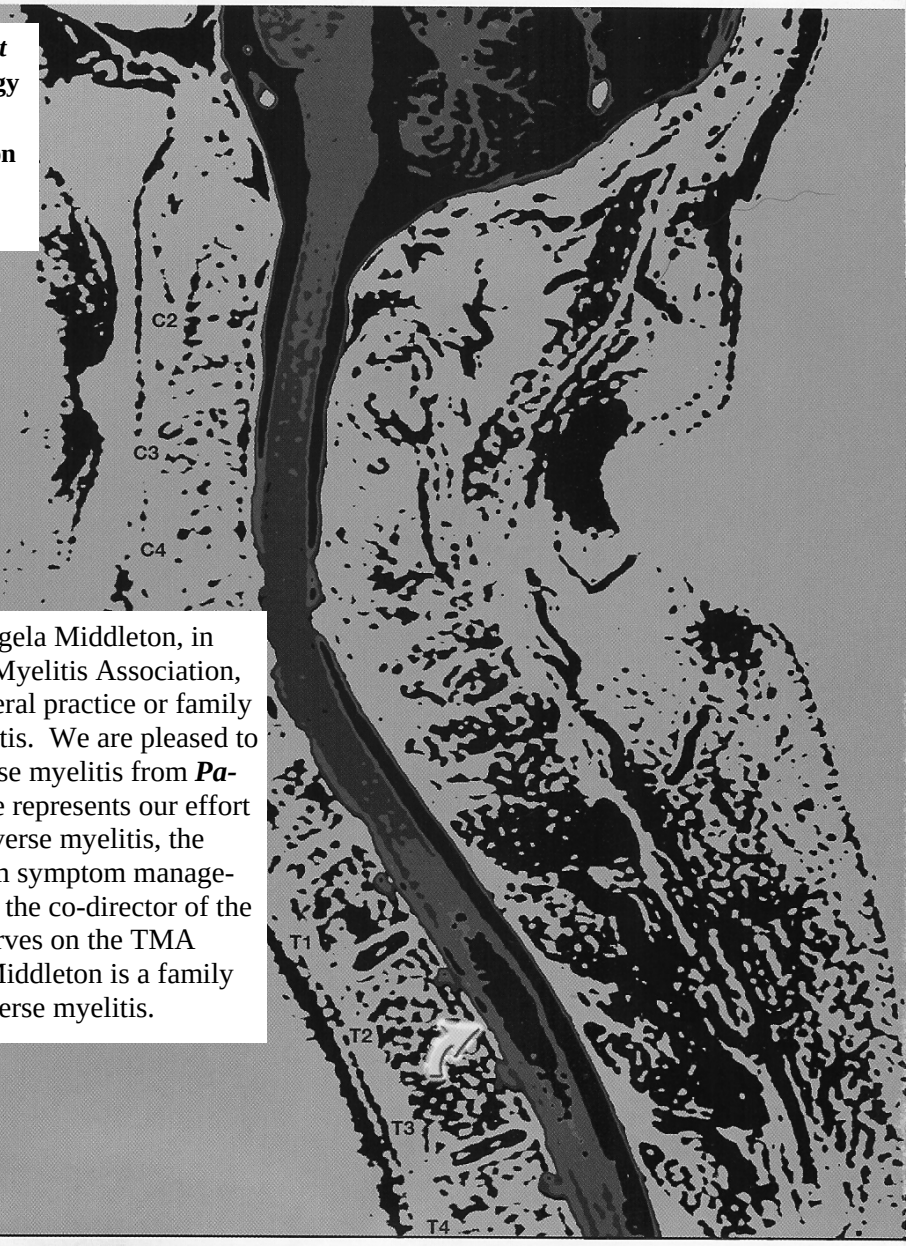

Drs. Benjamin Greenberg and Angela Middleton, in partnership with The Transverse Myelitis Association, have committed to educating general practice or family physicians about transverse myelitis. We are pleased to reprint their article about transverse myelitis from ***Patient Care***. This wonderful article represents our effort to educate physicians about transverse myelitis, the acute treatments and the long-term symptom management strategies. Dr. Greenberg is the co-director of the Johns Hopkins TM Center and serves on the TMA medical advisory board and Dr. Middleton is a family practice physician who has transverse myelitis.

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A primary care guide to transverse myelitis

Patients are being sent home from physician offices and emergency departments in the early stages of transverse myelitis, only to return later completely paralyzed. Here is what you need to know about it.

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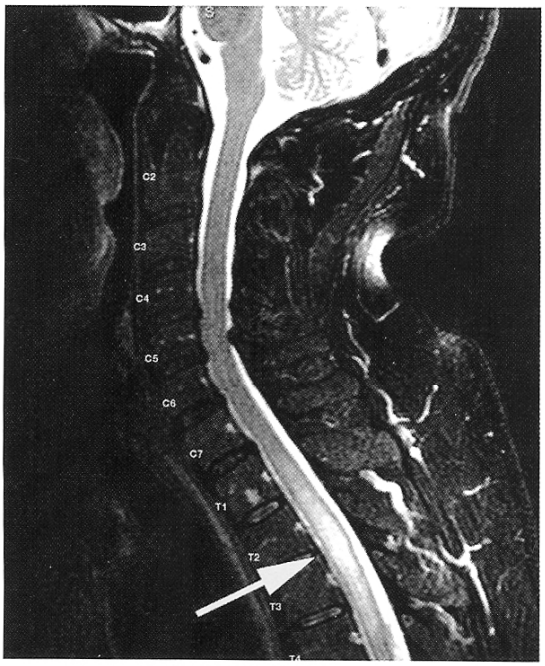
Transverse myelitis (TM) is a neuroimmunologic disorder that presents with a constellation of symptoms involving varying degrees of sensory, motor, and autonomic dysfunction. These symptoms may develop precipitously over a few hours or gradually over a period of several weeks, complicating evaluation and diagnosis. While TM is not a common disease (approximately 1400 new cases per year in the United States), it is both debilitating and treatable, thus requiring an accurate and efficient diagnosis. TM shows no race or gender preference, or familial predisposition. It can affect both children and adults of all ages; however, peak ages are between 10 to 19 years and 30 to 39 years.

This immune-mediated disorder involves inflammatory attacks within the spinal cord that can damage myelin, the protective covering of nerve cells, as well as the axons themselves. When myelin is damaged, nerves have difficulty communicating with the rest of the body. Potential causes of myelitis are numerous and may include infectious diseases, postvaccination adverse event, systemic autoimmune diseases, multiple sclerosis (MS), acute disseminated encephalomyelitis (ADEM), and neuromyelitis optica (NMO). When the culprit cannot be determined, the cause is deemed idiopathic.

VARIABLE PRESENTATION

While TM is a neurologic disorder requiring specialist consultation, initially, patients tend to be seen in either the primary care setting or in the emergency department (ED), depending on their symptoms. Those with acute onset of weakness and bladder dysfunction are more likely to visit an urgent care facility, while patients with subacute onset of sensory symptoms and less motor dysfunction usually visit a primary care provider. Therefore, both ED physicians and primary care physicians are challenged with recognizing this condition and initiating the proper workup.



This T2-weighted sagittal MRI shows a T2 hyperintense lesion from T1 to T4 with some cord edema in a patient with transverse myelitis.

IMAGE: BENJAMIN GREENBERG, MD, MHS, THE JOHNS HOPKINS HOSPITAL AND HEALTH SYSTEM

Sensory dysfunction

A variety of sensory dysfunction symptoms may be the first cause of concern. Adults are more likely to present with paresthesias (ie, burning, tingling) and a sensory level in the midthoracic region than children, who show a higher frequency of cervical spine involvement.[1,2] Other possible symptoms include sensory loss or numbness, heightened or diminished sensitivity to temperature, and allodynia—pain caused by nonpainful stimuli, such as touching the skin or simply wearing clothes. Patients may exhibit vibration or proprioceptive loss, though these may only be evident on physical examination. Patients may also experience pain in the back, abdomen, or extremities, as well as a tight, uncomfortable banding sensation around the trunk. Pain develops in most patients—even those who initially report none. When the maximal level of deficit is reached, 80% to 94% of patients will have numbness, paresthesias, or bandlike dysesthesias.

Weakness

Most patients with TM develop weakness in the lower extremities, to varying degrees. The upper extremities may also be involved depending on the level of spinal cord involvement. At the maximal level of deficit, 50% of patients have lost all leg movement.[3-8] Onset of paralysis tends to be rapidly progressive; complete paralysis can occur within hours. Some patients report muscle spasms initially; in others, spasticity may take time to surface after the acute phase. Regardless of when it appears, spasticity usually requires long-term management.

Autonomic dysfunction

Bladder and bowel dysfunction are common autonomic presentations of TM that occur in most patients. Acute urinary retention is typical, though patients may also note an increased urge to urinate. Constipation, another common TM symptom, may not be realized by the patient at the first evaluation. In the acute phase, the bladder has little or no sensation and, therefore, simply fills with urine. Sometimes the bladder becomes overly distended, causing overflow incontinence. Thus, indwelling catheterization is often required initially. Bladder dysfunction does not necessarily correlate with the severity of changes that may be exhibited by MRI.[9]

DIAGNOSIS

A thorough history and physical examination are essential to the workup and accurate diagnosis of TM, as are timely imaging, CSF analysis, and laboratory testing (see Table 1, page 21). Pleocytosis and an elevated IgG index suggest inflammation and are inclusion criteria for a diagnosis of TM.[10] Differential diagnosis should include ruling out Guillain-Barré syndrome (GBS), which is often confused with TM due to its association with rapidly progressive sensory and motor loss. Fortunately, TM and GBS each have distinguishing features that help prevent misdiagnosis (see Table 2, page 22).

Transverse myelitis

Article at a glance

- The presentation of transverse myelitis (TM) is complex and variable, with different degrees and combinations of sensory, motor, and autonomic symptoms developing either precipitously or gradually.
- At the maximal level of deficit, 80% to 94% of patients with TM have numbness, paresthesias, or bandlike dysesthesias, and 50% of patients have complete paralysis of the legs.
- Upper motor neuron disruption is often evident on physical examination.
- Contrast-enhanced MRI is the modality of choice for diagnosis, and high-dose IV corticosteroids are considered first-line treatment.
- Approximately one-third of patients recover with few or no sequelae, one-third are left moderately disabled, and one-third are left severely disabled.
- Patients may require long-term, outpatient management of chronic pain, bladder and bowel dysfunction, sexual dysfunction, and depression.

History

Many patients report a recent viral illness (involving fever, headache, nausea, vomiting, diarrhea, respiratory symptoms, or muscle pain) in the weeks preceding the onset of TM symptoms.[3-6,8,11-13] Other patients, particularly children, may have had a recent vaccination. Some case reports have demonstrated a close temporal relationship between vaccinations such as influenza or hepatitis B and the onset of TM; however, conclusive evidence is still lacking.[14,15]

Physical examination

Upper motor neuron disruption is often evident on physical examination. Brisk deep tendon reflexes, clonus, and positive Babinski responses are also frequently observed in TM. However, as in any acute spinal cord process, flaccidity and absent deep tendon reflexes may be noted initially. A sensory level can also be documented in most cases and is a reliable sign of spinal cord pathology. Some patients have a positive Lhermitte's sign (ie, shocklike sensations extending down the spine and into the limbs upon flexion of the head), indicating cervical spine involvement. A paraparesis is commonly observed; however, some patients present with complete quadriplegia depending on the size and location of the spinal lesion. Gait may be affected either from loss of proprioception or weakness.

Other physical findings, obtained via exam or history, that should be noted include rash, oral or genital ulcers, dry eyes, decreased salivation, adenopathy, uveitis or retinitis, organomegaly, and pleuritic or pericardial friction rub.[16] Such findings suggest that the TM may be a presentation of a systemic autoimmune disease such as systemic lupus erythematosus, sarcoidosis, Behçet's disease, or Sjögren's syndrome (SS).

Imaging

Rapid attainment of imaging studies is crucial to initiating proper treatment. Unless contraindicated, contrast-enhanced MRI is the modality of choice for TM diagnosis and has 2 primary purposes. The first is to rule out a compressive lesion in the spine. Tumors, herniated discs, spinal stenosis, hematomas, and abscesses can cause acute and subacute myelopathies, but these require very different management. The second purpose of the MRI is to identify areas of inflammation in the spinal cord. TM appears as an area of abnormal signal, typically hyperintense, on T2-weighted images.[17] Active inflammation often leads to enhancement following gadolinium injection, and this finding is one of the diagnostic criteria for TM.[10] Spinal cord swelling may be identified, and the lesion may extend over several spinal segments.[17-21]

A complete MRI study should address the cervical spine, thoracic spine, and brain. Imaging of the brain helps identify cases of MS, ADEM, and NMO, which can present as TM. Myelography, another option for diagnosis, involves the injection of a contrast medium into the subarachnoid space. The patient is then tilted up and down during fluoroscopy, which shows an outline of the spinal cord and any abnormalities. Visual evoked potentials are useful for identifying previous optic nerve damage, suggestive of MS or NMO. Once a structural lesion has been ruled out, CSF should be evaluated for evidence of inflammation.

TREATMENT

The focus of TM therapy is reduction of inflammation. Therefore, diagnosis is followed by first-line treatment with high-dose IV corticosteroids, known for their anti-inflammatory effects on TM's presumed immunopathogenic process.[22] Studies have suggested that this treatment can improve time to ambulation and result in a more favorable motor recovery overall.[22-26] The usual course consists of methylprednisolone sodium succinate (A-methaPred, Solu-Medrol), 1 g/d for 3 to 5 d.

Plasma exchange is considered for moderate to severe TM that is refractory to corticosteroids. Plasma exchange can also be considered in subsets of patients with suspected antibody-mediated disease, such as NMO. Pulse-dose IV cyclophosphamide (Cytoxan, Neosar) is another option for corticosteroid-refractory TM. When TM is believed to be recurrent, chronic immunomodulatory therapy with azathioprine (Azasan, Imuran), methotrexate (Rheumatrex Dose Pack, Trexall), or mycophenolate mofetil (CellCept) should be considered.[27]

LONG-TERM MANAGEMENT

Once the acute phase of TM subsides, most patients are left with sequelae that greatly affect their lives and whose course depends on early physical and occupational therapy. Therapists can help patients regain strength and teach them how to compensate for permanent deficits. Following hospital discharge, many patients will spend extended periods in rehabilitation before returning home.

Chronic pain

Outpatient therapy usually includes management of chronic pain, which, given its neuropathic nature, tends to respond poorly to narcotics. The following medications have proven efficacy in treating residual TM pain: antiepileptics (gabapentin [Gabarone, Neurontin], carbamazepine), antidepressants (amitriptyline), tramadol (Ultram, Ultram ER), and topical lidocaine.[16] Spasticity is another common long-term problem. Antispasticity drugs such as baclofen (Lioresal), tizanidine (Zanaflex), diazepam (Diazepam Intensol, Valium), and botulinum toxin (Botox) injections should be used in combination with active stretching exercises to maintain flexibility.[16]

Bladder and bowel dysfunction

Most patients continue to have some degree of bladder and bowel dysfunction—even those who obtain near or total recovery from other neurologic deficits.[28] Though bladder and urethral sphincter control are initiated in the midbrain and cerebral cortex, damage to the tracts in the spinal cord interrupts ascending sensory and descending motor messages. As spinal function recovers, bladder function also tends to recover. As this happens, patients may develop increased frequency of urination and urge incontinence. They may also have incomplete emptying of the bladder.

It is important for patients to see a urologist for long-term surveillance. Urodynamic studies can be valuable in assessing the particular type of TM-related bladder dysfunction: detrusor external sphincter dyssynergia, detrusor hyperreflexia, and detrusor areflexia, or detrusor hyporeflexia.[9] Depending on the

TABLE 1
Diagnostic tests in transverse myelitis

Imaging studies	Laboratory studies
MRI*	ACE level
Myelography†	ANA
	CBC
CSF studies	Coagulation studies
Cell count with differential	Electrolytes
Glucose level	Glucose
IgG index	HIV panel
Oligoclonal bands	Liver function tests
Protein level	MMA
VZV IgG and IgM‡	RPR
	SS-A and SS-B antibodies
	Urinalysis
	Vitamin B_{12}
	VZV IgG and IgM§

Key: ANA, antinuclear antibodies; MMA, methylmalonic acid; PCR, polymerase chain reaction; RPR, rapid plasma reagin; SS, Sjögren's syndrome; VZV, varicella zoster virus.

*With and without gadolinium contrast.
†Only if contraindication to MRI exists.
§Other viral PCRs, depending on the clinical scenario.
‡Other viral serologic studies as indicated.

■ Transverse myelitis

Drugs mentioned in this article

Amitriptyline
Azathioprine (Azasan, Imuran)
Baclofen (Lioresal)
Botulinum toxin (Botox)
Carbamazepine
Cyclophosphamide (Cytoxan, Neosar)
Diazepam (Diazepam Intensol, Valium)
Gabapentin (Gabarone, Neurontin)
Lidocaine, topical
Methotrexate (Rheumatrex Dose Pack, Trexall)
Methylprednisolone sodium succinate (A-methaPred, Solu-Medrol)
Mycophenolate mofetil (CellCept)
Tizanidine (Zanaflex)
Tramadol (Ultram, Ultram ER)

type of dysfunction, treatment may include medications, intermittent catheterization, electrical stimulation, or surgery. Patients should also be monitored for urinary tract infections, though the presence of bacteria without symptoms does not warrant treatment with antibiotics. Bowel dysfunction can be improved with a high-fiber diet, increased fluid intake, digital disimpaction, and a good bowel regimen obtained with prescription and OTC products.[16]

Sexual dysfunction

Due to similar innervation, sexual dysfunction often parallels bladder dysfunction. Phosphodiesterase V inhibitors can help men achieve adequate erections for intercourse. To a lesser extent, these medicines can help enhance sexual functioning in women.[27]

Depression

Coping with a condition such as TM can be both physically and emotionally demanding, as evidenced by the large number (25%) of patients with TM who become clinically depressed, irrespective of their level of disability.[27] Furthermore, suicide is the leading cause of death in TM. Patients should be routinely screened for signs and symptoms of clinical depression. Fortunately, patients with TM seem to respond favorably to medications and counseling.[27]

PROGNOSIS

Most patients with TM experience some degree of neurologic recovery but are also left with neurologic deficits. Though recovery is more rapid in the first 6 months after symptom onset, patients can experience some improvement for up to 2 years.[1-2,5,8,11] Approximately one-third recover with little or no sequelae, one-third are left moderately disabled, and one-third are left severely disabled.[3-8,11-13] Bad prognostic indicators include back pain at onset, rapid progression to maximal symptoms within hours, spinal shock, and sensory involvement up to the cervical level.[1,8,13,29,30] Lack of any improvement in the first 3 to 6 months makes significant recovery less likely.

Recurrence, which affects a small percentage of patients, is more likely in the presence of multifocal lesions within the spinal cord, demyelinating lesions in the brain, oligoclonal bands in the CSF, mixed connective tissue disorder, and serum autoantibodies (most notably SS-A).[31] Patients with longitudinally extensive TM—indicated by T2 signal abnormality extending over at least 3 vertebral segments—may go on to be diagnosed with NMO—a severe relapsing demyelinating disease.

TABLE 2
Differentiating transverse myelitis from Guillain-Barré syndrome

Characteristics	TM	GBS
Preceding viral illness	++	++
Rapidly progressive sensory and motor loss	+++	+++
Identifiable spinal cord sensory level	+++	
Brisk deep tendon reflexes	+++	
Absent deep tendon reflexes	+	+++
Loss of bowel/bladder function	+++	
Normal spinal MRI	+	+++
CSF pleocytosis	+++	
Elevated CSF protein	++	+++
Elevated IgG index	+++	

Key: +, may be observed; ++, commonly observed; +++, usually observed; GBS, Guillain-Barré syndrome; TM, transverse myelitis.

NMO selectively affects the spinal cord and optic nerve resulting in distinct episodes of TM and optic neuritis. Further testing is recommended, since prophylaxis therapy can reduce relapse frequency.[32-34] In all cases of relapse, the potential for an underlying disorder should be investigated.

In some patients, TM may be the first manifestation of MS. These individuals are more likely to have asymmetrical clinical findings, predominantly sensory symptoms, MR lesions extending over fewer than 2 spinal segments, abnormal findings on brain MRI, and oligoclonal bands in the spinal fluid.[18-19,35-39] Brain imaging in MS often shows multiple cerebral lesions in the white matter. These generally asymptomatic lesions are 80% to 90% predictive of MS.[35,40] The fact that long-term treatment for MS is very different from long-term treatment for TM reinforces the importance of obtaining brain imaging at the time of TM presentation. □

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Drs Middleton, Greenberg, and Foliaco disclose that they have no financial relationship with any manufacturer in this area of medicine.

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CME

Revised diagnostic criteria for neuromyelitis optica

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Abstract—*Background:* The authors previously proposed diagnostic criteria for neuromyelitis optica (NMO) that facilitate its distinction from prototypic multiple sclerosis (MS). However, some patients with otherwise typical NMO have additional symptoms not attributable to optic nerve or spinal cord inflammation or have MS-like brain MRI lesions. Furthermore, some patients are misclassified as NMO by the authors' earlier proposed criteria despite having a subsequent course indistinguishable from prototypic MS. A serum autoantibody marker, NMO-IgG, is highly specific for NMO. The authors propose revised NMO diagnostic criteria that incorporate NMO-IgG status. *Methods:* Using final clinical diagnosis (NMO or MS) as the reference standard, the authors calculated sensitivity and specificity for each criterion and various combinations using a sample of 96 patients with NMO and 33 with MS. The authors used likelihood ratios and logistic regression analysis to develop the most practical and informative diagnostic model. *Results:* Fourteen patients with NMO (14.6%) had extra-optic-spinal CNS symptoms. NMO-IgG seropositivity was 76% sensitive and 94% specific for NMO. The best diagnostic combination was 99% sensitive and 90% specific for NMO and consisted of at least two of three elements: longitudinally extensive cord lesion, onset brain MRI nondiagnostic for MS, or NMO-IgG seropositivity. *Conclusions:* The authors propose revised diagnostic criteria for definite neuromyelitis optica (NMO) that require optic neuritis, myelitis, and at least two of three supportive criteria: MRI evidence of a contiguous spinal cord lesion 3 or more segments in length, onset brain MRI nondiagnostic for multiple sclerosis, or NMO-IgG seropositivity. CNS involvement beyond the optic nerves and spinal cord is compatible with NMO.

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Neuromyelitis optica (NMO; Devic syndrome) is a clinically defined, severe CNS demyelinating syndrome characterized by optic neuritis (ON) and acute myelitis; the presence of CNS symptoms outside the optic nerves and spinal cord has until recently excluded the diagnosis.[1-3] Traditionally, the term NMO was applied to patients who experienced a monophasic event consisting of bilateral simultaneous optic neuritis and acute myelitis.[4] The NMO spectrum is now recognized to typically evolve as a relapsing disorder that also includes patients with unilateral ON and those with index events of ON and myelitis occurring weeks or even years apart.[5]

Early and accurate diagnosis is important because NMO carries a poorer prognosis than MS and generally accepted treatment approaches differ.[3,6] In 1999, we proposed NMO diagnostic criteria with three absolute requirements: ON, acute myelitis, and no symptoms implicating other CNS regions.[8] To enhance specificity, fulfillment of at least one of three major supportive criteria was required: 1) brain MRI at disease onset is normal or does not fulfill MS imaging criteria; 2) spinal cord MRI shows a lesion extending over ≥3 vertebral segments; and 3) CSF reveals ≥50 WBC/mm^3 or ≥5 neutrophils/mm^3. Alternatively, fulfilling two of three minor supportive criteria (bilateral ON, severe residual visual loss, or severe fixed post-attack weakness) suffices. We derived the criteria empirically and suggested that they be validated and may require revision.

International experience using the 1999 diagnostic criteria generally concurs with ours.[7-10] However, the criteria have limitations. They fail to capture patients with a disease course otherwise highly compatible with NMO but whose neurologic symptoms or signs implicate CNS regions outside the optic nerves and spinal cord or whose brain MRI reveals lesions that may meet MS imaging criteria.[9,11] Therefore, the full spectrum of the disease may be underappreciated. On the other hand, occasional MS patients

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with ON and an attack of partial myelitis may have an initial negative brain MRI, therefore fulfilling NMO criteria at least early in their clinical course.

Substantial evidence, including clinical, laboratory, neuroimaging, and immunopathologic data, suggests that NMO is distinct from MS; however, no diagnostic gold standard has been established.[12,13] An objective biomarker would enhance diagnostic certainty and definition of the NMO disease spectrum. The serum autoantibody NMO-IgG, which targets aquaporin-4, is a good candidate because it is >90% specific for NMO in patients presenting with an optic-spinal syndrome and is not detected in patients with classic MS.[14,15] NMO-IgG seropositivity also predicts relapse and conversion to NMO in patients presenting with a single attack of longitudinally extensive myelitis.[16]

We hypothesized that individual components of current NMO criteria differ in their diagnostic properties and that a quantitative evaluation of these criteria, with incorporation of the NMO-IgG disease marker, would allow formulation of optimal criteria to discriminate NMO from MS.

Methods. *Patients.* We evaluated the characteristics of 129 patients ascertained through the MS centers at Mayo Clinic sites in Rochester, MN, and Scottsdale, AZ, and tested for NMO-IgG. Typically, these patients had attacks of optic neuritis, myelitis, and had a normal MRI scan of the head, or one that was deemed to show minimal findings. We maintain a central database of demographic, clinical, imaging, and laboratory data from patients who present with syndromes compatible with NMO, transverse myelitis, or relapsing myelitis. Data are entered by one of the study neurologists who has either evaluated the patient or reviewed the medical record. The cohort (1999 to 2005) considered in this study is independent from that used to generate the 1999 diagnostic criteria.

Diagnosis. The reference standard for the study was a diagnosis of NMO or MS based on the final clinical diagnosis rendered by the study neurologist based on his or her integration of all available clinical, imaging, and laboratory data and the period of follow-up after disease onset. Patients must have had at least one attack of ON and myelitis to be eligible for the study. Those with a final diagnosis of MS comprise a group who presented with ON and myelitis combinations that suggested the possibility of NMO; patients with demyelinating disease syndromes in whom NMO was not an initial consideration were not included. Because we recognize the limitations of the 1999 Mayo Clinic criteria, we did not apply them formally for diagnosis for the purposes of this study but relied instead on the clinician's final diagnosis based on all clinical information and available information for the subsequent course. The clinical diagnoses were finalized without knowledge of the NMO-IgG serologic status in all cases except two who were not seen at Mayo Clinic but were ascertained because they were found to be NMO-IgG positive; diagnostic information was obtained from the referring neurologist in those cases.

NMO-IgG status. The Mayo Clinic Neuroimmunology Laboratory tested all serum samples for NMO-IgG using an indirect immunofluorescence technique described elsewhere.[15,17] Sera were scored as positive or negative by two independent evaluators (V.A.L. and S.J.P.) and titrated in doubling dilutions to determine the greatest dilution that remained positive. The assay evaluators were unaware of the clinical diagnosis. No serum was classified as equivocal or indeterminate and positive and negative scores were concordant.

Clinical data. Demographic and clinical information included sex, date of birth, age at disease onset, ethnicity (white or nonwhite, based on patient self-report), personal or family history of autoimmune disease, and family history of demyelinating disease. Neurologic symptoms and signs were recorded; for the purposes of criterion evaluation, we determined the occurrence and number of episodes of optic neuritis and myelitis and whether patients had experienced neurologic events implicating CNS regions other than the optic nerve or spinal cord. Motor weakness was graded using the Medical Research Council scale and was termed severe if more than one muscle in an affected limb was scored as 2 or less.

Available brain MRI studies were evaluated using Paty criteria, which require presence of four or more white matter lesions or three lesions when one is periventricular.[18] We used these older MRI criteria to ensure diagnostic consistency with our earliest cases. We recorded results as normal, abnormal but not meeting Paty criteria, or meeting Paty criteria. The brain MRI at disease onset was used if available; however, if a later scan was available and was negative, we assumed the onset scan also was negative. Spinal cord MRI studies were similarly reviewed and results recorded as normal, abnormal with a T2-weighted cord lesion extending over three or more vertebral segments, or abnormal with a smaller lesion or confluent lesions not suggestive of NMO. CSF leukocyte count and differential data were categorized as follows based on the 1999 criteria: WBC greater than 50/mm^3 or not; neutrophil count greater than 5/mm^3 or not. Serologic data, beyond NMO-IgG status, included the detection of one or more serum autoantibodies (antinuclear, extractable nuclear antigen, double-stranded DNA, rheumatoid factor, cardiolipin, thyroid or intrinsic factor antibodies). When data were not available, or the test not performed, that element was removed from analysis for that patient. We required valid data for at least two of the following supportive features: brain MRI, spinal cord MRI, and CSF results.

Evaluation of diagnostic properties. We compared NMO and MS patients with respect to demographic, clinical, and follow-up data as well as the frequency of meeting each individual diagnostic criterion; differences were determined using χ^2, Fisher exact, or t tests as appropriate (alpha = 0.05). We calculated sensitivity and specificity estimates for each criterion using the clinical diagnosis of NMO as the reference standard. We then evaluated the relative clinical utility of each test by comparing likelihood ratios (LR) for positive (sensitivity divided by 1 – specificity) and negative (1 – sensitivity divided by specificity) test results. For each estimate, 95% CIs were calculated. LRs are more useful than sensitivity and specificity because they may be used to adapt the results of a study to an individual patient using the principles of Bayes theorem and determination of pretest and post-test odds of disease presence.[19] LRs of >10 for a positive test result or <0.1 for a negative test result are expected to yield a conclusive change in the post-test odds of disease presence.

We used the LR data to guide construction of new diagnostic models, each consisting of two or three of the most accurate individual variables. We then evaluated the models in several ways. First, we calculated LR and associated CIs for each model. Second, we plotted receiver operator characteristic (ROC) curves for each model with sensitivity of a positive result on the y-axis and (1 – specificity) on the x-axis.[20] The area under each ROC curve (AUC) was then calculated as a measure of the overall discrimination that each variable or combination of variables can provide between NMO and MS. AUC values may be calculated for different diagnostic tests and then compared to one another.[21] An AUC of 1 represents a perfectly discriminatory test; an area of 0.5 represents a test that discriminates no better than random chance.[22] Finally, we used logistic regression methods to estimate ORs for each model.[23] The reference standard diagnosis was the dependent variable (NMO = 1; MS = 0) and individual variables or models were included as independent variables (positive test result = 1; negative result = 0). Goodness-of-fit was evaluated using the Hosmer-Lemeshow test.

Results. Demographic and clinical features of the sample are summarized in table 1. Women outnumbered men in both the NMO and MS groups but the NMO cohort was more likely to be nonwhite and older than 35 years at disease onset. Eighty-one (84.4%) of the 96 patients with NMO had an established relapsing disease course (at least one additional attack of either ON or myelitis after experiencing index attacks of initial ON or myelitis) at last follow-up (median 35 months; IQR = 4 to 48 months). More relapses occurred in patients with NMO than in pa-

Table 1 *Demographic and clinical features of patients with NMO and MS*

Characteristic	Valid n	NMO	MS	*p* Value
N (total)	129	96	33	
Female, n (%)	127	80/94 (85.1)	26/33 (78.9)	0.401
Non-caucasian, n (%)	119	35/91 (38.5)	2/28 (7.1)	0.002
Mean age of onset, y (SD)	123	37.8 (18.1)	32.4 (8.3)	0.113
Age onset > 35.0 y	123	56/92 (60.9)	10/31 (32.3)	0.006
Mean ON events (SD)	128	2.1 (1.5)	1.4 (1.4)	0.033
Mean myelitis events (SD)	128	3.4 (3.0)	1.8 (1.6)	0.006
Median follow-up, mo (IQR)	121	37 (21–85)	42 (18–103)	0.862
History of autoimmunity	112	23/83 (27.7)	9/29 (31.0)	0.733
Seropositivity for non-organ-specific autoantibodies	110	41/82 (50.0)	12/28 (42.9)	0.514
Family Hx autoimmunity	88	24/38 (63.2)	9/26 (34.6)	0.025
Family Hx demyelinating dis.	99	9/73 (12.3)	1/26 (3.8)	0.284

NMO = neuromyelitis optica; MS = multiple sclerosis; n = number of patients with validated data for each characteristic; Hx = history; ON = optic neuritis; IQR = interquartile range.

tients with MS despite similar follow-up duration. The frequencies of coexisting systemic autoimmune disease and seropositivity for non-organ-specific serum autoantibodies were similar in NMO and MS but a family history of autoimmune disease was more frequent in the NMO group.

At some time prior to diagnosis, 14 NMO patients (14.6%) had experienced neurologic symptoms indicating disease outside the optic nerves and spinal cord. Their characteristics are summarized in table E-1 (available on the *Neurology* Web site at www.neurology.org). In one case, vomiting was noted in association with a medullary lesion imaged by MRI, but in another case, vomiting was encountered without a demonstrable MRI lesion. Encephalopathy was associated with massive hemispheric lesions in one case, but in other instances of encephalopathy no definite inflammatory lesions were present. In these cases, a clinical diagnosis of NMO was reached on the basis of other clinical and laboratory features together with evaluation of the follow-up course.

Table E-2 summarizes the diagnostic properties of the 1999 criteria, individual components of those criteria, and NMO-IgG. The 1999 criteria were 85% sensitive but only 48% specific for NMO. The acceptance of extra-optic-spinal symptoms allowed for identification of all NMO cases but reduced the sensitivity to only 24%. This analysis confirms that the 1999 diagnostic criteria have inadequate diagnostic accuracy.

For more than 90% of patients we had valid data for all variables except CSF analysis. Individual variables with significant discriminative power included MRI evidence of a longitudinally extensive spinal cord lesion (sensitivity 98%, specificity 83%) and NMO-IgG seropositivity (sensitivity 76%, specificity 94%). The likelihood ratios for these variables demonstrate that NMO-IgG seropositive status (LR [+] = 12.2) or the absence of a longitudinally extensive cord lesion (LR [–] = 0.03) would have a large impact on the post-test probability of NMO diagnosis.

Table 2 and table E-3 summarize the diagnostic properties of combinations of variables and the modeling procedure. We did identify a combination with perfect sensitivity but inadequate specificity (model 3) and another that was entirely specific but insufficiently sensitive (model 4). Goodness-of-fit tests were not significant. By exploring several models that included multiple variables and interaction terms (not all shown), we found that the combination of a longitudinally extensive spinal cord lesion together with an onset brain MRI scan that does not meet MS (Paty) criteria was 94% sensitive and 96% specific for NMO. Addition of NMO-IgG seropositivity to this pair of variables created three supportive criteria. The model requiring at least two of these three supportive criteria for NMO diagnosis resulted in a nearly identical predictive model with 99% sensitivity and 90% specificity ($p < 0.0001$).

We evaluated several combinations of variables that in-

Table 2 *Diagnostic accuracy for NMO diagnosis of models combining clinical criteria and NMO-IgG status**

Model	Evaluable n (%)	NMO	MS	Sensitivity	Specificity	LR(+)	LR(–)
Model 1							
Cord lesion ≥3 segments AND onset MRI brain nondiagnostic	111/129 (86.1)	79/84 (94.1)	1/27 (3.7)	94 (89–99)	96 (89–100)	25.4 (3.71–174)	0.06 (0.03–0.15)
Model 2	117/129 (90.7)	61/84 (72.6)	2/33 (6.1)	73 (63–82)	94 (85–100)	12.0 (3.11–46.2)	0.57 (0.44–0.71)
NMO-IgG positive AND onset MRI brain nondiagnostic							
Model 3							
Cord lesion ≥3 segments OR NMO-IgG positive	129 (100)	96/96	7/33 (21.2)	100	79 (65–93)	4.71 (2.45–9.10)	0
Model 4							
≥3 segments AND NMO-IgG positive	114/129 (88.4)	63/86 (73.3)	0/28	73 (64–83)	100	∞	0.27 (0.19–0.38)
Model 5							
2 of 3 criteria	121/129 (93.8)	89/90 (98.9)	3/31 (9.7)	99 (97–100)	90 (80–100)	10.2 (3.49–30.0)	0.01 (0.002–0.09)
Cord lesion ≥3 segments							
Onset MRI brain nondiagnostic							
NMO-IgG positive							

* Not all evaluated models are shown.

Parentheses denote percent for proportion or 95% CI for point estimates of sensitivity, specificity, and likelihood ratios (LR).

NMO = neuromyelitis optica; MS = multiple sclerosis.

Table 3 *Proposed diagnostic criteria for neuromyelitis optica (NMO)*

Definite NMO
Optic neuritis
Acute myelitis
At least two of three supportive criteria
1. Contiguous spinal cord MRI lesion extending over ≥3 vertebral segments
2. Brain MRI not meeting diagnostic criteria for multiple sclerosis
3. NMO-IgG seropositive status

cluded one or both of CSF abnormalities or severe weakness, variables that were used to support NMO diagnosis in the 1999 diagnostic criteria. Although we confirmed that these features are more suggestive of NMO than MS, the best model (one of the three supportive criteria plus either severe, fixed, post-attack motor weakness or CSF pleocytosis >50 WBC/mm^3 or neutrophils >5/mm^3) achieved only 87% sensitivity and 85% specificity.

Discussion. We propose revised NMO diagnostic criteria that remove the absolute restriction on CNS involvement beyond the optic nerves and spinal cord and emphasize the specificity of longitudinally extensive spinal cord lesions and NMO-IgG seropositivity (table 3). Although brain MRI findings are generally either negative or nonspecific in NMO, brain lesions do not preclude the diagnosis.[9,24] CSF pleocytosis or neutrophilia and the occurrence of severe, fixed, attack-related motor weakness were also validated as characteristic features of NMO but with less diagnostic power. A history of systemic autoimmunity or presence of non-organ-specific autoantibodies was common in both NMO and MS but did not distinguish them. Our results provide quantitative data to support clinical NMO diagnostic criteria and are the first to incorporate the NMO-IgG biomarker.

Derivation or revision of valid diagnostic criteria in the absence of a pathologic or quantitative reference standard poses a difficult challenge. Ideally, the reference standard and the diagnostic test are evaluated in every subject independently and in blinded fashion. In our study, although we used 1999 Mayo Clinic NMO criteria as a guideline, we did not formally apply them to establish the reference standard. Therefore, we believe that our approach of evaluating each individual criterion and then constructing new combinations with optimal diagnostic properties is valid. The database allows maintenance of independence among the reference standard diagnosis, individual criteria, and the NMO-IgG result.

Our results highlight the difficulties inherent in using arbitrary and subjective clinical criteria for diagnostic purposes. The tradition of excluding NMO as a diagnostic possibility in a patient who has experienced any extra-optic-spinal neurologic symptoms is no longer valid. Continued use of this arbitrary requirement will undoubtedly provide a pure cohort but precludes a valid and complete assessment of the spectrum of NMO. The concept of pure NMO should be abandoned. Our data demonstrate that a wide variety of neurologic symptoms may precede or accompany NMO and may or may not be associated with an identifiable CNS lesion.

The revisions we propose improve the diagnostic properties of NMO criteria. It is imperative, however, that individual components be ascertained appropriately. Brain MRI results at disease onset must be reviewed if follow-up scans reveal lesions that meet MS criteria. We used older (Paty) MRI diagnostic criteria for MS[18] rather than those in current use[25] for purposes of consistency. However, because newer criteria are designed to enhance specificity for MS, failure to meet the more sensitive Paty criteria[26] should more likely yield a true negative result. The spinal cord MRI manifestation of a longitudinally extensive lesion is the single most useful diagnostic test but is also subject to timing issues, since a lengthy T2-weighted lesion may not have developed fully in the first few days after clinical symptom onset or it may have contracted or resolved with time. Some degree of redundancy and flexibility in the diagnostic criteria, such as the minimum requirement of only two of three supportive criteria, is therefore most practical for clinical use and we have demonstrated equivalent diagnostic properties with this model. The onset brain MRI and the initial spinal cord MRI are available after the presentation of the first myelitis event. Since diagnosis requires only two of three supportive criteria, access to NMO-IgG testing is not necessary to use this system.

Some of the difficulties noted above may be eliminated if additional biomarkers can be identified for NMO. The NMO-IgG autoantibody was 76% sensitive and 94% specific for a final clinical diagnosis of NMO. This is a powerful and clinically meaningful result since this cohort represents patients with optic-spinal disease, not other typical forms of MS, and the determination of whether a patient has NMO or MS may be difficult. The autoantigen to which NMO-IgG binds was recently shown to be aquaporin-4,[14] the principal water channel involved in fluid homeostasis in the CNS.[27] The involvement of aquaporin-4 in the pathogenesis of NMO has not yet been investigated. However, the specificity of the antibody as a marker for NMO and its immunoreactive sites in the spinal cord (abluminal surface of blood vessels and astrocytic foot processes),[28] where pathology occurs in NMO,[13] is consistent with it being a primary effector of disease rather than a secondary or nonspecific phenomenon.

We derived our data from a group of patients who had already experienced both optic neuritis and acute myelitis. However, the biomarker NMO-IgG is proving to be predictive of NMO development after a first event of longitudinally extensive idiopathic acute transverse myelitis.[16] Thus our newly proposed criteria will likely require further revision to include disorders that represent inaugural symptoms of NMO or limited NMO variants, including recurrent myelitis associated with negative brain MRI, recur-

rent isolated optic neuritis, or isolated optic neuritis or myelitis presentations associated with NMO-IgG seropositivity. Use of these criteria, and future refinements that allow earlier diagnosis, is also of therapeutic importance. Although existing reports include only small open-label experience and no randomized controlled trials, the generally accepted approach for attack prevention in NMO is immunosuppression using therapies that reduce serum autoantibody levels[6,29,30] rather than immunomodulation with currently approved MS therapies.[31]

We believe that the revised diagnostic criteria we propose represent an important advance in NMO research and clinical practice. The criteria for definite NMO diagnosis are simple, practical, and have excellent diagnostic accuracy. They discriminate NMO from MS beginning with optic neuritis and myelitis, a scenario in which NMO is a reasonable initial diagnostic consideration. Further validation and refinement of these diagnostic criteria, application to individuals of different ethnic and racial backgrounds in different countries and clinical settings, and continued evaluation of NMO-IgG and future biomarkers are necessary next steps in advancing the diagnosis and reducing the morbidity and mortality of this often devastating disorder.

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Article Title: Neuromyelitis Optica and Non–Organ-Specific Autoimmunity

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Background

Neuromyelitis optica (NMO) is a condition causing either or both attacks of optic neuritis or transverse myelitis. The acute attacks of myelitis occurring in patients with NMO are associated with MRI lesions in the spinal cord that are 3 vertebral bodies in length or longer (longitudinally extensive transverse myelitis or LETM). At Mayo Clinic, we recently discovered that NMO patients usually have antibodies in their blood that react with a protein called aquaporin-4, and this is now a specific test for NMO (NMO-IgG). Patients with systemic lupus erythematosus (SLE) or Sjogren's disease occasionally develop myelitis or optic neuritis. It is also the case that patients with myelitis and optic neuritis may be found to have autoantibodies in their blood and occasionally will develop clinical symptoms suggestive of SLE or Sjogren's disease after they are diagnosed with myelitis or optic neuritis. In these circumstances, they are usually diagnosed as having a complication of their SLE or Sjogren's syndrome. We suspected, however, that this may represent coexistence between neuromyelitis optica (NMO) and SLE or Sjogren's, rather than SLE or Sjogren's being the cause of the myelitis and optic neuritis.

Methods

We evaluated 153 US patients with NMO-type illnesses, either with both optic neuritis and myelitis or with transverse myelitis and positive test results for NMO-IgG. We also evaluated 14 French patients with NMO-type illnesses occurring in patients with systemic lupus or Sjogren's and 4 with NMO-type illness without systemic lupus or Sjogren's. Control patients from both the US and France included patients with SLE or Sjogren's without NMO symptoms. These patients were tested for NMO-IgG.

Results and Conclusions

1. No patient without NMO symptoms, including all the patients with SLE or Sjogren's was seropositive for NMO-IgG. This indicates that the NMO-IgG test is specific for NMO and is not falsely positive in SLE or Sjogren's patients.

2. About half of patients with NMO-type illnesses and SLE or Sjogren's were seropositive for NMO-IgG, and this was no different than those with NMO without these conditions. This suggests that optic neuritis and myelitis occurring in the context of SLE or Sjogren's is likely due to coexisting NMO.

3. Almost half of patients with NMO in the US had antibodies that could be associated with SLE, and about 15% antibodies associated with Sjogren's disease; rarely did these patients have clinical symptoms of SLE or Sjogren's. Thus, although patients with NMO frequently have autoantibodies that are found in SLE or Sjogren's, they do not commonly develop symptoms of these conditions.

4. Other autoimmune diseases occurred in approximately 20% of patients, the most common of which is autoimmune thyroid disease.

Practical Implications

1. If patients develop transverse myelitis (LETM) or optic neuritis and if they have a positive blood test consistent with SLE or Sjogren's disease, they likely have NMO **as well as** SLE or Sjogren's. The LETM or ON are not likely a direct complication of SLE or Sjogren's. There is at least a 50% chance that NMO-IgG will be positive and confirm the diagnosis of NMO. The chances that they will develop symptoms of SLE or Sjogren's is low, but still increased over the risk in the general population. Treatments directed at NMO are most appropriate in that circumstance.

2. Patients with NMO may develop other autoimmune disease more frequently than patients with MS, and should be monitored for these conditions.

The full text of this article may be read at the following link:
http://archneur.ama-assn.org/cgi/reprint/65/1/78.pdf?ijkey=pmBXnBsal3QNcQk&keytype=finite

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Rheumatic Diseases and Transverse Myelitis

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1) Introduction: The importance of a broad surveillance for rheumatic diseases in all patients with TM

My background as both a rheumatologist and a neurologist has reinforced the importance of ruthlessly pursuing the myriad causes of transverse myelitis. In most cases, transverse myelitis is "idiopathic," meaning that there is no known identifying cause. However, a subset of patients with transverse myelitis will have a background rheumatological disease, requiring a specific therapeutic strategy. Systemic rheumatic diseases are clinical syndromes where the body's immune system becomes maladaptive. Normally charged with protecting vital organs from infection and cancers, the body's immune system becomes a turncoat, ravaging the same vital organs. When disease is truly ***systemic,*** causing obvious clinical distress, such as fever or weight loss, rashes, joint pains and swelling, or kidney failure, then the presence of these rheumatic diseases is promptly considered, with treatment and therapy depending on further diagnostic evaluation.

At the Johns Hopkins Myelitis Center, I have established a Clinic devoted towards the care and evaluation of patients with neurological complications occurring in the context of systemic rheumatic disease. In the past two years, I have cared for patients with transverse myelitis evolving in the context of a wide array of rheumatic syndromes. In some cases, the background autoimmune disease is evident, for example, lupus can cause an inflammatory syndrome, which may include rashes, joint pains, and kidney damage. When patients with this constellation of symptoms and signs present with transverse myelitis, then the physician may already suspect an underlying rheumatic disease. However, in other cases, the symptoms suggestive of a rheumatic disease may be more circumspect and subtle.

Many rheumatic diseases are associated with abnormal production of proteins, called "autoantibodies." Antibodies reflect the ***normal*** and elegant repertoire of our body's capability to manufacture proteins capable of neutralizing a wide spectrum of infections. In rheumatic diseases, autoantibodies are ***abnormal*** and maladaptive, attacking crucial proteins on the body's cell and genetic material.

In this article, I discuss our increasing understanding of an important class of autoantibodies, called "antiphospholipid antibodies" (referred to hereafter as aPL antibodies), which can be seen in patients with transverse myelitis. I review specific clinical contexts in which aPL antibodies may be contributing to transverse myelitis. I emphasize the spectrum of treatment options which should be considered in patients with aPL antibodies. Finally, I communicate to the Transverse Myelitis Community planned research studies that we will undertake, which will incorporate sophisticated neuroimaging studies, and which will help in disclosing the causes of transverse myelitis in patients with aPL antibodies.

2) What are antiphospholipid antibodies, and what is antiphospholipid antibody syndrome?

As noted above, antibodies represent the sophistication of our biochemical machinery to neutralize damage from infections and cancers. In systemic rheumatic disease, the orchestrated and controlled production of antibodies goes awry; there is proliferation of these same autoantibodies against our own cells. Antiphospholipid antibodies (aPL antibodies) target the cell layers which are involved in regulating the fluidity and clotting of blood. These cell layers are called "phospholipids." Abnormal antibodies to these phospholipids increase the stickiness and likelihood of blood clots. aPL antibodies target "phospholipids" on the surface of arteries and veins. Furthermore, aPL antibodies may target proteins in the spinal cord or the brain, which can cause symptoms on MRI which can easily be confused with MS or "idiopathic" TM.

Antiphospholipid antibody (aPL) syndrome is a disorder of abnormal clotting or obstetrical/pregnancy complications, which are believed to be caused by antiphospholipid antibodies. Antiphospholipid antibody syndrome can be a "primary" autoimmune disease. In other cases, it can occur as a "secondary" syndrome, with antiphospholipid antibodies generated as part of a "primary" autoimmune disease, such as lupus or Sjogren's syndrome. As transverse myelitis is such an example of a "primary" autoimmune disease, it is imperative that rheumatologists and neurologists check all patients with transverse myelitis for these antiphospholipid antibodies.

3) When should the diagnosis of aPL syndrome be suspected? Examples of "red flags:"

In patients with transverse myelitis, the following are scenarios or "red flags," in which the diagnosis of aPL syndrome should be especially considered.

(A) History of obstetrical accidents or history of blood clots in veins or arteries

aPL antibodies cause clots in larger arteries and veins, and is associated with complications of pregnancy. Examples of these complications of pregnancies include recurrent episodes of spontaneous abortion; or episodes of pre-eclampsia (high blood pressure, sometimes with seizures, usually developing late in the third-trimester). Although blood clots in the legs are more common in patients with myelitis because of immobility, a history of recurrent or multiple blood clots (i.e., otherwise referred to as "unprovoked" clots), should prompt blood tests for the aPL antibodies.

With increasing age, patients may develop heart attacks and strokes, especially when there are risk factors for atherosclerosis. However, unexplained strokes or heart attacks in MS patients, especially when there are minimal to no risk factors for atherosclerotic disease (i.e., when there is no history of smoking, diabetes, high blood pressure, high cholesterol, or early family history of strokes/heart attacks), should prompt consideration of aPL syndrome.

(B) Rashes

aPL antibodies may be associated with different rashes. One pattern is called "livedo reticularis." I suggest that readers log onto the Internet, connect to Google, click the browser on Images, and type in "livedo reticularis." The rash of "livedo reticularis" presents as a mottling, faintly red, lace-like, reticular streaks, occurring more often on the legs than the arms. In severe cases, livedo reticularis may be observed on the trunk. The rash of livedo reticularis may be subtle, and require examination by physicians under proper lighting. In this past year, we have identified more than 10 people with this livedo rash, who were unaware of subtle mottling on their arms! Around the nails, the smallest blood vessels (called capillaries) may proliferate, causing a pattern of "corkscrewing." Under the nails, there may be tiny redness which look like splinters, and is therefore called "splinter hemorrhages."

All of these rashes are nonspecific, meaning they can occur in different medical conditions other than aPL syndrome. A subset of normal patients without any neurological disease can also have a livedo reticularis rash. So the presence of these rashes is not diagnostic for aPL syndrome, but does suggest that an experienced neurologist consider testing for aPL antibodies.

(C) Presence of any "primary" autoimmne syndromes associated with aPL antibodies

aPL antibodies may be "primary" or occur in the absence of any provoking systemic diseases. However, aPL antibodies also occur as a "secondary" autoimmune syndrome, occurring in the context of systemic autoimmune disease. Aside from rheumatic diseases (SLE, Sjogren's, rheumatoid arthritis, and vasculitis), other autoimmune diseases which have been associated with aPL antibodies includes inflammatory bowel disease (Crohn's disease or ulcerative colitis) and Hashimoto's thyroiditis. Therefore, aPL antibodies should be checked in patients with a new diagnosis of transverse myelitis who have a history of other autoimmune diseases.

4) How do my physicians know when aPL antibodies are causing my signs or symptoms?

This is a notoriously difficult question and requires further research. The mechanisms of how aPL antibodies cause neurological dysfunction are imperfectly understood. However, a quandary in the care of patients with blood tests showing aPL antibodies is that aPL antibodies are often ***not*** associated with any symptoms or disease. For example, aPL antibodies may be seen in up to 5 to 10 percent of normal, healthy people.

Furthermore, in 3(C) above, I emphasized that aPL antibodies are seen in autoimmune diseases. In some cases, aPL antibodies may reflect the manifestation of a global disturbance in the immunological system. In such cases, autoantibodies are a ***marker*** of a heightened autoimmune response, without necessary ***causing*** autoimmune disease. In other scenarios, aPL antibodies may directly contribute, if not cause, systemic damage, such as transverse myelitis. In the latter scenario, when aPL antibodies directly cause symptoms, they are regarded as ***pathogenic.***

The above paradox motivates questions frequently asked by transverse myelitis patients, and even by their referring neurologists: How do I know whether the aPL antibodies are "innocuous" (i.e., an innocuous marker of an autoimmune disease such as transverse myelitis) versus "pathogenic" (and causing disease)?

This dilemna is the subject of planned ongoing research projects. We should suspect that aPL antibodies are pathogenic:

(a) When you have any of the "red flags" listed in Section 3: (A) through (C) above;

(b) When you have a suboptimal treatment response to medicines used to treat TM.

5) Treatment for aPL antibody syndrome

Given our imperfect understanding of aPL antibody syndrome, there is no clear consensus regarding treatment in all situations. In patients who have aPL antibodies and repeated blood clots or complications of pregnancy, it

is incontrovertible that treatment should include "anticoagulation" or blood thinners. Such treatment might include the pill Coumadin or an injectable form of Heparin.

However, experts do not agree regarding treatment when there are abnormal blood tests showing aPL Abs, but without episodes of blood clots or pregnancy complications. At the Johns Hopkins Transverse Myelitis Clinic, we consider recent studies suggesting that aPL antibodies might affect the clotting not only in larger vessels, but also in the smallest capillaries. Treatment which target sludging and "stickiness" of cells in these smallest capillaries include Plaquenil, which is a medicine used in lupus patients, as well as "anti-platelet" agents (i.e., Aspirin, Plavix).

In patients with multiple episodes of transverse myelitis and aPL antibodies, a trial of "anticoagulation" may be reasonable. In such instances, collaboration between neurologists and rheumatologists is crucial.

6) Current research projects

As the above discussion suggests, improved diagnostic criteria, blood tests, and neuroimaging modalities are necessary to help clinicians understand how aPL antibodies cause neurological/rheumatic syndromes, not only transverse myelitis, but also multiple sclerosis, and inflammatory brain disease in lupus. We are considering the use of Magnetic Resonance Spectroscopy (or MRS), as a neuroimaging tool to understand whether aPL antibodies are "pathogenic." MRS produces a biochemical and quantitative assessment of different molecules in the brain which may be affected differently in MS versus aPL syndrome.

We hope that understanding these "biochemical signatures" will elucidate mechanisms of aPL syndrome. We are also interested in the clinical evaluation of patients who may have received conflicting and discrepant diagnoses of whether transverse myelitis is caused by aPL antibodies; as well as rheumatic diseases versus MS. In addition to immediate clinical and therapeutic benefit, our evaluation of these patients may pave the way for improved diagnostic criteria.

Any members of the TM Community with known or suspected aPL syndrome, or with known or suspected co-existing rheumatic diseases, or those with any other questions should feel free to Email me at jbirnba2@jhmi.edu.

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.

1. Recurrent Transverse Myelitis;

2. Transverse Myelitis with SLE (Lupus);

3. Transverse Myelitis with Sarcoidosis;

4. Transverse Myelitis with Sjogren's syndrome

5. Transverse Myelitis or NMO with HIV; and

6. 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

Acute Disseminated Encephalomyelitis (ADEM)

The ADEM list is being compiled by Barbara Kreisler. If you would like to be added to the list, please send your information to: bkreisler.imprint@verizon.net.

An ADEM Directory will be published and mailed to everyone who is on the ADEM list.

Neuromyelitis Optica (NMO) or Devics disease

The NMO list is being compiled by Grace Mitchell. If you would like to be added to the NMO list, please send your information to: gmitchell@myelitis.org.

An NMO Directory will be published and mailed to everyone who is on the NMO list.

The Johns Hopkins PROJECT RESTORE
Restoring hope, function, and lives to MS & TM patients

The Johns Hopkins Project RESTORE was founded in August 2004 as a multidisciplinary clinical and research effort to develop new basic research and clinical therapies in multiple sclerosis (MS) and transverse myelitis (TM). To help achieve the goals of Project RESTORE, we have a Board of Ambassadors whose members include leaders from all areas of professional endeavor, including grateful patients. The Chairman of the Board is Mr. Bruce Downey, CEO and President of Barr Pharmaceuticals, Inc., Vice-Chair is Mrs. Cindy McLean from Atlanta, GA. The Transverse Myelitis Association and The Cody Unser First Step Foundation are also on our Board of Ambassadors represented by Sandy Siegel, Cody and Shelley Unser. Our semi-annual Board meetings were held on September 20, 2007 and April 10, 2008.

EVENTS

Project RESTORE at the 2007 Ox Ridge Charity Horse Show

The Ox Ridge Charity Horse Show in Darien is one of Connecticut's oldest equestrian events. Proceeds from the June 21-24, 2007 event benefited Project RESTORE. Through this event, Christine Fitzgerald Dodge raised over $10,000 in support of TM Research in honor of her sister, Susan Matter.

Project RESTORE Honored at the GPhA Charity Golf Outing

The Generic Pharmaceutical Association (GPhA) served as the host sponsor of the Second Annual Project RESTORE golf classic at Talamore at Oak Terrace in Ambler, PA on September 10, 2007 and raised over $200,000 to benefit The Johns Hopkins Project RESTORE. Our heartfelt gratitude goes out to all of the generous donors, sponsors and volunteers for their support. Eagle sponsors included Barr Laboratories, Mylan Laboratories, and Teva Pharmaceuticals. Birdie sponsors included Williams and Connolly LLP and Winston and Strawn LLP. Par sponsors included Actavis, Merchant and Gould, Sutherland Asbill and Brennan LLP.

The Greater Lebanon Valley Lions Club Presented Renewed Vision to Restoring LIFE

On May 4, 2007 Dr. Kerr spoke at the Lantern Lodge Convention Center in Myerstown, Pennsylvania. He provided information about the current status of stem cell research. This year on April 11, 2008 The Greater Lebanon Valley Lions Club hosted an event titled **Renewed Vision to Restoring SIGHT** in an effort to forge new collaborations in the field of stem cell research. The speakers included Dr. Colin Barnstable of Penn State College of Medicine, Dr. Douglas Kerr of Johns Hopkins University, Dr. Thomas Gardner of Penn State College of Medicine and Dr. Mark Maria of Fava and Maria Eye Associates.

The First UK Transverse Myelitis Conference

On October 13, 2007 the London-based TM Society hosted a one day symposium that included talks from Dr. Douglas Kerr, Dr. Angela Vincent, Dr. Diane Playford and Tony Murphy. The TM Scotland Support Group met on October 17, 2007 with Dr. Kerr and discussed clinical management of these rare diseases and current research updates.

SCIENTIFIC UPDATE

Since its inception, Project RESTORE has raised approximately 2.5 million dollars through philanthropic effort, all of which has been applied to the following scientific initiatives summarized below.

ACCELERATED CURE PROJECT – DATABASE

Johns Hopkins University is the lead center and we have enrolled more than 250 patients in this study. There are more than 1000 patients who have enrolled in this protocol nationwide. Use of the CSF repository has been approved and a project is underway to screen for all known human pathogens (viruses and bacteria) in patients with demyelinating disease. A separate study with a local Maryland company to develop a blood test for MS is also ongoing. Dr. Greenberg chaired a meeting at Cold Spring Harbor in February 2008 with 30 scientists from around the world to discuss the gene-environment interaction in MS.

HIGHLIGHTS OF NEURO-IMAGING RESEARCH STUDIES

We have enrolled over 100 patients and controls and acquired over 200 sessions of data in vivo in the brain and cervical spine using magnetization transfer (MT) and diffusion tensor imaging (DTI). We have also begun preliminary investigations of magnetic resonance spectroscopic imaging (MRS) in the spine. We are currently examining correlations between these metrics with the expanded disability status scale (EDSS) and multiple sclerosis functional composite (MSFC) to assess the predictive and concurrent validity of these. The aim of this study is to classify individuals based on measures of disability, characterize their walking patterns, in order to detect specific kinematic deficits, and use this information to direct future rehabilitative strategies. We predict

that impairments of spasticity and ataxia seen in MS can be used as functional indices of damage to specific spinal cord pathways that leads to measurable differences in walking patterns. This study continues to be funded through the generous support of the Shawe family.

We have been the first to show that special MRI techniques, high resolution **diffusion tensor imaging (DTI)**, can be used to define and quantify tissue damage in rats with an animal model of TM (focal EAE). In our study, we found that DTI imaging detected not only pathology at a lesion site within rat spinal cord dorsal column, but also axonal loss and degenerating fibers within the ascending dorsal column fiber tracts related to the lesion. Measures of axonal injury correlated with clinical disability and with histologic injury in rats. The importance of this study is that we now can apply these same measures in humans with TM or MS as a non-invasive biomarker for disease severity.

Optical Coherence Tomography (OCT) - A simple non invasive high resolution technique used to detect changes in the Retinal Nerve Fiber Layer Thickness (RNFL) and Macular Volumes (MV) in an outpatient setting. We hypothesize that RNFL thickness will be a useful tool to quantify axon damage related to optic neuritis (ON) in MS patients, and therefore, will correlate strongly with the ultimate visual outcome 6-12 months later. In addition, we would like to measure the rate of change of RNFL thickness in MS patients with and without history of ON and use it as an early biomarker of permanent visual disability. We are currently enrolling patients with MS, ON and other neuroinflammatory diseases to assess the RNFL and MV and compare them to age matched controls using OCT. We have scanned about 453 MS, TM and NMO patients and 74 controls. Results show significant decrease in RNFL and MV in MS patients with and without history of ON. Among disease subtypes of MS, progressive MS patients seem to have more marked decrease in both RNFL and MV than Relapsing Remitting MS patients.

NEURO-REGENERATION STUDIES

Glial Restricted Precursor Stem Cells to Remyelinate Demyelinated Axons in TM

Preclinical Studies:

Glial Restricted Precursors (GRPs) are embryonic, lineage-restricted precursors of CNS glial cells and have the potential to differentiate into oligodendrocytes and astrocytes. In rodent demyelinating and injury models, GRP-derived oligodendrocytes remyelinate demyelinated axons, and GRP-derived astrocytes secrete growth factors that stimulate protection and axonal sprouting of damaged axons. We believe the inherent characteristics of GRPs render them a natural means to repair defects in myelin production in the CNS, and thus may be an ideal therapeutic for TM.

Stem cells, including GRPs, can be effectively pre-differentiated prior to transplantation using a variety of agents that we have discovered in a high through-put assay. This pre-differentiation allows the cells, once placed into the highly complex and injurious context of the CNS, to fully differentiate and myelinate host axons. We have also developed a strategy whereby stem cells are engineered to inducibly express a surface molecule that allows them to be delivered by intra-arterial delivery and to escape the circulatory system and migrate into the CNS to initiate repair.

Clinical Studies in Humans with TM:

This Will Be A Phase I Single Site, Non-Randomized, Open Label pilot study with dose escalation to obtain preliminary data on the safety and tolerability of glial restricted progenitor (GRP) cells in patients with disability from Transverse Myelitis (TM). We hope to gain FDA approval to begin enrolling for this trial in first quarter 2009. The safety and efficacy data to support this IND are currently being generated.

Motor Neuron Stem Cells: Large Animal Stem Cell Studies

We are currently using large mammals to generate the necessary preclinical data for a clinical trial set to begin in 2011. In this clinical trial, we will transplant infants with the fatal motor neuron disorder Spinal Muscular Atrophy (SMA) with human ES cell-derived motor neurons. Dr. Benjamin Greenberg is leading both the preclinical experiments and the planning for the clinical trial. We have had discussions with the FDA regarding the necessary preclinical data to support this clinical trial.

We have decided to initiate these studies with non federally-approved ES cells meaning that we cannot receive federal funding for this research. Since the intellectual property ownership of ES cells remains in legal dispute, corporate investment in ES cell approaches is minimal.

While the preclinical studies are underway, we plan to establish the clinical protocol for transplantation, including the patient population, sites of participation, enrollment criteria, surgical approach and outcome measures.

NEUROPROTECTIVE DRUG SCREENING

We are currently initiating a high through-put screen to define novel therapies in neurodegenerative and demyelinating disorders. The **goal** of this project is to find drugs to treat devastating chronic neurological disease - amyotrophic lateral sclerosis (ALS), and will have utility in other relevant disorders, including childhood motor neuron disease -spinal muscular atrophy (SMA), as well as MS and TM. These disorders have a common injury or involvement of glial cells and/or injury to neurons. Fundamental to this proposal will be the ability to rapidly translate discovery to clinical use through the collaboration of academic labs at Johns Hopkins with biotechnology companies experienced in the various procedural steps required in drug discovery. This academic/ commercial partnership will be based on the use of human stem cells to identify new pharmaceuticals and to rapidly bring these drugs to patients.

The proposal is divided into **two core projects,** based on *in vitro* cell models, derived from human ES cells, that recapitulate key features or therapeutic targets that are common to the pathophysiology of these diseases. The cell models, injured human motor neurons and glial cells, will be adapted for high through-put screens (**HTS**). Each project is divided into ***four common parallel phases***. The **first phase** entails the validation of each stem cell derived cell line for high through-put screening, followed by the **second phase** using a novel combinatorial drug screen to identify FDA approved candidate neuroprotective drugs that are synergistically effective when used in combination. Lead drug combinations will subsequently be validated in secondary assays and dose optimized. The **third phase** will examine the pharmacokinetic properties of the lead hits, such as blood brain barrier penetration. The final **forth phase** will test the biological activity of the candidate drug combinations in relevant disease models. This will involve pre -clinical testing of the identified drugs in disease models (e.g., ALS, EAE or TM mice), to evaluate pharmacokinetics, safety and efficacy (e.g., testing for prolongation of survival). At the end of this proposal, we will be poised to bring candidate drug combinations to clinical trial in several neurological diseases.

ONGOING CLINICAL TRIALS

Evaluation of Functional Electrical Stimulation Therapy on Disability and Function in Patients with Primary Progressive and Secondary Progressive Multiple Sclerosis

This is an open label phase I/II single site pilot study to obtain preliminary data on the safety, tolerability and efficacy of FES in patients with definite PPMS or SPMS. Ten patients in each group, PPMS and SPMS, will be offered entry into the study, if they meet all inclusion criteria and will receive rehabilitation with FES for six months in their home 3-5 times per week. Disability, quality of life and quantitative measures of neurologic function will be examined at baseline, 3 months and 6 months. Cerebrospinal fluid markers will be examined at baseline and at 3 months. This study was made possible through the generous support of Mr. and Mrs. Robert N. Snyder. One patient is enrolled in the study.

The Use of Erythropoietin in the Treatment of Acute Transverse Myelitis

This is a Phase I/II randomized, double-blind, placebo controlled, single site pilot study to obtain preliminary data on the safety, tolerability and efficacy of PROCRIT in TM patients. The study will enroll 30 patients over 2 years with a follow-up of 6 months. Patients will be offered entry into the study, if they meet all of the inclusion criteria and none of the exclusion criteria. Patients will be both male and female, aged 18-70 inclusive. Patients who consent to enter the study will be randomized to be given either a subcutaneous dose of 40,000 U PROCRIT (recombinant human erythropoietin) OR placebo. They will receive this therapy within 2 weeks of neurological symptom onset. This will be followed by another dose of 40,000 U PROCRIT or placebo two weeks later. All patients will receive a 5 day course of high dose steroids (1g IV solumedrol qd), which is presently the standard of care, followed by a steroid taper. The primary aim is to obtain preliminary information on the safety of PROCRIT. A secondary outcome measure of the study will be to obtain preliminary data on the change in function using the Expanded Disability Status Scale (EDSS) between baseline, and 6 month follow-up. Another secondary outcome measure will be to obtain preliminary data on the degree of spinal cord axonal loss at 6 months (compared to baseline) as assessed by novel MR imaging (conventional, DTI and MTw).

Research Lumbar Punctures

We have permission to consent patients for research lumbar punctures and plan to bank CSF from PPMS and SPMS patients.

Risk factors for TM study

In an effort to investigate possible causes of Transverse Myelitis, patients diagnosed with idiopathic TM in the last 2 years are recruited for this study. A simple questionnaire mailed to the participant and their medical records are reviewed. Currently over 100 patients are participating in this study.

The Transverse Myelitis Association

The Johns Hopkins PROJECT RESTORE
Restoring hope, function, and lives to MS & TM patients

The Transverse Myelitis Association in conjunction with the Johns Hopkins' Project RESTORE (Transverse Myelitis and Multiple Sclerosis Centers) present:

The 3rd International Rare Neuroimmunologic Disorders Symposium

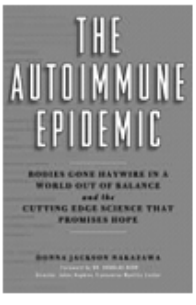
July 16 – 19, 2008, Seattle, Washington

http://www.myelitis.org/2008SeattleSymposium

The Transverse Myelitis Association and the Johns Hopkins Project RESTORE are co-sponsoring the 2008 Rare Neuroimmunologic Disorders Symposium, July 16 – 19, 2008 in Seattle. The symposium is an educational and networking opportunity for people who have Transverse Myelitis, Multiple Sclerosis, Acute Disseminated Encephalomyelitis, and Neuromyelitis Optica, their family members and caregivers, the medical professionals who provide clinical care to people with these disorders, as well as scientists and physicians who are performing research in rehabilitative and restorative therapies. There is no more intensive educational program offered anywhere in the world that focuses on all of these rare neuroimmunologic disorders of the central nervous system. A detailed program agenda is provided below. The world's experts on these disorders will be presenting at the symposium and will also be available to answer your questions. We know that by attending this symposium, you will become a more effective advocate for your medical care. We urge you to attend and we encourage you to bring your family members.

Featured Speakers

In 1996, **Allen Rucker** had no real complaints: happily married, two kids, a house in West Los Angeles. At the age of 51, his career as a television writer was looking up. Then one Tuesday, out of the blue, he started to feel a burning sensation around his waist. Within an hour, he was paralyzed from the waist down by transverse myelitis. *The Best Seat in the House* chronicles in the most honest and candid way Allen's experiences with getting TM. His very genuine, emotional and humorous insights make this a must read for everyone in the TMA community. Allen has appeared on the Montel Williams Show; he has traveled extensively as an advocate in the disability community and is a regular contributor to Ability Magazine.



Donna Jackson Nakazawa is a nationally acclaimed researcher, writer and public speaker on health and family issues. She is the author of the book, *The Autoimmune Epidemic: Bodies Gone Haywire in a World out of Balance and the Cutting Edge Science that Promises Hope* (Touchstone/Simon and Schuster), an investigation into the reasons behind today's alarming rise in rates of autoimmune diseases (multiple sclerosis, lupus, type 1 diabetes, thyroiditis, and dozens of other immune mediated diseases) in industrialized countries around the world. Donna Jackson Nakazawa's book contains a forward by Dr. Douglas Kerr, as well as an extensive discussion of Dr. Kerr's research at the Johns Hopkins Transverse Myelitis Center.

Hotel Information

The symposium will be held at the Redmond Marriott Town Center. To make your reservation at the special group rate (approximately $170 per night without taxes), you need to contact Katina Alley and ask for the "*Rare Disorders Symposium*" rate: (425)498-4024; from 8am - 4pm Monday - Friday PDT. If it would be easier for our international members to reach Katina by email, you may reach her at: katina.alley@marriott.com. 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.

Symposium Registration

The Symposium Registration Fee is $290.00 USD per person. The registration fee covers three breakfasts, three lunches, breaks and the Gala evening event dinner on Saturday; a value well exceeding the cost of registration!

Whether you pay the registration fee with a credit card or by check, you must register online at:
http://dev.esg.us/Seattle/registration.php

When you register on this page, you will receive a confirmation code. Please print this page for your records. You may make a secured credit card payment via paypal from this page or you will have the option of paying by check. If you pay by check, please include a copy of the registration page along with your check made payable to The Transverse Myelitis Association and send to:

Rare Disorders Symposium Registration
c/o The Transverse Myelitis Association
10105 167th PL NE
Redmond, WA 98052-3125

You must register online in order to receive the confirmation code and to ensure that we have a record of your registration. If you do not have internet access or a computer, please ask a family member or friend to perform the online registration for you.

Conference Cancellation Policy
Cancellations made before May 16, 2008 will be charged 50% of the conference fee. Registrants who cancel on or after May 17, 2008 will be responsible for the entire registration fee.

For assistance or general questions, please send an email to plazzeri@myelitis.org or call (425)883-7914.

3rd International Rare Neuroimmunologic Disorders Symposium Clinical Program

Wednesday July 16, 2008

4:00 – 6:00 pm	Onsite Registration
6:00 – 6:30 pm	**Welcome Remarks** Douglas A. Kerr, MD, PhD, Johns Hopkins University Sanford Siegel, PhD, Transverse Myelitis Association
6:30 – 7:30 pm	**RNDS Inaugural Presentation and Keynote** Allen Rucker, Author 'The Best Seat in the House'

Thursday, July 17, 2008

Morning Session

7:00 - 9:00	*Registration and Continental Breakfast*
9:00 - 9:15	**Introduction** Douglas A. Kerr, MD, PhD
9:15 - 9:45	**Neuroimmunologic Disorders: An Overview** Benjamin M. Greenberg, MD, MHS Johns Hopkins University, Baltimore, MD
9:45 - 10:15	**Brain, Spinal Cord and Cells: A Neuro-primer for Non-Neurologists** Carlos A. Pardo, MD Johns Hopkins University, Baltimore, MD
10:15 - 10:45	**Understanding the Immunopathology of Central Nervous System Diseases** Mariko Kita, MD Virginia Mason, VA
10:45 - 11:00	*Refreshment Break*
11:00 - 11:30	**Acute Disseminated Encephalomyelitis** Benjamin Greenberg, MD, MHS Johns Hopkins University, Baltimore, MD
11:30 - 12:00	**Multiple Sclerosis (MS)** James Bowen, MD MS Center at Evergreen, Kirkland, WA
12:00 - 1:00	*Lunch*

Afternoon Session

1:00 - 1:30	**Neuromyelitis Optica (NMO)** Sean Pittock, MD Mayo Clinic
1:30 - 2:00	**Transverse Myelitis ™** Douglas A. Kerr, MD, PhD Johns Hopkins University, Baltimore, MD
2:00 - 2:30	**Pediatric Transverse Myelitis** Frank Pidcock, MD Kennedy Krieger Institute, Baltimore, MD
2:30 - 3:00	**Pediatric TM as different from CIDP, and Pediatric ADEM** Gregory Barnes, MD/PhD Vanderbilt University, TN
3:00 – 3:30	**Neurosarcoidosis** Carlos Pardo, MD Johns Hopkins University, Baltimore, MD
3:30 – 3:45	*Refreshment Break*

3:45 – 4:15 **Neurological Manifestations of Lupus and other Systemic Rheumatologic Disorders**
Julius Birnbaum, MD
Johns Hopkins University, Baltimore, MD

4:15-4:45 **Accelerated Cure Project Presentation**
Benjamin Greenberg and Art Mellor

5:00 – 5:30 **The Auto-Immune Epidemic: Bodies Gone Haywire in a World Out of Balance and the Cutting Edge Science That Promises Hope**
Author: Donna Jackson Nakazawa
Panel Discussion and Q&A

Friday, July 18, 2008

Morning Session

7:30 – 9:00 *Continental Breakfast*

9:00 – 9:30 **Acute Therapies in Demyelinating Diseases**
Benjamin Greenberg, MD
Johns Hopkins University, Baltimore, MD

9:30 – 10:00 **Choosing a Treatment for New Diagnosis of Multiple Sclerosis**
Kathleen M. Costello, M.S., C.R.N.P., M.R.C.P. (UK), M.S.C.N
University of Maryland Medical Center

10:00 – 10:30 **Future Immunotherapies and Neuroprotective Therapies**
Mariko Kita, MD
Johns Hopkins University, Baltimore, MD

10:30 – 10:45 *Refreshment Break*

10:45 – 11:15 **Fatigue in Autoimmune Neurological Diseases**
Kathleen M. Costello, M.S., C.R.N.P., M.R.C.P. (UK), M.S.C.N
University of Maryland Medical Center

11:15 – 12:00 **Depression and Cognitive Dysfunction**
Adam I. Kaplin, MD, PhD
Johns Hopkins University, Baltimore, MD

12:00 - 1:00 *Lunch*

Afternoon Session

1:00 – 1:30 **Medical and Interventional Approaches to Neuropathic Pain and Paresthesias**
Denise Taylor, MD
University of New Mexico, Albuquerque, NM

1:30 – 2:00 **Sexual Dysfunction**
Bobbie Severson, ARNP
MS Center at Evergreen, Kirkland, WA.

2:00 – 2:30 **Bladder Dysfunction and Management**
Claire C. Yang, MD
University of Washington, Seattle, WA

2:30 - 3:00 **Spasticity Management**
Frank Pidcock, MD
Kennedy Krieger Institute, Baltimore, MD

3:00 – 3:30 **Patient Centered Care: The Role of Self-management**
Stephen Wegener, PhD
Johns Hopkins University, Baltimore, MD

3:30 - 3:45 *Refreshment Break*

3:45 – 4:15 **Self Advocacy and Employment with Disabilities**
Sandy Hanebrink, OTR/L

4:15 – 4:45 **Obstetric Issues in Women with Demyelinating Disease**
Donna Chattin, BSN, RN
Benjamin M. Greenberg, MD, MHS

5:00 – 6:30 **Workshop Sessions**
Workshops will be rotated twice
Session 1 – 5:00 – 5:40 pm
Session 2 – 5:50 – 6:30 pm

A. Adjusting to the Disease: Pitfalls, Precautions and Pleasures for Patients and their Caregivers
Adam I. Kaplin, MD, PhD

B. Support for Women during Pregnancy and Preconception
Donna Chattin, BSN, RN

C. Spasticity
Frank Pidcock, MD

D. Pain Management
Denise Taylor, MD

E. Complementary and Alternative Therapies AND Equine Therapy
Pat Kennedy, RN, CNP
Moira Baynes, RN

F. Positive Growth in the Face of Adversity
Stephen Wegener, PhD

G. Self Advocacy: Navigating Government and Community Support Programs
Sandy Hanebrink, OTR/L

Saturday, July 19, 2008

Morning Session

7:30 – 9:00 *Continental Breakfast*

9:00 – 9:30 **Genetics and Autoimmunity**
Corey Ford, MD
University of New Mexico, Albuquerque, NM

9:30 – 10:00 **Relating Sensorimotor Function to MRI**
Kathleen M. Zackowski, PhD, O
Kennedy Krieger Institute, Baltimore, MD

10:00 – 10:30 **High Dose Cyclophosphamide in Multiple Sclerosis**
Chitra Krishnan, MHS
Douglas A. Kerr, MD, PhD
Johns Hopkins University, Baltimore, MD

10:30 – 10:45 *Refreshment Break*

10:30 – 10:45	*Refreshment Break*
10:45 – 11:15	**Hematopoietic Stem Cell Transplantation in Multiple Sclerosis** James Bowen, MD MS Center at Evergreen, Kirkland, WA.
11:15 – 11:45	**Optical Coherence Tomography (OCT) and Neuroprotection** Laura J. Balcer, MD University of Pennsylvania, Philadelphia, PA
12:00 - 1:00	*Lunch*

Afternoon Session

1:00 – 1:30	**Neurorehabilitation – Now and the Future** Reggie Edgerton, PhD UCLA
1:30 – 2:00	**Neurodegeneration and Neuroregeneration – The Future** Douglas A. Kerr, MD, PhD Johns Hopkins University, Baltimore, MD
2:00 – 4:00	**A Moderated Discussion** Sanford J. Siegel, PhD, President TMA Chitra Krishnan, MHS, Johns Hopkins University
6:00 – 9:00	**Dinner and Keynote** Presentation of TMA Distinguished Service Award

Please note, this program is subject to change

If you are coming to the Rare Neuroimmunologic Disorders Symposium in Seattle, you will be able to enroll in the Accelerated Cure Project Repository. This is a national repository of samples and data available for use by scientists studying TM, ADEM, NMO, ON and MS. We will be enrolling people who have one of these diseases and will also enroll family members as controls for the studies. A team from Johns Hopkins will be setting up shop at the hotel and will be collecting blood samples and questionnaires from willing participants. This is an important effort to augment the number of patients with rare neuroimmunologic disorders within this repository. For meaningful studies to be done, we need to substantially increase the numbers of subjects with these rare disorders in the repository. The Seattle symposium represents an incredible opportunity for us to begin to achieve this important goal; it is the only time we bring together a significant number of people with these rare neuroimmunologic disorders. The repository data is being used by researchers around the world trying to determine the causes of these disorders, identifying better tools for diagnosing these disorders and finding more effective treatments.

In order to participate, you will need to do the following:

1. Download and fill out the ACP questionnaire. Be certain to bring the questionnaire with you to Seattle. Both patients AND controls need to fill out the questionnaire. You can download the questionnaire at http://www.acceleratedcure.org/repository/downloads/ACP_CRF.pdf or contact Jana Goins to be sent a copy by mail.

2. Contact Jana Goins at Johns Hopkins **(jgoins3@jhmi.edu; 410-502-6160)** as quickly as possible. Please let Jana know that you are enrolling in the repository. We will need an accurate count of the people who will enroll so that we can bring adequate supplies.

3. Encourage family members who are coming with you to enroll in the repository to serve as controls in studies. Please report the number of family members who will be enrolling as controls to Jana Goins. Any family members who are not coming with you can instead enroll at our sites in Worcester, MA; New York, NY; Baltimore, MD, Atlanta GA; Dallas, TX; or Phoenix, AZ. See http://wwww.acceleratedcure.org/repository/contact.php for location information.

4. YOU MUST BRING MEDICAL RECORDS AND MRIs WITH YOU TO SEATTLE. We will need your earliest set of MRIs available (preferably around the time of diagnosis) and any subsequent MRIs you have had. Please do not bring any more than three subsequent MRIs. We will want clinic notes, hospital notes if available and any lab studies you have had done as part of your initial evaluation/diagnosis. This is a good opportunity to collect your complete medical record if you haven't already done so! MRIs WILL BE REVIEWED ON SITE AND RETURNED TO YOU.

5. YOU WILL ALSO NEED TO HAVE A SHORT SECTION FILLED OUT BY YOUR NEUROLOGIST.

6. Once we know how many people to expect we will set up a schedule for enrollment and email everyone the day and time they should report for enrollment.

For more information about the Accelerated Cure Project Repository, go to http://www.acceleratedcure.org/repository/ or contact Sara Loud, Repository Director, at (781)487-0032 or sloud@acceleratedcure.org.

Studies and Clinical Trials

JOHNS HOPKINS BLOOMBERG SCHOOL of PUBLIC HEALTH

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

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

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

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

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

Research Volunteers Needed for a Pain Study

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

You may be eligible if you are:

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

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

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

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

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

This is your chance to help! We are enrolling patients with multiple sclerosis, transverse myelitis, optic neuritis, acute disseminated encephalomyelitis, neuromyelitis optica (Devic's) or clini-

cally isolated syndromes (one demyelinating attack, but not fulfilling the diagnostic criteria for MS). Those who are currently patients at Johns Hopkins will be able to join the study without a referral from their physician, and will just need to contact the Johns Hopkins project coordinator for study enrollment information. Johns Hopkins patients who are aware of their next scheduled clinic date may get in touch with the project coordinator *beforehand* in order to schedule a study meeting during this clinic visit. Subjects participating at Johns Hopkins will be offered a $25 check to compensate for lunch and parking on the day of the visit, but will not be reimbursed for any travel expenses. At this time, patients receiving care outside of Johns Hopkins will be subject to additional enrollment requirements.

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

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

This is a very exciting opportunity for both patients and researchers around the country to take part in a large-scale dynamic project that will work to improve our knowledge about demyelinating diseases. 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

Grant Awarded to the Accelerated Cure Project: A Partnership to Foster Research and Clinical Care

The Transverse Myelitis Association has established a partnership with the Accelerated Cure Project. In November 2007, the TMA awarded a $35,000 grant to ACP for the purpose of enrolling people with TM, NMO, ADEM and ON into the ACP repository. The Accelerated Cure Project represents a wonderful opportunity to foster and facilitate research on these rare neuroimmunologic disorders. Researchers are provided with access to a large database of information and samples that would not otherwise be available to any single medical research institution. The TMA is actively engaged in recruiting adults and children with TM, ADEM, NMO and ON into the ACP repository. The TMA is represented on the ACP oversight committee.

The Accelerated Cure Project has been focused on finding the causes of MS. We began our collaboration with ACP because we came to understand the relationships between the neuroimmunologic disorders of the central nervous system and believe that by encouraging research into all of these disorders we will more effectively develop an understanding of each of them. Thus, ACP has expanded its efforts to include all of these disorders in their repository.

The ACP and TMA partnership is also focused on an advocacy effort to encourage effective medical care for people with all of these rare neuroimmunologic disorders. These disorders share many of the same symptoms, and the same symptom management strategies are effective across these disorders. Thus, we are encouraging neuroimmunologists with expertise and experience in one of these disorders to offer medical care to people with all of these disorders. And while

there are differences in the long-term treatments between MS and recurrent TM or NMO, there is a significant convergence of approaches for acute therapies. Thus, we are encouraging neuroimmunologists to provide medical care to people at the most critical time; during an inflammatory attack.

Our relationship with ACP is growing; there is great potential for collaboration. Dr. Benjamin Greenberg, a co-director of the Johns Hopkins TM Center and member of the TMA Medical Advisory Board, also serves on the ACP scientific advisory committee, is instrumental in the development of the ACP repository and directs the repository collection at Johns Hopkins along with Jana Goins. Dr. Greenberg and Art Mellor, President of ACP, will be presenting about the ACP project at our symposium this July in Seattle. If you have TM, ADEM, NNO, ON or MS, you will also be able to enroll in the ACP repository at the symposium in Seattle.

As of May 2008, there were 1,131 subjects enrolled in the ACP repository and these include both adult and pediatric cases: MS: 733, CIS (clinically isolated syndrome): 30, TM: 70, NMO: 13, ON: 4, ADEM: 6, and 275 controls.

The ACP repository could help us find the causes and possible cures for TM, NMO, ADEM and ON. But this will only happen if we can raise the money to support specific research projects on these rare disorders. At present, almost all of the ACP repository studies are focused on MS. When scientists learn about MS, they are also learning about these other disorders. The more they understand about the immune system and the more they understand how and why the nervous system is vulnerable to these attacks, the more they may gain insights into each of these disorders. To learn the causes of TM, ADEM, ON or NMO and to develop better diagnostic tools, researchers need to specifically study these disorders. The TMA will be targeting fundraising efforts in order to specifically support TM, ADEM, NMO and ON studies from the ACP repository. We will need your help to make this happen.

myDailyApple™

Dear Friends of the Transverse Myelitis Association:

Since our debut in 2007 we have received great feedback from our ever-expanding group of partners and the influence that Curbside.MD has had on people's lives in making sense of the world of medical information. It has been encouraging to know that we are making a difference. Our efforts were further validated by being voted best health search engine at the 2007 Health 2.0 conference, beating Healia, Kosmix, Medstory/Microsoft and Healthline.

We are pleased that The Transverse Myelitis Association, one of the original members of the Myelin Network, has continued to provide Curbside.MD as a free resource to its supporters since its official debut last year. Our partnerships are increasing and we are pleased to announce our most recent member: The Christopher and Dana Reeve Foundation.

As of April 2008, Curbside.MD has had a new name: MyDailyApple.com (www.mydailyapple.com). Unlike other search engines, MyDailyApple.com responds to naturally phrased questions, in addition to the usual keyword query, filtering the focus of online research at will. MyDailyApple.com will have a new look as well: a modified format in response to patients who wish to have anonymous profiles and to keep them informed on breaking news of peer-reviewed medical publications on topics of interest. Finally, we are happy to announce that MyDailyApple.com made its debut as an integrated service on the new Google Health platform in early May of 2008!

Google Health is a new product that allows users to store, organize, and manage their medical records online. MyDailyApple gives Google Health users access to health news, blogs, and research information from the most trusted sources along with the ability to personalize that information to individuals' health profiles.

Google Health is available on the web at www.google.com/health.

We are very proud of our work with Google and hope that the new availability will make it easier for you to access the many services made with you in mind.

Our site is evolving, but the message remains the same: to unlock the value of medical information and make it personal to each individual. We started with literature, and are moving on to news and social media. The amount of information out there is overwhelming and we continue to work on making it manageable through natural language medical search, trusted medical sources, and user-friendly display organization to make the data easier to digest. The answers are out there, and we believe it essential to connect people to the right information in a timely and personal way.

These are just a few of the changes coming your way. We hope you approve!

Retreat Weekend for teens and young adults at VJGC: 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. 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 this 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.

VJGC TM-ADEM-NMO Family Week, August 18-24, 2007

Thank you!

Since the Children's and Family Workshop in Columbus, Ohio in 2002, the TMA has been seeking ways to bring families together who have children with rare neuroimmunologic conditions. Through the efforts of Leslie Cerio (mother of a child with TM), the compassion and advocacy of Dr. Peter Sim (Medical Director of VJGC) and the generosity and kindness of Pattie and Kyle Petty (Executive Director of VJGC), the TM-ADEM-NMO Family Camp at Victory Junction was established. We had families come to camp in North Carolina from across the country and around the world. The families were able to share in a camp experience which was entirely inclusive for their children; the recreation program and the facilities are completely adaptive and everyone had so much fun! The staff and volunteers at VJGC are incredible. In addition to the families, Drs. Pidcock, Greenberg, Kaplin and Kerr, from our medical advisory board, came for the week, and most of them came with their families. The physicians, joined by Dr. Sim, made formal presentations to the parents during three morning sessions. One of the parents, Thomas Nybo, who attended from Denmark, is a physical therapist. Thomas gave an excellent presentation on a medical procedure that they had done for their son to treat his spasticity. The physicians were available all week long to speak with parents and to respond to questions. It was a truly wonderful week for everyone involved!

We are all so incredibly grateful for the opportunity the Petty's have created for the TMA community at Victory Junction Gang Camp. The children with these disorders have difficult lives. The everyday lives for these families are filled with incredibly challenging experiences. To share in a

week long break from these challenges was a transformative experience for everyone. From the awesome water park to the arts and crafts, to the bowling and golf and archery, to the horseback riding, to the dancing at every great meal to the carnival and talent show, it was a week filled with smiles and laughter.

Thank you, Pattie and Kyle.
Thank you, Directors and Staff.
Thank you to the wonderful volunteers who come from all over the country to make a difference in these children's and families' lives!

Awesome! That is what we thought of as we were at the camp and as we tell friends and family about our experience at the camp. When the dancing started after dinner the first night at camp, we knew that this was not any ordinary camp. It was a GREAT camp, per our son, Jason, age seven, onset of TM at 10 months. Our daughter Erin, age 12, "This was our best vacation ever." She also liked that everyone was included and there was something for everyone. Michael, age 3, liked how one of the nurse volunteers took care of his bear that needed some tender loving care and a few small repairs. The bear was well taken care of in the clinic. For Mom (Amy) and me (Darian), it was a great way to spend a wonderful week with families that understand our lives and to reconnect with friends we have not seen for many years. The volunteers were great. Erin also thanked Jason for the gift of the camp. She knew that if Jason did not have TM, we would not have had this great opportunity!
While Erin and all of us would prefer that Jason did not have TM, it is awesome that Jason was able to give a gift to her since he does take a lot of care. He was very proud. This is what it is all about - a great gift provided by the donors, staff and volunteers, to the families and time for the families to share a great experience. On the way home I wrote the following poem that our family would like to share.

Victory stands for overcoming the challenges we face, with grace,
Junction stands for a place we come to gather as one, to have fun,
Gang stands for those that volunteer their time and joyful spirit, they really know how to make it special,
Camp stands for an awesome place,
Transverse, even though a medical term, stands for how we have gathered from around the world, even those that could not have gathered in person,
Myelitis stands for a disease that I wish I had not known, but it is why we gather with family and friends, for it will not overcome us,
Association stands for a group of family and friends that are there to always support, share, have fun, love, lean on, they understand,
Week stands for a magical time that will never be forgotten, never.
Thank you VJGC and TMA.
The Vietzke Family

We cannot express how grateful we are to you two for what happened last week. It meant so much to the kids and their families and it just brought a whole community together. A community -including the health care providers and the Transverse Myelitis Association - that is now more committed than ever to CURE this disease! To see the kids acting normally and laughing, even though in some cases they were ventilator dependent, was just amazing. To see the kids all of a sudden realize that they are part of a community that supports each other and is working hard to get rid of Transverse Myelitis was incredible. To see the families and caregivers not only get a break from the constant demands of caring for these kids but also to see their children enjoy life as a normal child for a while was stunning.
Thanks so much for everything. This was a life-altering experience for all of us.
Doug, Kathleen, Caroline and Vivian Kerr

When asked "tell me about what you liked about Victory Junction?" Riley replied, "Wow, it was so awesome, wow! They had horses, a water park, bow and arrows, I liked everything! I cried when we had to go. I miss all of my friends there. I want to go back!"
Riley Blee

My experience at Victory Junction was the highlight of my summer. The camp itself has been expertly put together to provide all the fun, excitement, challenge and opportunities for anyone of any age. The staff had just the right mojo. I was blessed to be crew chief for Conner and his mom & dad, Mary and Dan. Wow, from the moment I met Conner, we hit the ground running. If it weren't for Huey joining our crew, I'm not sure I could have survived. Each day was full of adventure, laughter and a growing friendship. The opportunities that the families experienced that week were outstanding. I was fortunate to have my two brothers, Danny & Perry, and my sister, Paula, and her son, Jesse, there as well. That's something special that we will all share for the rest of our lives. My hope remains eternal that transverse myelitis will be cured and the quality of all the lives it has touched will be improved. A big enormous thank you to everyone who was a part of this awesome experience at Victory Junction Gang Camp!
Peace and Love,
Donna Bain

A week at Victory Junction Gang Camp; what a week!! It must be every child's dream to be in such a place, filled with other happy kids where you can just play, play, play! And when you're used to being the 'not-so-

normal-kid' back home, it's just great not having to think about your disability for almost a whole week!

The Danish Viking family wants to thank Kyle and Pattie Petty and the staff at VJGC for a great week this August. Adam has had TM since he was 1 year old, and as we don't know of any other kids in Denmark with this diagnosis; it is almost unbelievable for him (and all of us) to meet other kids who have had the same disease. Our week with the other TM kids was well worth the long journey. Our counsellor, Cara, was wonderful, and the whole family enjoyed being spoiled by all the happy volunteers at the camp. We would also like to thank the TM specialists who were all extraordinarily friendly and good at explaining complicated matters. We left VJGC a whole lot cleverer and with a feeling of hope for the future. A special thanks to Sandy, without whom none of us would probably have ever met!!

We hope to see you all again soon – hopefully at the VJGC!! (We felt sooooo good!!)
Magnus, Adam, Mette and Thomas
Nybo, Denmark

The week we spent at Victory Junction with the Transverse Myelitis Families was beyond words. The words "Thank you" do not say enough. We are very grateful for this opportunity to explore your wonderful accessible camp filled with lots of fun things to do. We loved the Nascar theme. Our kids loved the "45" car and games inside. Their smiles and laughter were captured in so many of our pictures. We thank you!

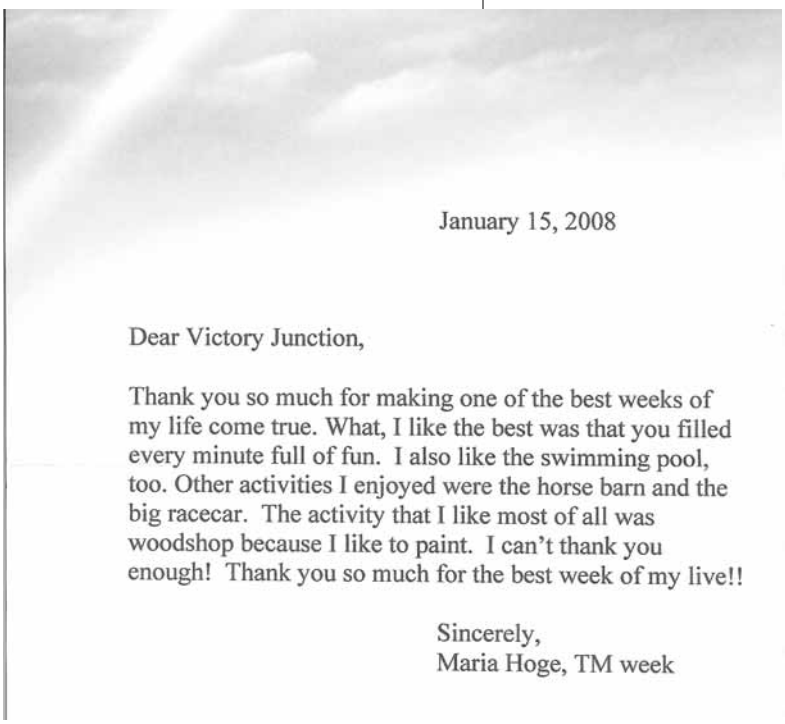
It was nice to meet so many wonderful families that live with TM. Sharing one's experience with others that truly understand means so much. Children seeing that they are not alone. Yes, there are others that live just like them is so important. Even siblings had a chance to talk, listen, and share. We thank you!

Wow, what an unbelievable staff and volunteers! They were eager to please, always smiling, friendly, and helpful. Molly and Bob helped the kids grow out of their shells and experience a great week at camp. From singing and dancing to fishing and swimming. We thank you!

Thank you also for giving us an opportunity to learn from the many physicians that was there. There is so much to learn. It was easy to do knowing that the children were having fun and not too far away in case they needed us. We always want to make sure that we are doing everything possible to make sure that our children have the best life possible. We thank you!

Adam Petty, what a special person! To have a dream at a young age to build a place for children with special needs to have fun. What an insightful person! Wise beyond his years!

We are so very blessed for this opportunity. Victory Junction is a little piece of heaven here on earth. We thank you from the bottom of our hearts!
Yours truly,
Morgan and Pamela Hoge



January 15, 2008

Dear Victory Junction,

Thank you so much for making one of the best weeks of my life come true. What, I like the best was that you filled every minute full of fun. I also like the swimming pool, too. Other activities I enjoyed were the horse barn and the big racecar. The activity that I like most of all was woodshop because I like to paint. I can't thank you enough! Thank you so much for the best week of my live!!

Sincerely,
Maria Hoge, TM week

Victory Junction,

Thank you for the wonderful week that my family had at Victory Junction camp. We had a lot of fun and met a lot of families that my sister could relate with. I am still in contact with two older siblings of people with Transverse Myelitis. We have discovered that we have a lot in common with each other. This all came out of the week that we had laughing and learning with one another. I want to thank all the staff who helped everyone out and made the week that much more enjoyable. Our counselors, Molly and Bob, were awesome, fun-loving people that helped both the kids and parents to have fun.

Thank you Victory Junction!

Carla Hoge

A Free Medical Camp!!

Providing Traditional Camping Experiences to Children and their Families

The Center for Courageous Kids is a multi-disease therapeutic camp for children with a serious illness or chronic condition located in Scottsville, Kentucky. Our mission is to uplift children who have life-threatening illnesses by creating experiences year-round that are memorable, exciting, fun, build self-esteem, are physically safe, and medically sound. There is absolutely no cost to the children or their families! We offer 9 weeks of summer camp, designed for children 7 to 15 years of age with a chronic illness that cannot normally participate in fun childhood memories of camp. We also offer family retreat weekends for the whole family, designed to provide respite, recreation and support programs for families dealing with a child between 3 and 17 years of age suffering from a chronic illness. Visit our website at www.courageouskids.org. For additional information, contact Tina Smith, RN or Mariah Hayes at (270)618-2900 or tsmith@courageouskids.org or mhayes@courageouskids.org.

Advances in Neurorehabilitation: Linking Evidence to Clinical Practice

Drs. Kaplin, Kerr and Levy Present at Physiatrist's Annual Meeting

On February 19-23rd, the Association of Academic Physiatrists held its annual meeting in Anaheim, California, and featured presentations by three members of the Medical Advisory Board of the Transverse Myelitis Association. Physiatrists are physicians who specialize in helping people gain the most independence and function in illnesses such as transverse myelitis. These presentations were part of a course, "Advances in Neurorehabilitation: Linking Evidence to Clinical Practice." Douglas A. Kerr, MD, PhD presented "Stem Cells and Neurogenesis," Charles E. Levy, MD presented "Driving Innovation in Neurorehabilitation," and Adam I. Kaplin, MD, PhD presented "Neurogenesis in the Hippocampus and Depression." Although it might not be obvious from the titles, each presentation drew from the research and clinical experiences of these physicians in treating transverse myelitis and related disorders. Each lecture was attended by approximately 100 physiatrists. Lively discussions followed the presentations. Frank Pidcock, MD, also on the TMA medical advisory board, joined the others on Saturday, February 23rd to take part in the California TM Symposium.

2008 California Rare Neuroimmunologic Disorders Mini-Symposium, Anaheim

Debbie Capen, Secretary TMA; California Support Group Leader
Cindy McLeroy, California Support Group Leader

Dr. Charles Levy advocated for and organized a rare neuroimmunologic disorders session at an annual meeting of physiatrists in California. Dr. Levy, the founding member of the TMA Medical Advisory Board, suggested that we organize an all-day educational meeting with our California Support Group while four of our Medical Advisory Board doctors were together in California. Drs. Douglas Kerr, Adam Kaplin and Frank Pidcock were excited about this educational opportunity and agreed to attend with Dr. Levy.

The California Support Group learned of this opportunity in October of last year. We felt that we could not pass up this rare offer, and with only a few months to plan the entire symposium, we took on the challenge. We had a lot of help from all of our Southern California support group members that meet regularly in Garden Grove. We called all of our members, sent emails, wrote letters, and invited everyone to attend.

We were able to negotiate a very reasonable contract with the Disneyland Hotel people to hold it at Paradise Pier, right next to Disneyland. We had a huge response from our members, who were really excited about our February 23rd event. Even with the short notice, almost 100 TMA members attended the mini-symposium. As is always the case when we have a large group of people with TM getting together, most of our attendees had never met another person with TM; so it was a very emotional day.

Dr. Kerr presented his latest research

findings on transverse myelitis, optic neuritis, ADEM, NMO and Devic's disease. Dr. Kaplin made us all appreciate how important it is to recognize when depression is interfering in our lives, causing our TM symptoms to worsen, and causing the quality of our lives to deteriorate without our realizing it. Dr. Levy shared his observations about evaluations for fitting people for chairs, walkers, and orthotic devices. He had many compliments regarding how well people in the audience were fitted and we all appreciated his comments. Dr. Pidcock raised issues regarding botox injections and alternative symptom treatment, which helped many to rethink their issues, and prepared them to bring many questions into their primary care providers.

We hope that this is the first of many "mini-symposia" which will be held around the country. There is a lot to fit into one day, but we would be able to bring more information to smaller groups who are unable to travel to the east coast or to the west coast for the larger conferences.

We can not thank our medical advisory board enough for making this possible. Thank you, Drs. Levy, Pidcock, Kaplin and Kerr!

Children's Database

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

1. To develop a contact list that will be used by the TMA to notify and recruit families and older teens and young adults for the family camps and the older teen/ young adult retreat opportunities, such as those that were held at Victory Junction Gang Camp;
2. To develop a contact list to recruit for pediatric studies and clinical trials related to TM/ NMO/ADEM/ON; and
3. To develop a directory that can be used by TM/NMO/ADEM/ ON families to share information and support between families in similar situations.

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

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

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

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

1. The information provided will not be incorporated in the TMA website in any way;
2. Your family will only be included in the directory at your request;
3. The directory will be published and mailed **only** to members who agree to be included in the directory;
4. Only the following information from the data base will be included in the directory:

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

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

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

If you would like to participate, please send your information to Linda Malecky via email: LAMALECKY@VERIZON.NET. If

you do not have internet access, you can send Linda the information via the postal service: 107 Tweed Way, Harleysville, PA, 19438.

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

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

We have tried to identify as many children as possible in our community, and Linda has attempted to reach many of you via emails to request this information. We believe that this project will help us better serve the families in our community by making you aware of important opportunities and by facilitating a support network for our families. We are grateful to Linda for her willingness to make this critically important project possible.

Allen Rucker

I am so pleased and proud to announce that Allen Rucker will be a regular contributor to The Journal of the Transverse Myelitis Association. Allen contracted TM in 1996 at the age of 51 and was paralyzed from the attack at the T-10 level. Allen recently published a memoir about his life after getting TM; "The Best Seat in the House" is now available in paperback. As his memoir so brilliantly conveys, Allen is on a journey. That journey has taken Allen into a life as a speaker and an advocate for the transverse myelitis and disability communities. Through his many speaking engagements, his appearance on the Montel Williams Show, and as a contributing writer for ABILITY and New Mobility Magazines, Allen is raising awareness about transverse myelitis. Allen has such a human perspective on life; Allen is such a *mench*. I am so honored and grateful that Allen is willing to share his wonderful perspective with our community as a contributing writer.

Allen Rucker was born in Wichita Falls, Texas, raised in Bartlesville, Oklahoma, and has an MA in Communication from Stanford University, an MA in American Culture from the University of Michigan, and a BA in English from Washington University, St. Louis. He is the author or co-author of nine books of humor and non-fiction. "The Sopranos Family Cookbook," one of three books he's written about the Sopranos, was a New York Times #1 bestseller. The memoir co-written with country music star, Gretchen Wilson, "Redneck Woman," is currently #29 on the New York Times bestseller list.

As a TV writer-producer, he co-founded the experimental video group, TVTV, and has written numerous network specials, documentaries, and teleplays, including the series, "The History of White People In America," with Martin Mull; "Christopher Reeve: A Celebration of Hope" (Emmy nominee); the original HBO movie, "Hometown Boy Makes Good," starring Anthony Edwards; "CBS: The First Fifty Years;" "Big Guns Talk," a history of the Western; and "Family Values: The Mob & The Movies."

His most recent TV project is an adaptation of David Maraniss's bestselling book on Vietnam, 1967, "Two Days in October," originally broadcast on PBS's "American Experience" in October, 2005. The highly-acclaimed program won both the 2006 George Peabody Award and the 2006 Emmy Award for Exceptional Merit in Nonfiction Filmmaking.

He is the recipient of the duPont-Columbia Journalism Award, the Writers Guild Annual Award, and two CableACE Awards, among others. In 2005, he received the special WGA Joan Young Award for career distinction as a writer with a disability. "The History of White People In America" was honored by the Museum of Television & Radio in 2001 and TVTV was given a full MTR retrospective in 2004.

Allen also teaches at the USC School of Cinema-TV. He lives in LA with his wife, Ann-Marie. They have two sons.

Learning on the Job
by
Allen Rucker

From the moment I began to flog my memoir about life after transverse myelitis, "The Best Seat In The House," I shamelessly passed myself off as a world-class expert on this strange malady. It was easy – not one radio, TV, or print reporter I encoun-

tered had ever heard of it. For all they knew, I could have been talking about the bird flu or lumbago. As I told a group of TM cognoscenti at a recent symposium in Anaheim, I could say anything and the half-listening media types would eat it up. "Yeah, researchers now believe TM comes from UFO's and largely attacks people living in trailer parks in rural Arizona…" Mad Mel in The Morning, the AM radio jock on the other end of the phone, would invariably go, "Wow, man, that is so f-ing cool – you got a disease from Mars, man!"

I was on semi-safe ground. I certainly knew what is was like to be hit by TM and to try to figure my way out of the fog, but I had only a George Bush-level of knowledge of what actually hit me. I could have easily picked up a world of insight from others who already had it, but frankly, in the early years of living with the condition, I didn't want to know other people who already had it. I didn't want to hang out with disabled people of any sort. If you think you're a freak, you don't want to broadcast it by joining a freak parade. I saw it like being obese and going to a convention of other obese people. "Jeez, I'm the fattest one here!" I was in that nether world between abled and disabled and felt uncomfortable and out of place in both. I was both an outsider among insiders and an outsider among outsiders, too.

So I first set my sights on feeling comfortable in the able-bodied world, since that was the universe of a) most of the people I knew and b) most of the people I'd be getting a job from in my newly disabled state. A big chunk of the book I wrote deals with just that – how to use humor, one of the only arrows in my personal quiver, to negotiate my way through all the awkward and embarrassing public dealings with "them." As I wrote, I felt like the paralyzed equivalent of the only black man at an all-white Kiwanis Club meeting. Beyond the Kiwanians who avoid you all together, you have to face the walking-on-eggshell nervousness of the ones who called you "my man" and wanted you to know that they knew who Miles Davis was. Hey, they're just being nice, you tell yourself, patronizingly nice. To this day, my wife can't understand why I grit my teeth every time someone sees me getting out of the car and runs up, grabs my half-assembled wheelchair, and says, "Can I help you, sir?"

"No!" I want to shout (but never do), "How do you think I got into the g-d car! I'm not helpless! I'm just paralyzed!"

Anyway, somewhere along the line, despite my best efforts to only associate with "normal" people, even the jerks who wanted to treat me like their granddad, I began to mingle with other disabled types. A representative at the Writers Guild of America, my union which just won a big strike, called me to give me an award – the WGA Joan Young Award for distinction as a disabled writer. I was terribly flattered and ended up at an industry award ceremony honoring disabled performers, writers, producers, and fellow travelers in TV and film.

"Hey," I said to myself, after a couple of glasses of free wine, "I like these people. They're just like me!"

Soon I was going to regular meetings of the Writers With Disabilities Committee at the WGA. The mission here was simple: get more disabled writers jobs so they can write more disabled characters for more disabled performers. For a host of reasons, Hollywood has an anathema to including the disabled in the zillions of hours of entertainment it pumps out annually. A studio will knock out a film every few years starring Dustin Hoffman or Tom Cruise as a heroic cripple, bag a shelf full of awards, and feel they've done a bang-up job of promoting diversity. You try to let them know that there are 56 million disabled people out there and only a pathetic .05% of all speaking characters on TV in a given year are disabled. They're getting the point, slowly. Really, really slowly.

But the cause is only part of the reason I make these meetings. Mainly I show up for the other members. They are a collective hoot. One of my favorite lines ever about who should be counted as "disabled," a constant debate in the diversity world, came from a longtime WWD member named Karol Silverstein, disabled since birth from a rare arthritic bone condition. In response to the view that anyone from marijuana abusers to neatniks should be included, Karol made a droll announcement.

"I think a disabled person is someone who has to put their underwear on with a stick."

Amen. Next item.

The more Karols I ran into, the more I realized I was operating under a culture-wide delusion, even after I had become paralyzed. I always thought disabled people came in three distinct personality types – Mean, Crazy, or Pathetic. Sure, there are occasional media idols like Christopher Reeve, but I figured even the celebrity crips were probably mean, crazy, or pathetic after they got home from a day of holding Oprah's hand. The heroic-seeming stiff upper lip, I know from personal experience, is a face many of us put on just to make the full-bodied feel better. Unfortunately, the myth of the Heroic Disabled feeds the misperception, even to ourselves, that we aren't just, you know, normal.

So, in only a few short years of laughing it up and learning from all kinds of people who just happen to be disabled, I've come full-circle. I don't avoid them now. I go looking for them. This

search has led to all kinds of memorable encounters, from kindred souls like Sandy Siegel to speaking before the disabled employees of the Nashville branch of Goodwill Industries, a great organization, to spending a day with single and double amputees from Iraq and Afghanistan at Walter Reed Hospital in Silver Spring, Md. That was a hell of an experience, believe me. I left that building with my first deep connection with the wars being fought in our name.

Whenever I can, I steal a line from a report by Dr. Adam Kaplin from Johns Hopkins on TM, MS and their relation to depression, a report I first read in this very journal. He quotes a study done by a researcher named Steven Mohr from UC-San Francisco, wherein Mohr and his troops simply called up a broad sampling of people with MS and asked them how they were doing. The statistic that I tout to anyone who will listen is that a full 60% of the respondents said that having MS had enriched their lives. I repeat – to these people, MS had enhanced the full measure of living. They went on to say that it had made them more sensitive, more tolerant, even more motivated to achieve.

I love to mention this stat because first, people like to hear it, and secondly, it's true. At least it's true for me. After TM, my life didn't become more circumscribed and less varied, more worrisome and less free-spirited, more inward and less outward. It became richer in the variety and soulfulness of the people I've encountered, richer in the friendships I've made, and richer in purpose.

Unfortunately, it didn't make me any richer financially. I guess that will come with the movie version of ''The Best Seat In The House." If George Clooney were in a wheelchair, he'd have a clean shot at playing the lead character.

In Their Own Words

In each issue of the Journal, we will bring you a column that presents the experiences of our members. Their stories are presented ***In Their Own Words*** by way of letters they have sent us. We are most appreciative of their willingness to share their very personal stories. It is our hope that through the sharing of these experiences, we will all learn something about each other and about ourselves. It is our hope that the stories will help us all realize that we are not alone. It is important to bear in mind that all newsletters and journals are archived on our web site. Should someone do an internet search of your name, your article is likely to be identified in their search results. You may submit your stories by sending them either by e-mail or through the postal service to Sandy Siegel. Please be sure to clearly state that The Transverse Myelitis Association has your permission to publish your article.

Logan's story by Rachi Botha (mother) Leraatsfontein Witbank South Africa

On 7 February 2005 I dropped my perfectly healthy 5 month old baby at the day mother. When I picked him up 6 hours later, he was completely paralyzed from the neck down. Every imaginable test was done and four days later, they came up with the diagnosis of transverse myelitis at C3 level.

As the neurologist was explaining the disease to me, I felt my world collapsing and then came his prediction that Logan would probably spend the rest of his life in bed linked to a ventilator. This was almost too much to bear, but by the grace of Jesus Christ, we found the strength to continue and to never accept the fate the doctors bestowed on him.

Although they kept the ventilator next to Logan's ICU bed, ready the instant he stopped breathing, he never needed it. A miracle in its own right, he kept breathing on his own through the whole ordeal. We were able to take a completely flaccid little boy home two weeks after the onset of TM and the slow road to recovery began.

Only someone whose been faced with a debilitating disease can comprehend to which extent your life changes. I had to quit teaching to look after my paralyzed baby and 2 year old son, who was thoroughly traumatized by the weeks his parents spent in ICU with his brother. Being without a second income and having the extra expenses of a special needs child wasn't fun either.

My time was completely consumed with caring for the kids, taking Logan to therapy and spending hours on the internet searching for anything that might help our baby. Being on an emotional rollercoaster is such a cliché, but it really is an accurate description. The one moment your heart will be breaking when you see your child next to a normal baby. You'd give anything to have him moving around, learning to crawl, walk, and exploring

his world. And then the next moment you'll experience heavenly joy when your 15 month old starts to leopard crawl or sit on his own.

Logan is an amazing little boy. He wants to do everything himself and is, at this stage, not bothered at all by his situation. He can crawl to where he wants to be, he can play, feed himself, drink from a cup, page through a book, do everything a normal 2 year old can do, but walk.

We've tried everything we could find that posed no risk to Logan: from terribly expensive nutritional supplements to unconventional eastern European rehabilitation centers. We've just returned from a visit to Euromed in Poland. They offer extremely intensive rehabilitation sessions lasting four weeks and consisting of five hours of therapy six days a week.

Logan was able to gain a lot of muscle strength and his progress can especially be seen in his hips, trunk, left hand (which was the worst affected) and speech. The fact that he's still not walking can largely be attributed to psychological factors: he's never been able to walk and prefers to crawl. He needs to realize the benefits of walking.

In this regard we've recently been to a clinic in Yorkshire that makes the most amazing walkers. We believe that Logan will see the advantages of walking when he gets his walker in six months time. I can't wait to take my little boy outside for a walk….

Samantha Bradshaw
Amanzimtoti, Kwazulu Natal, South Africa

When Sam first fell ill she was fit and healthy and very involved with her horse and show jumping. She started with a headache just after Christmas. The following day it got worse and we took her to our GP who thought that she was getting the flu and prescribed some antibiotics for her. The next day her lower back started getting sore so we took her back to the doctor. He was not happy with her condition and took a sample of blood from her to send to the laboratory.

When I got back from work the following day, she called me to her bedroom and told me that she was frightened because her legs were feeling very weak and painful. We rushed her to the local hospital and when we tried to get her out of the car, she just collapsed on the floor. She was totally paralyzed from the waist down. She was immediately transferred to St. Augustines Hospital in Durban where Dr. Farhana Motala attended to her. This lady doctor was fantastic. They did every type of test on her for days before they were able to detect what the virus was. I will never forget what Doctor Motala said to us that evening: "thank G-d you got your child here so quickly; maybe we will be able to save her." Those few words nearly killed me.

Sam was 17 at the time and due to start her matric year at school. Sam spent a month in the hospital and thereafter was in a wheelchair for about **seven months** before life started coming back to her legs. She used crutches for most of the rest of the year before she was able to walk unaided. To this day, nearly four years later, she still walks with a slight limp and the muscles in her left leg are a lot weaker than her other leg. During the time she was in the wheelchair, we were able to get her to school each day. She passed three of her subjects that year and did the other three subjects the next year through Damelin.

She then spent the next year at the Damelin Equine College in Johannesburg, studying equine stud management and then went over to Kentucky in America and spent six months working on a stud farm there. She is now back home and working in Cape Town with Basil Marcus, learning all about the training of race horses.

The underneath of her feet are still very tender and still feels a burning sensation when she gets into the pool or walks bare feet on the wet grass. Her bladder is the only thing that did not really come back to life. There is a brilliant urologist here in Durban, Dr. Roger Mierzwinski. He did the Botox injections on Samantha (into the bladder) and you cannot believe how it helped her bladder. From going to the loo every half hour, she now only needs to go 2 to 3 times a day. The botox relaxes the bladder muscles and lasts anything up to 10 months before having to be repeated, depending on the person. With Dr. Roger and the botox, she is able to lead a normal life.

Ivor Claassen
Pretoria South Africa

I am 50 years old and my name is Ivor Claassen. I was diagnosed with Transverse Myelitis on the 11th of May 2007. Thinking back, my symptoms started about three weeks prior to my diagnosis. At times, I would get out of my bed in the morning and walk/bump into the bed or chest of drawers on my way to the bathroom. My wife also noticed it, but we put it down to clumsiness or dizziness from getting out of bed and standing up too quickly. At one point, my fingers started going numb. My left elbow was sore for no particular reason. There were times that I felt very anxious. While at work one day, I had an intense pain stab me in my shoulder blade. This pain then moved to my spine and up my neck. Strange things were happening to me;

things that I had never previously experienced. I consulted my general practitioner on numerous occasions during this period with various symptoms. Mostly his diagnosis was hypertension/stress. He would then prescribe one thing or another and send me home. The numbness in my fingers he put down to hyperventilation and he told me to get myself a brown paper packet and blow into it. Nothing helped.

Then on the 9th of May, I found I could not pass water. I consulted my GP who again said that my problems were due to hypertension and assured me that things would get better. On the 10th of May, 24 hours later, I had still not been able to urinate. I decided to go to the emergency unit at the Wilgers Hospital. They immediately catheterised me, did various blood tests and sent me home with instructions to come back the next day so that they could remove the catheter. That afternoon I had another pain attack my shoulder and neck. The pain was so intense that my wife insisted we go back to the hospital. I received various pain medications to relieve the pain but to no avail. The doctor treating me at the emergency unit was apparently confused by my condition and telephonically sought the advice of a neurologist, Dr. Anton van As. He instructed that I be admitted to the hospital for observation. Dr. van As came to see me on the 11th of May and initially he thought that I might be suffering from depression as I had recently experienced a personal trauma. He then called a Psychiatrist.

Later that afternoon I had another attack in my shoulder and neck. I then insisted that the nursing staff call Dr. van As back. He did, and it was then that he said that I should go for a MRI scan. Even though it was after 5:00 on a Friday evening, he arranged for a scan to be done at 6:00 that evening. By this stage I had great difficulty in walking due to weakness, unsteadiness and loss of balance. My left arm didn't function at all. My wife pushed me in a wheelchair to the car, helped me in the car with great difficulty and took me to the MR Building. The MRI revealed a high intensity lesion in the cervical spinal cord and a diagnosis of Transverse Myelitis of the cervical spinal cord, level C2 to C4, was made. Dr. van As informed us that high dosages of cortisone was the only way to keep the inflammation at bay and that he was going to put me on a 5-day course of 500mg intravenous Solu Medrol. By the time my wife had me back in the ward, the nursing staff was ready to set up the drip.

At this stage, I could do nothing for myself. My wife fed me all my meals. Bathing was a nightmare. Getting in and out of the bath was almost impossible and I was unable to bath myself. Even with my wife's help, it took almost an hour to bath, wash my hair, shave, brush my teeth and get dressed. By then, I would be totally exhausted, almost unable to get back to my bed, and would then, quite literally, "pass out." It was pathetic. Here I was, unable to take care of myself and yet a month ago I had been playing squash for up to an hour at a time with no problems. Most of my life I had been fit and healthy. Although never a fanatic, I had always looked after myself pretty well and had never been overweight. What was happening to me? What was this all about? I had never heard of this Transverse Myelitis and neither had anybody else I knew!

The cortisone did wonders. It's magic. It made me feel much better (even though my body, especially my feet, was all swollen and my skin totally dried out). With much grit and determination, I started walking; at first very unsteady, but eventually I was marching up and down the corridors. I was determined that this was not going to get me under! At this stage, I was still catheterised. After removal of the urinary catheter, I still had major problems with urine retention. On the 14th of May a Physiotherapist came to see me and showed me various exercises which would help me with my balance, co-ordination, etc. My legs had dramatically improved, but my left arm was weak and almost useless. A small blessing was that my right and dominant arm/hand was never affected.

On the 17th of May, a follow-up MRI confirmed the abnormal signal in the cervical spinal myelum. A SSEP was also done which was clearly abnormal and showed marked slowing of conduction centrally in the region of the cervical spinal cord.

On the 18th of May 2007, after eight days in hospital, I was discharged. After a few days at home, I suffered a relapse. My walking had deteriorated; I was still battling with my bowel and bladder and had severe pain in my left arm. I was re-admitted to the hospital on the 24th of May 2007 and received a further three dosages of 500mg cortisone. A lumbar puncture was also performed specifically to rule out MS. I had informed Dr. van As that my cousin has MS and due to my relapse, Dr. van As wanted to make sure that I did not have MS. The cerebrospinal fluid was abnormal with a raised level of protein, but otherwise normal, with no signs of MS. What a relief!

I was discharged on the 20th of May 2007. I was weak and the relapse had had a major effect on me. At first, walking to the corner of the street was as far as I could go. With time and perseverance, I am now able to walk briskly for half an hour to an hour with no problems. I also saw a Biokeneticist who gave me a set of stretching exercises, as well as exercises for balance and my left arm. When I started doing these exercises, I could barely do them and would be absolutely exhausted after 5 minutes; but I am now

able to cope much better.

I went back to work on the 2nd of July 2007. For two weeks I worked half day. Most afternoons I was exhausted and went to rest / sleep. Thereafter, I started working full day again and even though I am usually in bed by 20h30, I have been able to cope.

Dr. van As has been wonderful throughout my ordeal. He has reassured me when I needed it and answered all my questions. Consultations with him usually last up to an hour. He is even telephonically available. These kind of doctors don't exist anymore – time and money are usually all that count. He has made a real contribution towards my rehabilitation and peace of mind. Currently, the most important issues to him are improvement in my bladder and bowel, balance, muscle tone and my left arm. While nothing is "back to normal" at this stage, there has been improvement in all aforementioned areas. This has given me hope for the future.

On the 10th of August 2007 it will be three months from my initial diagnosis. I acknowledge that I have come a long way since then. One of my biggest fears was that I have MS. I have been assured by Dr. van As that there is no sign of MS. Another fear was that I would not be able to control my bladder / bowel. I still have problems with both. I still get up between 2 and 4 times during the course of the night, but I have never lost control and for that I am very grateful.

My short/long term goals are the following:

- I want to be back on the squash court by the end of the year.
- I want to be able to ride my motorcycle again. This I have already partly achieved and last Saturday afternoon, I rode my bike to Brooklyn.
- I want to be "myself" again. At this stage I am positive that, with time, I will make a full recovery.

Presently I am still suffering from the following symptoms: bladder / bowel problems; left arm is weak and I am unable to lift my arm in front of me. I am, however, able to use my hand – eating and using a computer, etc.; my hands are "dead" and have pins and needles sensation; my joints and muscles are constantly sore; my skin has crazy sensations including hypersensitivity, pain, cold, wet, hot, tingling, burning; I am unable to sit for long periods of time; When adjusting my sitting position, I have "bugs" running down from my neck to my toes.

I have had tremendous support from my wife, Karin; my daughter, Tammy; my colleagues; my mother and father in law, my church – numerous visits from Rev. Beryl Donkin and prayers from the prayer chain group; and Dr. Anton van As.

Becoming a Nurse
Marieke Dufresne
Quebec Canada

In March of 2004 I was diagnosed with TM at T1. I was completely paralyzed from my chest down. Lying in bed, I said to myself, I want to be a nurse, a good nurse, like the ones taking care of me now. Six months later, I went back to work in a wheelchair as a Pre-K teacher. During my time as a teacher, I had the opportunity to have nursing students work in my classroom during their pediatrics rotation. Every time I had a student nurse work with me, I would pump them with questions about nursing school; what they liked/disliked, how it was taught and what was covered. I was very interested and had always wanted to go into nursing.

While I was in a wheelchair, I was concerned that nursing would be impossible. But I was working very hard in physical therapy to be able to walk once again. In March 2005 I sent in my application and said to myself that IF I was accepted, then I would really force myself to walk and not use my chair anymore. In mid-April I got my acceptance letter. I was ecstatic! So the decision was made. I would ONLY walk. As of mid-June, I stopped using the chair for everyday things and only used my leg brace and cane. I had until the end of August to be able to do this, and lo and behold, I did it; though I would still tire easily.

School started and I felt as though everyone was staring at me. I made a few close friends right off the bat which made things easier. At first, I wasn't sure how teachers would react. The first clinical teacher I had was a little weary but gave me the benefit of the doubt. During clinical I would try to sit down as much as possible while still being able to do all that my classmates were doing. I did not want special treatment from anyone, nor did I want to look like I could not handle it. At times, it was just so very hard. The first year was not bad. Clinical was only once a week and both clinical teachers I had were very good and gave me high praise at the end of the year. We did not do that much as first year students; AM care, bed making, giving meds both oral and injections and basic wound care.

The second year was harder when it came to the material we needed to know and we had clinical twice a week. I found that because of my TM, I would fatigue faster and the need to study and keep up was harder. While many of my classmates could get up at 6AM and go to class then home and study until midnight, I was wiped out by 10PM and many days had to take a nap when I got home from class. The two days of clinical was also hard at first; getting up at 5AM, being on the

ward from 7:15 - 3:30 and then going home and having to work on care plans or look up unknown drugs. It was so tiring. We covered so much more material that had to be applied in clinical as well as used for class projects or tests. I found myself questioning if I could actually do this.

We had obstetrics, pediatrics and advanced medical-surgical. We took care of newborn babies which scared me, because I was afraid I would drop a baby and was worried that the parents would not trust me with their precious little newborns! It turned out fine in the end, and, yes, I can carry a baby without dropping it! But the clinical teacher I had gave me many problems. She just did not think I belonged in nursing due to my disability. In the end she gave me a good evaluation, but I did not enjoy my six weeks in OB.

Pediatrics was great. I love kids and the teacher I had was fantastic. She didn't see my disability as a problem and made sure that I got to experience many things and practice as many new skills as possible, such as suctioning a child. Med-surge was a big challenge. I was put on an internal medicine ward and the teacher I had said right from the start that she did not think it was safe for me or my patients to be a nurse. I was angry and disgusted! How dare she pre-judge me after two days in nursing lab. I did all the skills just fine during those two days and there was no reason to doubt my abilities as a nurse. I spent the next four weeks in clinical thinking she was trying to find reasons to fail me. Well, during week four she came up to me, put her hand on my shoulder, and told me how proud she was of me. She had changed her opinion of me and said that she was blown away not only by how I handled myself in clinical, but also how I helped my group-mates and taught them things they needed help with. She was impressed to see the others come to me to ask for help with physical duties, such as transferring patients or moving them up in bed. You see, she still saw me as a person with a cane, whereas my classmates had stopped noticing any differences. At the end of the year, even this teacher had stopped seeing the cane. I know this as she told me. This made me very happy. I finally felt like I had proven myself.

Nursing school is hard enough without going into it with a disability. I have spent two years proving not only to others, but to myself that I can do this. I am now in my third and final year of nursing school. I am very excited and cannot believe that three short years ago I was paralyzed; lying in bed and saying to myself that I want to become a nurse!

Marieke Dufresne,
Nurse,
TMA Support Group Leader, Canada

Traci Duke
St. Maries, Idaho
June 10, 2007

In January 2007, I went to Coeur d'Alene, Idaho to shop with my children. That night I started having a burning sensation on the tops of my feet. I would rub them and it seemed to help. My lower back was bothering me a little bit, but I attributed that to the driving. I went to bed and on Sunday the 14th; I woke up to more back pain and the burning had moved up to my knees. Again, I thought I had just hurt it and that the pain would go away on its own. I took some ibuprofen and used a heating pad the rest of the day. The pain in my back kept getting worse. I continued with the ibuprofen and I also took Tylenol to see if it would help. The burning was moving up my legs. By Monday the 15th I was in so much pain, I could hardly stand it. I kept taking the ibuprofen and Tylenol to function. That night around 7:00, I told my husband to take me to the hospital. I couldn't stand the pain, and the burning was now up to my waist. The hospital didn't know what was going on, but they ruled out a pinched nerve. They gave me a shot for the pain and some Darvocet until I could get in to see my doctor the next day.

I live in a small town; including the surrounding areas, there are about 3,000 people. The staff at the clinic and hospital hadn't seen anything like this before. I had x-rays done on my visit on Tuesday the 16th. The doctor didn't have a clue what was going on with me. They did know that my symptoms were not consistent for a back injury; they were moving in the wrong direction. They don't start at the feet and go up the body. I was told to take Naproxen and they gave me Tylenol 4 with codeine for the pain. Around the 23rd, I started having problems urinating. I thought it was from one of the meds, so I stopped taking both of them. After a few hours, I was able to urinate normally again. I started taking the ibuprofen and Tylenol again. By now, the burning had gone from my feet to my waist and was now from my waist, up my trunk, down my arms and to the ends of my fingers.

On Wednesday the 31st, I was able to have my first MRI. I requested the MRI. They were trying to convince me that I had a slipped or crushed disc.

My husband's birthday is February 2nd. My daughters and I planned to surprise him with dinner at the Casino in Worley. I had been having some more back pain and decided to take the Tylenol 4. I had taken one earlier in the morning and by 5:30; I had to take another one. I started having problems urinating again. But this time it lasted longer. In fact, I was still having problems in the morning. By 3:00 Saturday afternoon, I was having my daugh-

ter take me to the ER for my first catheter. They pulled off 1200 cc's. I went home and was told not to wait so long to come back to the hospital, if I continued having problems. I limited what I drank the rest of the day and lasted until 10:30 pm. I was back in the ER and this time they left the catheter in.

While I was there, the doctor looked up the results of my MRI that had been done on Wednesday. It didn't show anything. I told the nurse I was also having problems having bowel movements. The doctor told me to take an over-the-counter liquid laxative and if that didn't help, to try an enema. I tried both and was up, off and on, all night as they helped me some. As the night went on, I noticed I was having problems walking. My legs were giving out on me. I had to wake my husband up around 4:00 am to help me into the bathroom. I now knew that whatever was going on was bad.

I woke up around 8:30 on Sunday the 4th. I couldn't support myself anymore. I woke my husband up crying and told him I was scared and that whatever was going on with me was bad and I didn't know what to do. I waited until around 10:00 and then called the hospital. I told them I wanted to come in and have them run every test they could on me. I then called my sister and told her I was going into the hospital and asked if she would tell our parents, who were at her house. I then hung up because I was crying so hard. My Mom called back about 10 minutes later to tell me they were all coming and to go to the hospital. They would be there as soon as they could. They live in Montana.

I then had my husband tell my children I was going to the hospital. He had to take me out to the pick-up and load me in it. I got to the hospital and, thank G-d, I had a doctor that had somewhat of a clue what was going on. He was the fourth doctor I had had since I started having problems. He thought what I had was GBS. I didn't know that GBS and TM had very similar symptoms. He had me get a CAT scan with the dye. He then admitted me to the hospital. He told me I needed to see a neurologist as soon as possible.

My family from Montana showed up around 3:00 and my kids came to see me. My kids at the time were 27, 23, 15 and 14. We were all scared.

The next morning, the doctor told me that they were trying to get me in to see a neurologist as soon as they could get me to Coeur d'Alene. I was shipped over at 11:30 am. It was now the 5th of February. I was admitted into Kootenai Medical Center and by now, I could not support myself at all. I had two different MRI's that day, and the next morning I had another one on my head. I also had a spinal tap. By the 6th of February, I could not move anything below my armpits. I was paralyzed.

They started me on high amounts of steroids; plus a load of other meds. I was paralyzed for about four days. I had a lot of support from my family and friends. I thank the Lord for all of them. I was able to stay strong because of them.

My doctor was now changing my diagnosis from GBS to TM. I was told that the two main reasons were that I never lost my reflexes and that I had swelling in my spine. Plus, GBS doesn't have the burning sensation I was having.

I think the one physical therapist was a key to my recovery. He came in and asked what I wanted to be able to do and what I wanted for my options. I told him the bed I was in was not an option for me. I told him I wanted out of it and that I wanted to sit in the chair across the room or even the seating by the window. He asked when I wanted to do it and I said I wanted it now. He came back in about 10 minutes and helped me into the chair. I sat there about two hours. I was in a lot of pain, but the last thing I wanted was to be in the bed I had been in for four days. They had me in the chair longer each day. This had been the longest I had ever been in a hospital and I wanted to leave.

One of those days, I had the PT lady helping me into the chair and I apologized for them having to support me to get me into the chair. She informed me that I had supported myself. I was shocked. I didn't know I had helped at all. I had felt the pressure in my legs, but didn't know it was because I was on them. Now, I knew what that sensation meant. I had a terrible pins and needles effect going on in my feet and lower legs. It was worse when I was putting pressure on them. Now I knew what to feel for when transferring to and from the bed. Awesome. Over the next few days, I wanted to do more and more. I was able to finally try and stand on my own. My sister took pictures. It was such a great feeling. Then they had me try walking. The walker was a big adjustment. I made it to the sink to brush my teeth. Then into the closet. Oh, wait, it was the bathroom. Huh, imagine that, a bathroom; too bad I couldn't use it. I had to sit on the toilet for a few minutes. I had over done it and was dizzy and nauseous. I made it back to the bed which was about ten feet away. I lay down and was sweating. But, I had walked.

I was on the second floor for a week and then taken down to the rehabilitation facility for another week. I was in a wheelchair most of that time. Physical therapy and occupational therapy was hard. Who knew it was so hard to learn to walk. No wonder kids have such a hard time. I had to work so hard. Also, they pulled my catheter the second day in rehab. On top of all the therapy, I had to get cathed 8-12

times a day. I never lost that sensation. I knew when I was in need of a bowel movement or when my bladder was full. I also could feel the catheter. Not fun. But after a couple days, they taught me how to cath myself.

I came home after a week in rehab. I tired easily. But I never used the wheelchair, and I only used the walker for about two weeks and that was when I went out of the house. I still have numbness; the outside of my left leg from my hip to my toes and my left knee. My toes and feet have some numbness but not too bad. I still have to cath myself now and then, but for the most part, I can urinate by myself. I have some numbness across my back and down my left side. My left leg has gotten more numb in the past week. I walk with a slight limp. If you didn't know me, you wouldn't notice.

I am back to work. I have a daycare I run out of my home. My Mom and older daughters helped me during the first month when I got out. I work full time. I don't tire too much these days. It was pretty bad the first few weeks. So far, this is my story.

Kim Harrison
Atlanta, Georgia

I live in Atlanta, Georgia and was 45 when I got TM. I was on a business trip to Dallas, Texas when I was stricken with this disease. I went to Dallas on September 4th, 2004 and was to be there for only a week. I used to live five miles from the facility I was helping at in Dallas. I was scheduled to come home to Georgia on Oct 8th. I almost made it home.

I got up on the morning of October 6th and my right foot was asleep. I kept taping my foot on the floor to wake it up. I figured I slept wrong and pinched a nerve. By 9:00 am, I could not walk at all. The tingling had moved up past my knee cap. When I tried to walk, I kept walking into walls and falling down. The crew at work kept telling me to go to the ER. I just laughed at them, because I assumed that my foot was just asleep!

Well, by 10:00, I couldn't walk at all and was carried to a car and off to the ready care. The doctor there did a few quick tests and sent me to the ER. He thought I was having a stroke. When we got to the ER, five miles away, they were waiting outside for me. I kept joking that they offered curb side service. They rushed me to a room and there started the "barrage of tests." At 3:00 pm and 2 MRI's and 3 CAT scans later, the ER doctor remained totally baffled.

The "tingling" had now moved up past my thigh. I could no longer move my right leg at all; not even wiggle my toe! So, while joking about making sure that they tell my Mom that I have clean underwear and all, I was admitted to the hospital. By now, my husband back in Atlanta was totally freaking out and I was still making light of the whole situation.

Lucky for me, I had family close by and someone was with me until my company flew my husband, Brian, out to Texas. When I woke up the next day, my left foot started to tingle. I knew at that point that something was really wrong. It took the neurologist until Monday, five days later, to finally tell me what I had. After all the tests, the doctors finally labeled my onset of TM as idiopathic. To this day, they can not tell me how I got this.

I was in the hospital a little over a week and then moved to a rehab facility next to the hospital. It was more like an old folk's home; I was the young kid there at 45 years old. After a week in the rehabilitation facility, I was sent back home to Georgia. I went back to work a month after getting out of the hospital. My boss has been very supportive and made my return back to work much easier than I ever thought it would be.

I use my walker around the house and wheel chair in public. My right leg still drags like I've had a stroke. The "banding" pain around my waist and the burning in my feet are my two primary issues. I can not wear pants unless they have elastic so I can pull them up over my belly button due to the banding pain. I also can no longer wear shoes. Even socks hurt my feet due to the burning and stinging sensations. This makes it hard to use my AFO's, because I can't take wearing shoes on my feet.

It is so hard to explain to people that I in no way saw this coming. That I got up one morning and within eight hours, I was paralyzed. But life does go on and it's just the adjustment we all have to learn to deal with, daily, regardless if you have TM or any other medical condition. You work and live life with the circumstances that have been dealt to you in the most positive way you can.

Cindy Ranii
California
January 22, 2008

How does one start to tell a life-changing story? In the case of the story of my onset of Transverse Myelitis, I don't even know when the story begins. Was it with our fairytale trip to Scotland in July of 2005? Was it with the coughing and sneezing children in the plane to Ireland? Was it the first sign of a backache a few days after we returned? Was it the loss of feeling in my left foot and my falling into a glass coffee table? More than likely the beginning of the story is something I will never know, when some unknown virus entered my body and started the mysterious chain reaction that led to my being a paraplegic (T-3, complete, ASIA - A).

Late in July of 2005 my partner, Shelly, and I and other members of our family had just returned from Scotland where we had participated in our daughter's destination wedding. A castle in Scotland, men in kilts, and a stunning bride made for a never-to-be-forgotten event. Also, we had played golf five or six times, including at the home of golf, St. Andrew's. Returning back to California we spent a couple days at a resort near San Diego, California. I played golf once there before our drive back up the coast to Santa Cruz.

All seemed well when we returned home, and we were happy to play with grandchildren, and I remember lifting them over my shoulders and running down the hallway of our house. When I awoke with a backache in the middle of the night, I attributed it to lugging golf clubs halfway around the world, being cramped in cars and planes, and carrying grandchildren around on the unforgiving hardwood over cement floors. My 58 year old body would bounce back, I was sure, but I knew it might take a day or two.

I got out of bed that Monday morning, did some yoga poses, which I did every morning, and willed myself to get back to work. I trusted that being active would do the trick for my post-travel back stiffness. My work as superintendent of a high school district was busy and demanding, and I was returning to it after the first full three weeks off in many years.

Throughout the day, however, the pain did not go away. That night I was unable to sleep. I tried sleeping on the floor, which gave me some relief. I went to work again on Tuesday. Again, at night the pain was intense, and I stayed home from work on Wednesday, and arranged to see my doctor on Thursday.

Leaving the house on Thursday for my doctor's appointment, I reached for my briefcase by the front door and fell backwards onto the floor bumping my head on a coffee table. Never before had I ever fallen. My left foot had just buckled under me like it was asleep. I drove the 30 minutes to work and worked for an hour or so to catch up on some issues before driving to the doctor's office. The doctor had been called away to deliver a baby, and I was told I could reschedule. I said that I would wait however long the wait might be. I somehow knew that something was going on, but I had no idea what it was.

I saw the doctor an hour or so later. She was seriously concerned but unable to diagnose what the source of the back ache and loose left foot was. She prescribed pain medication (Vicodin) and an anti-inflammatory (steroid) and said, "I don't think you have had a stroke." A stroke? I had never even considered that what was going on could be really serious. I had assumed a pinched nerve or a "tweaked" back and that a trip to the chiropractor or the doctor would put me back in shape. The doctor said not to go to a chiropractor until we had determined what was going on. She also said that if the pain worsened or if I lost control of bowel or bladder to get to the emergency room right away. That sounded ominous. I still assumed, however, that the post-travel back ache and foot looseness was temporary.

I went to the pharmacy to fill the prescriptions, and while waiting in line, I realized that I was not able to stand without wobbling. I asked someone to hold my place in line, and I went to the cane aisle and picked out a cane. I sat on a bench near the pharmacy counter until it was my turn, and with the help of the cane, which I purchased, I made it back out to the car and home.

Immediately I took the medications and lay down on the couch hoping for some relief to the now excruciating back pain. Unfortunately, within two hours, the pain had worsened, and I was unable to control my bladder. I called our health insurance hotline and the nurse confirmed that I should get to the emergency room stat.

Shelly drove me to the emergency room, and using the cane, I was able to walk. My left foot was slightly drooped and dragging and my back hurt like crazy. I checked in with the triage nurse and then found a comfortable place in the waiting room, along with some 10-20 other people. I knew from experience that it would be a long wait, and I was readying myself physically and psychologically for an extended stretch of sitting. My first sense of "oh, no" was when the triage nurse called my name ahead of everyone else's.

Doctors of various specialties came in right away and performed multiple tests. Within several hours I had seen a neurologist, orthopedic surgeon and a cardiologist. The orthopedist and the cardiologist each announced to us that I was fine, as far as their specialties went. With smiles, each of them left for the evening … not their case on a

late evening in the E.R.

The neurologist was puzzled, although he assumed that I had probably had a stroke. I was admitted to the hospital for further observation and testing and to make me comfortable. After an MRI and other tests, the neurologist concluded that I had had a stroke in my spine, a spinal infarction. He made calls to a local rehab center and suggested that it would be best to go there for a week or two and that I should regain the movement of my left foot within 4-6 weeks. It would take some work, but I should be fine.

I met with the president of my school district's Board of Trustees and we named an acting superintendent, because it looked like I would be out of commission for several weeks. I was using a walker in the hospital. Some friends and family visited and we even had an impromptu birthday party on the patio for a dear friend. On the way back to my room, using the walker, I walked with my three-year-old grandson. We arrived at my room and I started to turn in. He said, "Let's go down to the end of the hall and back." I was totally out of energy but the grandma in me agreed. As we got to the door of the room, he looked up and said, "We'll get you back, Grammy." That was on a Friday, and it was the last time I ever walked.

Over the weekend the lack of feeling in my left foot moved upwards and soon I could no longer move my left foot or leg. Also, my right leg lost its sensory function. I had been doing range of motion exercises the best I could. I awoke in the middle of the night on Sunday night and I thought that since I was awake anyway I might as well do the range of motion exercises. My feet and legs, however, did not answer the call. I could not feel or move either leg, and my midriff also had no feeling. I lay there alone and whispered to myself, "Oh, ----. I'm screwed."

I saw the neurologist the next morning and he seemed truly perplexed. He said that he would transfer me to a larger regional hospital, Stanford University. He didn't know what I had or what to do about it.

At this point my body went into "spinal shock" and two weeks of intense pain ensued. It was after three weeks of hospitalization that the terms Transverse Myelitis were first used to describe my condition, although the neurologist noted that my presenting signs were neither transverse nor myelitis. Some say that there is no worse fate than being a medical anomaly in a teaching hospital. The doctors concluded that my case was probably prompted by an unknown virus, thus my case was idiopathic. Dozens of doctors were interested in my case, but the focus was on describing my case, not on treating it. All treatment focused on controlling the pain and protecting my bodily systems. After the pain had been put under control, I was told that I would be transferred to Valley Medical Center to its spinal cord injury rehabilitation center. It was then that it became clear to me that there was no treatment for my condition. The focus would now be on my learning how to live with it.

That was reconfirmed when I settled into my room at the rehab center. A nursing assistant was taking some vital signs and asked, "How long have you been a paraplegic?" I actually started to turn around to see who she was talking to. It was a long, sobering moment when I realized that she was, of course, talking to me.

Many chapters of my life have been lived since my "onset" story of two and a half years ago. I'm now 60 years old with more grandchildren and more time to enjoy them. Although I returned to work after six months, I am now retired. I work out at a rehab gym twice a week, play wheelchair tennis, some golf, and enjoy the increased space in my life. Shelly and I have put 26,000 miles on a Toyota Sienna ramp van which is fitted with hand controls for me, and we have made the necessary modifications in our home to make it accessible and comfortable. We are a four wheelchair family: manual chair for most days, power chair for long outings or when my elbows and wrists act up, a commode chair for toileting and showering, and my favorite, the tennis sports chair. Our life has changed dramatically, but with Shelly's positive spirit and the love and help of wonderful family, friends, and neighbors, we have been able to move on and embrace life. It's more difficult, of course, but I have also found that I am more patient, kinder to others, and more appreciative of all that life offers.

If I can be of any help to any TMers or their loved ones, please do not hesitate to get in touch with me. Life does come at us sometimes. I can be reached at ssjchr@sbcglobal.com; 1036 Laurent Street, Santa Cruz, CA, 95060 or by phone at 831-426-5363.

All my best to you and yours on your journey.

Barbara Sattler
Tucson A Z

Like most Americans, September 11, 2001 is a day I won't ever forget. Of course, I will remember the horror of the planes hitting the World Trade Center and the towers falling down. It was also the day I was diagnosed with TM. Like many of you, it took several months to find out what was wrong with me. It all seemed to start with a searing pain every time I bent in a certain position. The pain reminded me of several years before when I had shingles. It was intermittent pain and I ignored it hoping it would go away. A

week or so later, I woke up with a fever and flu-like symptoms. For ten days, I shivered and sweated, had stomach pains and endured blood tests, CAT scans, an ultrasound and a visit to the emergency room. I was alternatively diagnosed with a virus, possible appendicitis and, ultimately, the only finding was constipation. By the time the fever ended, while I felt okay, I had a partially paralyzed left leg.

I went to several more doctors. I had more tests, more pain and fatigue and was hardly able to walk. I was finally referred to a neurologist. What followed were months and months of being unable to sit down due to the pain in my waist and abdominal area. I had bladder and bowel issues and pain, including the inability to wear clothes that were binding from my chest to my knees. I had never before considered that wearing underwear could be a privilege. While I never was totally paralyzed, my right leg also became affected and for a while I could barely walk more than a few steps.

Finally, after about eight months that included a steroid injection and steroid pills, a tens unit, numerous pain medications and medications to deal with my bowel and bladder problems, I began to recover. I went back to work after I was able to wear some underwear and bought myself a small wardrobe of comfortable non-binding clothes. About three weeks after I returned to work, I woke up in the middle of the night to use the bathroom, tripped and broke my ankle in two places. Because of my lack of balance from the TM and still being weak, crutches were out of the question. So I spent the next eight weeks in a wheelchair.

Even though I still take pain medication daily in order to function, I consider myself one of the lucky ones. I was able to go back to my career as a Judge and I find much satisfaction in what I do. I have a very supportive husband and son plus a large network of friends. Almost six years later, my legs are completely normal as is my bladder function. I still take medication for bowel issues and constipation, several non-narcotic pain medications, as well as morphine daily. I can wear underwear and somewhat more stylish clothing, although I still cannot tolerate any zippers or buttons at the waist or any even semi-tight shirts.

Recently I had a setback. Several months ago I reduced my morphine by one-fourth. I believed that I was getting better (even if it was in tiny incremental steps). I had reduced some meds, experiencing pain on medication less and less often, being able to workout and hike and just feeling better. I was sure I was on the road to permanent recovery and would slowly be able to get off my medication. But then the pain increased and I was back to the old dose. I guess I am facing for the first time the idea that I will never get any better than I am now. I was also recently diagnosed with type 2 diabetes, although I am not overweight, exercise often and never smoked. I was told that one risk factor for diabetes was the steroids I took. This was something I didn't know.

I am generally an optimistic person and doing okay. I can never adequately thank the TMA, Sandy Siegel and all the contributors to the TMA cause for providing the information, resources, and the knowledge that others were going through the same experience (and much worse). I never heard of this disease before I got it and don't personally know anyone else that has it. I would be glad to start a support group in Tucson, Arizona but so far I haven't found any members. I try to donate all I can and know others do the same. Perhaps, I could share some things I've learned over the years about medical care and certain aids in recovery and coping that maybe will help someone else.

- Medical professionals don't always tell you what you need to know. After my steroid treatment, I had a steam bath and sauna and afterwards was in horrible pain. I found out heat was bad for nerve pain and that I should have avoided the sauna and steam and even hot showers.
- Many of us suffer dry mouth from our medications. There is a toothpaste and related products, such as mouthwash and gum with the brand name Biotene which totally eliminates dry mouth. My dentist told me about it after she explained that dry mouth not only is uncomfortable but can also cause serious dental problems. It is available at most drug stores without a prescription.
- After being on numerous medicine schedules, I've found that if I set my alarm for an hour before I get up and take my pain pills and go back to sleep, I feel much better than if I take them when I wake up.
- Fighting against taking pain medication if you need it is counterproductive. I used to pride myself on holding out, but finally learned to take the medication as prescribed. The longer you are in pain, the longer it takes the meds to kick in once you start taking them.

Don't give up when one regime or pain clinic doesn't work. You should be able to find a doctor or clinic that will work with you and make a difference. Don't let a doctor minimize your pain. Be open to non-traditional remedies, such as hypnosis and acupuncture. For several months, hypnosis supplemented my pain meds and really helped.

Maggie Winston

I could think about and write about Maggie Winston using thoughts and words like tragic, difficult, challenge, sad, pain. All of those thoughts are so very real. Maggie got TM just a few years ago. She became totally paralyzed from the neck down and ventilator dependent on her twin sons' first birthdays. Maggie lives in Kenai, Alaska, a small town of 5,000 people about an hour drive from Anchorage. Maggie had a serious fight for her life in those months following her attack. And her life has been filled with enormous and difficult challenges since her attack. She was impacted high on the cord and suffered all the horrible symptoms that readers of this journal know all too well. Maggie also has suffered with unrelenting nausea from the damage done to her brain stem. She has been able to get off of the vent but her breathing is impacted and she is prone to bouts of pneumonia. And she lives in a small town where there is snow on the ground for most of the year and daylight during the two weeks of spring and summer.

Everything about this young 20-something's life changed in an instant; her physical relationship with her children, her ability to work, her family relationships, her friendships, her recreation, her social life, everything. Or was it really everything?

When I think of Maggie, I most definitely don't think tragic, sad, pain. The essence of this human being is one of the most vibrant and positive spirits I have ever met in my life. I would never discount her struggles or the suffering that she experiences from all of her difficulties. She has plenty of struggles and suffering. How could a human not have those experiences under these circumstances? But that is not who Maggie is. She makes choices for herself. She must make these choices for herself many different times during her day. This is one really amazing and wonderful human being.

I met Maggie in a small plane going from Charlotte to Greensboro, North Carolina. We were all on the way to Victory Junction Gang Camp for the teen and young adult retreat weekend. This was the third leg of a two day plane flight from Alaska to North Carolina. Maggie was carried onto the plane with no jet ramp and placed into her seat during a driving rain storm. Her beautiful blue and black hair was dripping wet; she was wet from head to toe. And laughing and smiling. And from that moment, we made a connection with Maggie that is special in a way that is difficult to describe in words.

Maggie reminds us so much of our children. She is so full of life and such a character. I once called Maggie and she sheepishly responded to one of my gazillion "parental" questions that she had lost a cap that allowed her to take nourishment through her feeding tube, and hadn't done anything to replace it for two weeks. After telling her that I expected her to call the doctor when we hung up the phone and that I would be calling in a couple of days to check to see if it had been replaced, we both laughed heartily about her predicament and her reaction to it. It reminded me of the time I found our son, David's, retainer under the couch.

I talk to Maggie often. I talk to Maggie often because I care about her, I am concerned about her, I want to check in on her, and I want to be sure she hasn't lost any important pieces of her equipment. And I speak with her often because I love Maggie. If she lived in Columbus, she would be the best of friends with Aaron, Hanni, David and Kat. They have so much in common. Our children would love Maggie.

We talk about many serious subjects; Maggie has serious stuff going on with her. But we always laugh a lot and I always hang up the phone with a smile on my face and in my heart. Maggie is the most incredibly positive spirit. Nothing moves on the outside, but the complexity of the emotional and spiritual movement on the inside of this human being is something very special and unique. We all have great hope that Dr. Kerr and his colleagues will find the cures for these horrible diseases. If we could bottle the essence of Maggie, we might be able to find the cure for the ravages of the human spirit. I wish I understood how this worked, because if we understood it, we could repair so much human suffering. What I have learned from people like Maggie and Jim Lubin is that human beings can suffer horrible and difficult things in their lives – even permanent things – and still hold onto the most positive part of who they are, how they see themselves, how they feel about themselves, how they relate to others. I don't understand how they do this. I don't understand why some people find a way to do this and some cannot. As I answer the phone every day and talk to people who are suffering mightily from these horrible experiences, this remains the greatest mystery for me.

Maggie wrote a wonderful poem. It is all Maggie. I asked her if I could share it with the TMA community and she consented. Thank you, Maggie. You are in my thoughts and heart every single day; and you never fail to bring a smile to my face and in my heart!

Choices

what is the most beautiful part of being alive?
we were brought to this world with a powerful gift
so powerful is this gift, that when utilized...
the universe is a blank canvas to create what you will
every word uttered from your tongue
every sound heard by your ears
every sight your eyes have seen
every single breath you've taken
every experience brought to your existence...
has made you exactly as you are
whether you spoke words that were hurtful or complimentary
whether your ears heard wonderful music or obnoxious clatter
whether your eyes saw beauty or horror
whether your breath came with ease or with difficulty
whether your experience was pleasant or painful...
it all brought you to this moment...now...here.
now i'll ask you my friends
look at yourselves...as you are now...really look
look at yourselves in the mirror
close your eyes and look inside yourselves
look at and really feel every single aspect of your lives
physically
mentally
spiritually
do you like what you see?
do you like what you feel?
to those of you who said no
to those of you who don't know
to those of you who can't even take a moment to look...
to really feel what's inside and all around you
to those of you who desire something better
CHOOSE IT
make the CHOICE now to CHOOSE complimentary words
and you'll find yourself complimented
CHOOSE to hear wonderful music in all sounds
and you'll find your life to be musical...even in silence
CHOOSE to see beauty...even in horror
and you'll find yourself surrounded by beauty
CHOOSE to take a healthy breath with ease
and you'll breathe without difficulty
CHOOSE the experiences that bring you never ending pleasure
and you'll find yourself in a painless existence
the most beautiful part about being alive is CHOICES
the powerful gift we were given is the ability to CHOOSE
we were brought to this world with free will...it flows in our veins
it was our very first birthday gift and our birth-right
so at times when you find yourself to be anything other than abundant
abundant in all things that bring you bliss
abundant in every way life can possibly offer to you...
CHOOSE ABUNDANCE
follow your bliss and it will take you to that blank canvas
so...what marvelous experiences will you create?
the universe awaits…

Cindy Neveu

On March 14th, 2007 Cindy Neveu died after a brave battle with liver cancer. She was 40 years old and lived in Oakland, California. Cindy sent me this photograph shortly after her very special 40th birthday celebration.

Cindy had TM for 16 years; she also had hemophilia factor-I, HIV, Hepatitis-C, she had suffered a stroke, and finally died from liver cancer.

Shortly after Cindy died, I received a letter from her good friend, Charlotte Cook.

I always think that the real Cindy was the one who could find and articulate the irony she found everywhere ... you know, her humor. When I first knew her, she would say these very odd ... even daffy ... funny things to me. I always felt like she wasn't really talking to me ... that there was someone else in the conversation who really "got it." Then one day I "got it" and realized that she was developing in me a brighter, less serious person. It's a toss-up whether people think I'm in-

tense and focused or delighted and delightful. I try to keep people around me who foster the latter, though it is the former that helps me get my work accomplished. But with Cindy ... she always played to the latter as if that was the only Charlotte there was.

To me that's the real Cindy.

Pauline and I met Cindy in Seattle in 1999. The meeting in Seattle was quite amazing as this was the first time we had brought together a large group of people who had TM. It was great spending time with her. Cindy came to the symposium in Baltimore in 2001. When the symposium was completed we met Cindy at the airport afterward and we had a chance to share dinner before our flights. Over the years I was in regular contact with Cindy.

In all of our conversations, I never once heard Cindy complain about anything! I was very aware of Cindy's very complex and difficult medical issues. None of these health issues defined Cindy in the least. Cindy was such an incredibly positive spirit and such a remarkable human being. Cindy touched so many people's lives; my heart just aches for her loss.

Cindy sent me a pen that she gave to all of her guests at her 40th birthday celebration. The inscription on the pen reads, ***Bloom where you are planted***.

For 40 years, Cindy did just that; and all who knew her and were touched by her wonderful life are in awe and rejoice in every glorious bloom.

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

Timothy A. Mulvihill

It is with great sadness, that the TMA announces that the founder of Devics-support, Timothy A. Mulvihill, has passed away.

Tim developed the Devics-support site in early 2006. His partner, Robert Keith Burden, had been stricken with Neuromyelitis Optica in early 2005, and Tim soon discovered that information about this rare disease was sparse. Tim was determined to change this, and embarked upon the task of educating himself in the technical aspects of the disease, reading anything and everything that he could get his hands on. He soon became one of the country's most educated laypersons on the subject of Neuromyelitis Optica.

With the launching of the group, individuals affected with NMO finally had a place to discuss diagnosis, maintenance, and treatment options for this rare disease. Tim and his partner, Grace Mitchell, also began a campaign to get many of the internet sites to update their NMO information, thereby reflecting the true nature of this serious condition. They were very successful and Grace still continues in this effort.

Tim often stepped out to take responsibility for his members. He frequently arranged peer to peer consults, visits to the more prominent research facilities, sorted out insurance issues, and most importantly, lent his very strong shoulders to the weak. He was well loved by all of his members, and had wonderful offline friendships with many.

Devics-support continues on as a legacy to Tim's hard work and dedication. It has grown by leaps and bounds, and now provides support for members from all over the world.

He is deeply mourned by his partner, Robert Keith Burden, his mother, Marta, and siblings, John and Carrie.

An Open Letter Nominating Dr. Charles E. Levy for the American Academy of Physical Medicine and Rehabilitation Distinguished Public Service Award

The Officers and Board of The Transverse Myelitis Association are nominating Charles E. Levy, M.D. for the American Academy of Physical Medicine and Rehabilitation Distinguished Public Service Award. Dr. Levy is the Chief, Physical Medicine and Rehabilitation of the North Florida/South Georgia Veterans Health Service. We are making this nomination to recognize the exceptional contributions Dr. Levy has made to our organization and to the very special people of our community.

My wife, Pauline, got transverse myelitis in 1994. Within a matter of seconds, she was completely paralyzed from the waist down. TM is not very well understood; in 1994, there was very little in the medical literature about TM. There was no information available for the patient population and there was no support network of any kind. Working with a family from Tacoma, Washington whose 18 month old daughter got TM, we started The Transverse Myelitis Association. We began doing this work shortly after Pauline's attack. Our work proceeded very slowly. The internet was not widely used and there was not an easy way for people with the TM diagnosis to find us. None of us involved in this work had medical backgrounds. I have a PhD in Cultural Anthropology. And none of us had any experience in doing this type of support work. Additionally, there were no physicians anywhere in the world that specialized in the treatment of TM, and there was no

research being done on this neuroimmunologic disorder.

Pauline was admitted to Dodd Hall, at The Ohio State University Medical Center, a week after her diagnosis. She did extensive rehabilitation at Dodd for almost two months as an inpatient. It was during this time that Pauline met Dr. Levy in the wheelchair clinic. Pauline was skeptical that Dr. Levy could serve her, but he won her over, and soon she was wheeling with the best of them. As her recovery slowly progressed and limited walking became feasible, Dr. Levy performed a gait evaluation for Pauline and helped provide her with an AFO and special grip canes.

As Dr. Levy got to know us better, he learned about our efforts to start a support network for people with TM. Dr. Levy was tremendously supportive of our work and approached us about starting a medical advisory board. We discussed the importance of professional medical guidance in our work, which we totally lacked to this point in our efforts. Dr. Levy volunteered to start the medical advisory board and to serve as our first physician on the board. He followed up these initial discussions by recruiting other physicians such as Dr. D. Joanne Lynn, M.D. who also serves on our Medical Advisory Board. Dr. Lynn is an Associate Professor of Neurology and the Director of the MS Center at The Ohio State University.

In October 1997, Dr. Levy and Dr. Lynn published an article for The Transverse Myelitis Association Newsletter focused on the symptoms, causes and diagnosis of TM and enumerated the treatment strategies for managing the many difficult and complex symptoms of TM. The article represented a courageous effort to communicate critical information to the people with this rare disorder. It was absolutely courageous, because they had so little information in the medical literature upon which to base their explanations and guidance. This article was so important for our community that it remains a cornerstone piece of the information we send to every recently diagnosed person who signs up for membership in the Association. Dr. Levy and Dr. Lynn's article also represented the first of many physician articles that are published in our newsletters and journals. They set the framework and the high level of expectations that we developed for the professional information that we provide to our members in our publications. Our publications are not only read by people with these disorders and their family members; our readership includes the neuroimmunologists, physiatrists and other specialists who provide clinical care and conduct research on these rare disorders.

In the winter 1997, Dr. Levy approached the officers of the TMA and told us that he was organizing a conference for patients with another rare disorder, fibrodysplasia ossificans progressiva. Dr. Levy, who was very active and an advocate in the FOP community, had invited the world experts in FOP to present in Columbus to the membership of the FOP. Dr. Levy discussed with us the importance of this type of educational conference and support opportunity in the rare disease community. He invited the TMA to participate in this conference. As we were a fledgling organization with minimal resources, Dr. Levy entirely funded the TMA participation in the conference.

The International FOP rehabilitation conference took place on May 7 -10, 1998 in Columbus, Ohio. Dr. Levy brought the officers of the TMA together for the first time at this conference. There were other members from the TMA who attended this conference, as well. For almost every person with TM, this conference represented the first time they had met another person with TM. One woman had TM for more than 40 years and she was meeting another person with her disorder for the very first time! Although this may not seem meaningful to the casual reader, this was a very profound moment for us all. The officers of the Association also had the opportunity to meet with Dr. Lynn for the first time. Dr. Levy taught us so much at this meeting. It was from this watershed experience that the TMA decided to sponsor and hold our own symposia for our community.

The TMA held its first symposium in Seattle in July 1999. Dr. Levy helped us organize the symposium and made presentations along with physicians from across the country. More than 200 members from our community attended this first meeting of the TMA. Our Medical Advisory Board has since grown to nine members. We have both pediatric and adult specialists in neuroimmunology and in physical and rehabilitative medicine. Dr. Douglas A. Kerr started a Center of Excellence in TM at Johns Hopkins Medical Center shortly after attending our symposium in Seattle in 1999. Dr. Kerr and Dr. Benjamin Greenberg are Co-directors of the TM Center and both also serve on our medical advisory board.

Dr. Charles Levy has been an integral participant in all of our symposia. These meetings have since been held in 2001, 2004 and 2006. We have another symposium scheduled this summer in Seattle. In July 2002, the TMA sponsored a Children's and Family Workshop. Children as young as 5 months old get TM. The workshop provided four days of physician education to the parents while the older children were provided an adaptive recreation adventure and the young children were taken on fieldtrips to the Columbus Zoo and a children's science museum. This workshop was offered at no cost to the families. As the TMA

has very limited resources, Dr. Levy and the other physicians who attended and presented at the workshop funded their own travel. Most of the physicians brought their own families and many family members volunteered to serve as companions for the adaptive recreation adventure and fieldtrips.

During the 2006 symposium in Baltimore, Dr. Levy organized a gait and orthotics clinic for the members who attended. He brought together a group of physical and rehabilitation medicine physicians and orthotics specialists who participated in an afternoon clinic. Evaluations were offered on an individual basis and each participant was provided specific recommendations which they could take home to their physicians for discussion. All of the participants were able to observe each of the evaluations and thus learned about how an evaluation was performed and developed some sense of expectation about what they should receive from their own physician. We received very high praise and gratitude from our members for Dr. Levy's effort. Many people in our community have a difficult time finding this type of evaluation. There is no concentration of TM anywhere in the country. Many of our members live in rural areas or small communities away from large medical centers where medical care for a rare disorder is often difficult to find.

Dr. Levy is committed to raising awareness about the rare neuroimmunologic disorders and in supporting the education of medical specialists about these disorders. Dr. Levy spearheaded the effort to raise awareness of rare neuroimmunologic disorders at the Association of Academic Physiatrists' annual meeting held in Anaheim in February 2008. Dr. Douglas Kerr and Dr. Adam Kaplin from the Johns Hopkins TM Center joined Dr. Levy as presenters to the AAP. Dr. Levy also created the opportunity for the TMA to hold a one-day symposium in Anaheim on Saturday, February 23rd. Dr. Levy, Dr. Kerr and Dr. Kaplin were involved in presenting the course at the AAPM&R meeting. Dr. Pidcock also attended these meetings; he is a pediatric physiatrist, and all four physicians also serve on our medical advisory board. Invitations were sent to our California TM Support Group, and 100 people attended a one-day symposium offered by these four wonderful doctors about TM, acute disseminated encephalomyelitis (ADEM), neuromyelitis optica (NMO), and optic neuritis (ON), and symptom management strategies.

Dr. Levy has brought The Transverse Myelitis Association leadership, compassion, exceptional medical guidance and organizational support from almost our inception. Without his support and guidance, we would not have become a professional and internationally recognized organization. Dr. Levy has provided so many critical opportunities for our Association. When Dr. Levy became involved in the TMA, we had fewer than 200 members. Today, we have more than 6300 members, including the medical specialists who focus on the treatment and research on the neuroimmunologic disorders of the central nervous system. Our membership grows by approximately 40 – 60 people per month. The TMA advocates for people who have TM, neuromyelitis optica, acute disseminated encephalomyelitis and optic neuritis. Our members are from every state in the US and from more than 80 countries around the world. We have support groups across the US and in Brazil, Colombia, England, Scotland, Ireland, France, Germany-Austria, Italy, Romania, Denmark, Sweden, Australia, New Zealand, South Africa, Ghana, India, the Philippines and Sri Lanka. The TMA has no employees. All of the work that is done for the Association is done by volunteers, including all of the officers and all of the support group leaders. There are no membership fees and the TMA receives no institutional support. We depend on the generous and voluntary contributions of our members.

What I have described in this letter does not touch on Dr. Levy's work with people with fibrodysplasia ossificans progressiva, his research on stroke recovery including fMRI, his research on power assist wheelchairs, his medical work in Africa, his work in shaping Medicare and the VA policy regarding prosthetics and orthotics and wheelchairs, or his testimony before Congress concerning telerehabilitation. Dr. Levy is now focusing on helping combat veterans with mild traumatic brain injuries, and is using telemedicine/telerehabilitation for those with cognitive and emotional impairments. I know most intimately the transformative work he has provided to The Transverse Myelitis Association.

I would be most grateful for your careful consideration of our nomination of Charles E. Levy for the Distinguished Public Service Award. He is most deserving of this consideration.

Sincerely,
Sanford J. Siegel

We Don't Want to Lose You

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

The Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States

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

Increased Postage Costs

The US Postal Service recently raised postage rates. When reporting about these increases, the media focuses on the cost of mailing a letter that weighs less than an ounce. Almost none of the TMA's mailings involve an envelope or package that weighs less than an ounce. Our mailing rates will increase a great deal more than the increase you are hearing about in the news. The rate increase impacts every class of mail and it also impacts all of the fees that are charged by the US Postal Service. We pay an annual fee which allows us to use the not-for-profit bulk mailing rate and that will also increase. Our international mailing rates will increase substantially. Postage is a significant cost for the TMA, and this increase will have a substantial impact on the Association's operating expenses. With this rate increase in mind, it becomes increasingly important for our members to maintain accurate information in our database. Please keep your information current. If you move, please provide us with your new postal address. We appreciate your cooperation. And if you can support the TMA, we strongly urge you to do so. Thank you!

Support Groups

ADEM Support Network

I spoke with a mother today whose 3 -year-old son was diagnosed with ADEM. It was a relatively new diagnosis so there were lots of questions to answer. During my conversations with parents and with adults with ADEM, one of the first things I do is to send them to the TMA web site: www.myelitis.org. There is excellent information under the link 'about ADEM.' You can view streaming video of physician presentations from many of the TMA-Johns Hopkins Symposia. These presentations describe ADEM, as well as symptom management strategies for the symptoms of ADEM. I urge anyone with a personal involvement with ADEM to check out these incredible resources. Knowledge is the power behind battling ADEM.

You can also learn about how others have successfully adapted ADEM into their lives by reading the "in their own words" articles from newsletters and journals in the archives under the link 'Newsletters.' There is also excellent information for caregivers and family members. You can learn about what's happening in the medical community, such as the Accelerated Cure Project which will be a valuable tool for researchers who want to study ADEM.

I urge everyone to try their best to attend the symposium in Seattle, July 16 – 19. It will give you an opportunity to meet folks who have ADEM and families who have learned, and who continue to learn, what it means when ADEM affects your life. It is a wonderful opportunity to learn from neurologists and other health professionals about the neuroimmunologic disorders, how to manage symptoms and the most recent research.

We are currently working on a database of people with ADEM who are members of the TMA. The database will serve to facilitate research and clinical trials and will foster networking opportunities. For people who are interested, we will also be publishing a directory of ADEM members so that we can more easily find each other to share information and support.

It is one of my goals to raise public consciousness about Acute Disseminated Encephalomyelitis and to make a difference in the lives of individuals and families living with ADEM. We've been slowly accumulating a wide range of stakeholders. There's still much to be done. We invite you to become a partner in our fight against ADEM. Your financial support is vital; please support The Transverse Myelitis Association.

Dr. Benjamin Greenberg has recently established the Johns Hopkins Encephalitis Center, and serves as its director. Dr. Greenberg is an Assistant Professor of Neurology, Co-Director of the Johns Hopkins Transverse Myelitis Center and serves on the TMA Medical Advisory Board. Please review the web site for information about the Center:

http://www.hopkinsneuro.org/encephalitis/index.cfm

As someone who has been dealing with ADEM for 1 ½ years, I know the importance of speaking to health professionals. What I also know is that it is incredibly rewarding for me when I speak with family members who have just confronted ADEM. I hope that in some small way, I have been of value

to them.

I've coined us "ADEMights;" I think it is an appropriate name for those of us who have become stronger from our experience with ADEM!

Barbara Kreisler
(703)366-2861

Brazil

Meu nome é Ricardo Borges. Tenho 30 anos de idade. Estarei liderando o grupo de apoio do Brasil com a Patricia Eichler. Aos 12 fui acometido de MT.

O mais peculiar de tudo é minha lembrança de eu caminhar pelos corredores do hospital na madrugada de sábado. E domingo de manhã eu já não podia caminhar.

O processo começou dois dias antes, na sexta-feira, com dores na coluna, nas proximidades dos rins. Como meu pai já tem um histórico de problemas renais, então fui medicado como se as dores fossem provenientes dos rins. Mas as dores aumentaram, no sábado fui internado, no domingo eu já não andava, e na segunda fui enviado para um hospital especializado – Hospital Neurológico de Goiânia. Lembro que o primeiro exame que fizeram foi do líquido da medula, e constataram uma inflamação.

Fui cuidado em menos de dois meses fui enviado para casa. Não havia um diagnóstico exato de TM. Fui para casa em dezembro com a processa de que até em fevereiro eu estaria bom (andando) novamente.

Em algumas semanas eu estava com escaras enormes e profundas. Foi feita uma séria intervenção por conta das escaras.

Em janeiro minha família conseguiu vaga em um excelente hospital – o melhor – que trata de problemas de locomoção, reabilitação etc. Fui para o Sarah Kubitschek , em Brasília, onde fui informado ainda no ambulatório, que eu tinha MT.

Fiz uma cirurgia para fechar a escara que desde dezembro passado estava aberta. A reabilitação foi tranqüila e depois de 8 meses voltei para casa, e retomei meus estudos.

Logo os problemas com escara voltaram. Me esforçava ao máximo para não abandonar os estudos. Ao concluir o ensino médio [técnico em patologia clínica], em 1995, eu reservei algum tempo para me recuperar de escaras que haviam aberto novamente. Fiz então outra cirurgia. Como eu passava todo o meu tempo na cama, e precisava de uma das mãos livres, então eu ficava de lado. Como eu preferia ter a mão direita livre, então eu ficava sento sobre meu lado esquerdo, o que me causou uma escoliose muito grave.

Em 1996 eu conheci a mulher com quem viria a me casar quatro anos depois. De um rapaz que passava todo o tempo na cama, com vergonha do próprio corpo, coberto de lençóis até o pescoço independente dos 40°C que fazia aqui os trópicos, passei a uma pessoa mais auto-confiante e desinibida.

Neste mesmo ano comecei a trabalhar na área de tele marketing. Um ano depois as escaras voltaram a aparecer. Eu parei com o tele marketing e comecei trabalhar em casa com internet [comércio eletrônico]. A renda era bem menor, mas então eu podia trabalhar da minha própria cama, com o computador à frente. Aos poucos voltei a me sentar. Em 2000 me casei e comecei a trabalhar com promoção de eventos – shows de rock, e cheguei a organizar eventos com bandas dos EUA, Austrália, e Alemanha.

Com o uso de um assento de água, as escaras ficaram cada vez mais raras. Com o passar dos anos criei resistência física, percebendo que era possível retomar os estudos. Em 2005 passei em primeiro lugar no vestibular para Psicologia da Universidade Católica de Goiás. Atualmente estou no 3° ano da graduação em Psicologia.

Estarei trabalhando com a Patricia Eichler liderando o Grupo de Apoio de TM no Brasil. Nosso grupo de apoio é para pessoas com TM, ADEM, NMO e ON. Adoraríamos ter o máximo de pessoas envolvidas e também gostaríamos de ter mais líderes de grupo. Seria excelente se conseguíssemos ter líderes de grupo de apoio em cada capital e região do Brasil. Meus contatos para informação seguem abaixo, e esperamos seu contato em breve.

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My name is Ricardo Borges and I am 30 years old. I will be leading the Brazil support group with Patricia Eichler. When I was 12 I got TM.

My most peculiar memory from this experience was that I was walking through the halls of the hospital on Saturday night, and Sunday morning I could no longer walk.

The process started two days earlier, on Friday, with a deep pain in my spine, near the kidneys. As my father has a past history of renal problems, I was medicated as if the pain were because of some kidney problems. But the pain increased. I was hospitalized on Saturday and by Sunday, I couldn't walk. On Monday I was sent to a specialized hospital, Hospital Neurológico de Goiania. I remember that the first examination that was done was extracting liquid from my spine, and they detected inflammation.

I received care and in less than two months, I was sent back home. There wasn't an exact diagnosis of TM. I went back home in December, and they told me that by February, I would be fine (walking) again. Within a few weeks, I had large and deep pressure sores. The pressures sores required a serious surgical intervention.

In January my family was able to get me into an excellent rehabilitation hospital; the best hospital in Brazil for working with locomotion problems. It was while I was in Sarah Kubitschek Hospital in Brasilia that I was told that I had TM. The pressure sore that had been open since December was surgically closed before I left the hospital. My rehabilitation had gone well and after 8 months, I went home to return to my studies.

The problems with pressure sores came back. I struggled with myself as much as I could to not abandon school. After finishing high school (technical in clinical pathology) in 1995, I reserved some time for myself to allow for the pressure sores to heal that had opened once again. I had to have another surgery. I was bedridden for a very long time. I had to have a hand free to be able to write and to feed myself. As I am right-handed, I was forced to lie on my left side for very long periods of time. As a result, I developed very severe scoliosis.

In 1996, I met the woman who would marry me four years later. From a boy who spent all of his time in bed, and who became ashamed of his own body (covered with sheets to the neck even with 40°C heat here in the tropics), I turned into a person with good self-confidence and self-esteem.

In that same year, I began working in telemarketing. A year later, the pressure sores struck me again. I had to stop the telemarketing work and went to work at home in electronic commerce on the internet. The money was much lower, but I could work while in bed with my computer. Gradually, I was able to sit again. In 2000, I was married and started working with a company that promoted rock concerts. We organized events for bands in the USA, Australia and Germany.

By using an anti-pressure-sores waterseat, the pressure sores became rare. Over the years, I became physically more resistant, realizing that it was possible to return to my studies. In 2005, I was approved in the selective process (with the highest scores) for Psychology at the Catholic University of Goiás. Currently, I am in my third year of studies in Psychology.

I am going to be working with Patricia Eichler to lead a TM Support Group in Brazil. Our support group is for people with TM, ADEM, NMO and ON. We would love to get as many people involved as possible and would also like to have more support group leaders. It would be great if we could have support group leaders from every major city and region in Brazil. My contact information is below, and we are looking forward to hearing from you.

Canada: Montreal Quebec

My name is Kimberley Kotar and I was born and raised in Montreal, Quebec. I am a 38-year-old female that was struck with sudden paralysis and power loss in both of my legs, but predominantly the left one in March of 2006. This was devastating at the time as I was training to complete the Ottawa International Marathon later that year. I ended up in the emergency room of the Montreal General Hospital on March 14th and on March 17th an MRI of the spinal cord showed that there were in fact two demyelinating lesions that spanned from T10 to T12.

I can remember being in the doctor's office and receiving the news, and later leaving the hospital feeling helpless and that my future was very uncertain. I was told I would probably never be able to complete another marathon. I felt like my life was over. Upon giving me the diagnosis, my neurologist told me to take two weeks off from work and to go home and sleep as much as possible. Two weeks later some of the symptoms got better, but I was still left with horrible neuropathy in the legs in the form of pins and needles, a strong burning sensation, and a slight bit of paralysis remained.

I went back to the neurologist and told him that some of the symptoms remained. I was told that I would get used to it and to get on with my life. I couldn't believe that was it; no treatment, no diagnosis and no answers. It was horrible.

I turned to running to help me deal with the emotional devastation and feeling of helplessness. The more I ran, the less some of the symptoms appeared and before I knew it, in September of 2006, I ran the Montreal International half marathon. I went on to run 8 half marathons from September 2006 to September 2007, finishing in the top percentile of every race. While I would like to say that it was easy and painless, it hasn't been and there were times during a race where the power loss in my legs was awful, but I was living my dream. Day-by-day over the past 21 months, some of the symptoms have decreased and some of the things I lost have returned and others got worse. But most of all I had managed to create a new life for me that can be as gratifying as my old life.

In January 2007, I found a new neurologist and I finally received the diagnosis of acute transverse myelitis. While no one knew much about it, at least I had a name for the culprit that stole my life. Again, I left the doctor's office with no treatment plan and was told to stay active, keep running and to

keep doing what I was doing.

During the past 21 months, I have had extreme difficulty in finding physicians that have any kind of knowledge about transverse myelitis so that I could receive the best medical advice and treatment. Transverse myelitis always appears to be something they have heard about, but don't have any idea how to treat or recognize the symptoms. I also had difficulty dealing with the symptoms and the physical disabilities I have been left with as a result of the lesions' damage to my spinal cord.

As a result of the difficulties I have faced, I decided to form a support group as I knew I could not be the only one who felt lost at times and had trouble getting the medical help needed. I also know that our friends and families do not always understand what those with transverse myelitis go through on a day-to-day basis as hard as they try to. My goal is to form a support group where transverse myelitis patients can come together to share their experiences, help each other deal with the devastating diagnosis and the accompanying symptoms and to encourage those affected to find strategies to rebuild their lives as I have.

Transverse myelitis has taught me a lot about myself and those around me. I am stronger than I ever knew and I take great pride in how far I have come with little or no treatment. I have also come to know that there exists a "fighter" in all of us; we just need to find it in ourselves. If I can give one person with transverse myelitis hope or inspiration that one day it will get better, then I will consider the group a huge success. There is no doctor with a magic wand to make it all go away. Sometimes in life I believe that we just have to create our own magic!

My group is in the very early stages of development. If you are interested in joining the group and meeting on a monthly basis to share your experiences or hear the stories of other patients, please feel free to contact me. I believe together we can conquer anything we choose, one step at a time, one day at a time.

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Colombia

Es para mí un gran reto ofrecer mi ayuda para liderar un grupo de apoyo para las personas con Mielitis transversa en Colombia. Luego de 11 años de convivencia con esta enfermedad, conozco de cerca algunas cosas, el shock inicial, el mundo extraño de los daños neuronales, los problemas para la adaptación a una limitación en un medio tan agreste lleno de escaleras y obstáculos, los problemas legales y con las EPS que causa una enfermedad neurológica.

Mi experiencia con la mielitis transversa tuvo un comienzo abrupto, en menos de 20 minutos estaba totalmente paralizada de la cintura para abajo y tuver perdida de fuerza en los brazos, ha sido una larga experiencia de paciencia y aceptación, no hay un modo fácil de hacerlo, y espero que al encontrar esta asociación puedan sentir que no están solos.

No se mucho de medicina, pero estaré abierta a ayudarles en todo lo que pueda. Sientase libre de contactarme si creen que les puedo ayudar.

It is a great challenge for me to offer my help to lead a support group for people with TM in Colombia. After 11 years of living with this disease, I know some things about it; the initial shock, the "crazy world" of the neural injury, the problems in adjusting to the limitations in an environment filled with a lot of stairs and obstacles, legal and insurance problems that are caused by this neurological illness.

My experience with transverse myelitis had a rough start; in less than 20 minutes, I was totally paralyzed from the waist down and lost part of my arms strength. It has been a long experience of patience and acceptance. There is no easy way to do it. I hope when you find this association, it will help you feel that you are not alone.

I am not a doctor, but I will be open to help in any way I can. Please feel free to contact me, if you think I can help.

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Sharecare Ghana

Nana Yaa Agyeman

Sharecare Ghana now a registered charity
December 2007

After many months and tons of paperwork, the Ghana Support Network, Sharecare Ghana, has been registered as a non-governmental organisation. Now that this legal requirement has

been fulfilled, we are going to open an account and start raising funds for research. Rare neuro-immunologic diseases are very new to Ghana and it is only since 2003 that they started coming to the notice of the doctors. But since then, significant numbers have been diagnosed. Sharecare Ghana includes Multiple Sclerosis and Lupus among these diseases, because they are just as new and rare here. We have also been approached by people with rheumatoid arthritis, but we have not formalised their membership yet, though they will be welcome when we start our meetings.

We have contacted a research institute in Accra, Ghana, (Noguchi Memorial Institute) about the possibility of researching neuro-immunologic conditions in Ghana and they assure us that they will take that up. One area of particular interest to us is nutrition or diet and its effect, if any, on these conditions. It is generally accepted that a particular diet can be used to improve the conditions of people with MS. Would this diet benefit people with other auto-immune diseases?

The membership of Sharecare Ghana is gradually growing, but home visits are our only activity so far. One member has volunteered her home for a group meeting, because some of the members are reluctant to use public places. Hopefully, we should be able to meet as a group soon.

We have done letters to other NGOs, Parliament, the media and the relevant government offices to inform them of our registration and to give notice that we will be calling on them for assistance. We have also applied to the Ghana Federation for the Disabled for membership. At a meeting with them, it was revealed that they had no idea about auto-immune diseases and only focus on specific disabled groups, like the blind, the physically disabled, etc. They did not know about cross disabilities. They asked for a write-up on rare neuro-immunologic conditions, which we did, using the TMA website as the resource, among others. We are yet to receive their reply.

That's it so far for the Ghana Support Network. We are scouring the TMA website for fund raising ideas to add to whatever we can come up with. In addition to creating awareness and raising funds, Sharecare Ghana intends to:

- Get specialists to give educational talks to members and their families;
- Act as an advocacy group to put pressure on local and national health authorities to treat neuro-immunologic diseases with the seriousness deserved in the national health care delivery system;
- Advocate for subsidized long-term drug treatment.

The directors/members are: Doris Obodai-Sai, Naa Torshie Sai, Suzy Ofosu, Sylvia Amoako, Adadzewa Otoo and Nana Yaa Agyeman. Mr. Egbert Faibille, a legal practitioner, is Secretary. The Medical Advisors are Dr. Albert Akpalu, Physician Specialist/Neurologist at at the Korle Bu Teaching Hospital and Dr. Nii Bonney Andrews, Neurosurgeon at neuroGHANA (a private hospital).

Sharecare Ghana, the Ghana Support Network holds first meeting
March 2008

The first meeting of Sharecare Ghana was held on Saturday, March 22nd in Accra. The meeting exceeded our expectations. Twenty-five people showed up, including people with rare neuro-immunologic conditions, their families and carers and two officials from the Noguchi Memorial Institute for Medical Research.

The conditions represented were: Neuromyelitis Optica (NMO), Polymyelitis, Multiple Sclerosis, Spondylitis, Rheumatoid Arthritis, Lupus and Hypothyroidism. Members passed a resolution to make the support group open to all people with auto-immune diseases and to add on the functions of an association since the objectives include advocacy. Members agreed to meet fortnightly.

A local newspaper captured the meeting in its columns, which we later syndicated to other local newspapers. We have their permission to reproduce the articles.

Auto-immune Diseases in Ghana; Noguchi Memorial Institute to Begin Research; Sharecare Ghana Holds Inaugural Meeting
The Accra Daily Mail, Tuesday March 25, 2008

The Noguchi Memorial Institute for Medical Research (NMIMR) is to begin a study into auto-immune diseases in Ghana. This was disclosed by officials of the institute at the weekend to members of Sharecare Ghana, a support group and association of people with auto-immune diseases and their families in Ghana.

The study being spearheaded by Dr. Margaret Armar-Klemesu, a nutrition expert, head of the Department of Nutrition at NMIMR and Dr. Michael Ofori, an immunologist is as a result of earlier discussions between members of the association and NMIMR on the seeming rise of auto-immune conditions in the country.

Officials of Noguchi agreed that a study needs to be done to establish the numbers as the basis for fuller research into the prevention and possible control of auto-immune diseases.
At the meeting, the Noguchi officials outlined the various diseases classified as auto-immune and the fact that they affect more women than men, but are more dangerous when they do affect men.

Members of the association welcomed the idea of research and said this initiative is long overdue. They said auto-immune diseases should be covered under the National Health Insurance Scheme since they all pay the NHIS tax directly or indirectly.

Founded in 1979, the Noguchi Memorial Institute for Medical Research is considered to be "the leading biomedical research institute in Ghana". Sharecare Ghana is the initiative of Nana Yaa Agyeman, herself diagnosed with Devic's Disease, a close relation of Multiple Sclerosis (MS), and has since attracted many members with similar or related conditions.
Auto-immune diseases and diseases of the central nervous system often don't show a clear pattern of symptoms and are therefore difficult to diagnose. The symptoms may include some or all of the following: numbness, vomiting, loss of body co-ordination and muscular spasms, vision impairment or loss, fatigue, tingling sensation, weight changes, depression, constipation, diarrhea and others.

Auto-immune diseases include the following: Rheumatoid Arthritis, Acute Disseminated Encephalomyelitis (ADEM), Multiple Sclerosis (MS), Transverse Myelitis, Neuromyelitis Optica (Devic's Disease), Lupus and others. Ghana's healthcare delivery system is more geared towards the treatment of diseases like malaria, HIV/AIDS, the five killer diseases in children with very little attention being paid to other equally debilitating ailments. There is practically only one practicing neurologist in the country, whose work load gets heavier by the day as a result of the rising numbers of people being diagnosed with auto-immune diseases.

A Good Initiative Worth Supporting
The Accra Daily Mail Opinion, Tuesday, March 25, 2008

The story about Noguchi Memorial Medical Institute agreeing to start research into auto-immune diseases in Ghana is welcome indeed. This is one area where research, diagnosis, treatment and professional care are almost ignored by the country's healthcare delivery system, but from all indications, which is as debilitating as any of the more popular ailments that attract all the attention and funding.

Though a Disability Act has been passed by the government, very few people know that many disabilities are as a result of auto-immune diseases. If disability is so important as to have an Act of Parliament passed to support people with disabilities, is it not equally important for the country's healthcare delivery system to turn its attention to the causes of some of those disabilities?

That is why we are very happy with the initiative Noguchi has taken to research into the seeming rise in auto-immune diseases in Ghana. Funding of course would be the main problem. We therefore wish to call on health authorities and establishments, philanthropists, corporate Ghana and the international donor agencies to support Noguchi's noble initiative. It may be a small area of research but could yield huge amounts of data that would eventually support the treatment and elimination of the better known ailments like malaria and HIV/AIDS.

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New Hampshire

When TM Changed my Life

My name is Suzanne McCutcheon and I would like to share my story with all of you. The date was December 16th 2002 and my husband and I had just purchased our first home 3 ½ months before in Rochester NH, having both grown up in neighboring towns. We lived a fairly simple life, having two children and one cat. We both worked full time jobs to support our family.

It was a Sunday evening and I went to the grocery store alone to shop for the week's groceries. I was walking through the grocery store and suddenly I had intense pain in both of my arms and I started to hunch over. Fear filled me. I spoke to someone I knew and told him that there was something wrong. He laughed at me and said that I was just getting old and it's what happens after you pass the age of 30. I had heard this before but I knew that

there was something terribly wrong. I managed to finish the shopping and drove the 5 miles home at a speed of 20 mph.

When I pulled into the driveway, I leaned on the horn until my husband came out. I told him that something was wrong and he helped me into the house. Having four nurses in my family and no health insurance, I decided to call my mother-in-law instead of going directly to the hospital. She walked us through the steps to make sure that I wasn't having a stroke. As I spoke with her and got into my pajamas, I realized that my entire left side of my body, from my chest down, was extremely numb. I told her that I was going to wait and see how I felt in the morning. The thought of huge hospital bills frightened me. I can say to all of you now that your health is worth more than that. Not that anything would have been different for me, but I should've gone to the hospital right away.

The next morning I woke and tried to get out of bed. I fell to the floor and screamed for Jeff to come and help me. We called a walk-in hospital and told them of my symptoms and they told us to get directly to the emergency room. By this time I had lost the ability to walk. My husband carried me into the emergency room. After all the paperwork and lectures for not coming right away, I was placed in a room where doctors performed multiple tests on me, including blood work, an MRI and a spinal tap. Having children didn't hurt as badly as that spinal tap. This left me with questions as well. How could I feel so much pain inside if I couldn't feel the touch of my hand on my skin? But at this point, all I really wanted was to sleep. I was put on IV steroids to help bring down any inflammation in my spine that may have been causing my paralysis.

A day or so later, my neurologist came into my room and informed me that I had had the flu 10 days prior, and for some reason my own immune system had attacked my self instead of just ridding me of the virus. I thought back and counted the days and realized that he had the date exactly right when I hadn't felt well and no one had believed me. He diagnosed me with Transverse Myelitis, which took me months to remember. I had never heard of such a thing but all other diseases were ruled out and I was told that besides my TM, I was perfectly healthy.

He informed me that he wanted to send me to a rehab hospital and I informed him that I had no insurance to cover such expenses. They had to do for me what they could right there at the hospital. I continued with the steroid treatment and pain pills, because the pain I felt inside of my legs was horrifying! We began physical therapy immediately and I can still remember what it felt like to be able to wiggle my toes again for the first time. We worked at different times throughout every day that I was in the hospital. Finally, two days before Christmas, I was being sent home with medication and pill form steroids. I would be going to physical therapy as an outpatient. Eventually, I was put into an aqua program for therapy, which was one of the best things I have ever done for myself.

With time I was able to give up my cane and I can walk on my own. My body is far from the same as pre-tm. I still have no outside feeling on my right side, from the chest down, from the middle of my stomach, to the middle of my back. My right side, though, is extremely strong and I can feel a constant pain on the inside. My left side is weak and my ankle doesn't bend correctly when I walk. I can't really run or play sports as I could before, and I have to be extremely careful when walking down stairs. My pain is worse in the winter, but is still there in the summer, as well. My memory isn't what it used to be and whether that is tm related or not, I probably will never know. The steroids caused a weight gain that I have been fighting since, but I feel that this is the year that I will finally take it off.

My life changed on December 16th, 2002 and though I would never wish tm on anyone, I can honestly say that it has made me a better person. It made me realize what is really important in this life and that is you and me. Our own attitudes can be the difference in our lives. I may never again be what I once was, but there is nothing "wrong" with who I am today. I walk a little funny, have pain that isn't "normal," have numbness in my body and I can't do all of the things I could do before. All we can do is strive to be the best with what we have and to keep our attitudes as positive as we can. There are moments when I look back with regret at what I have lost, but the friends I have gained and the thoughts that now fill my mind are far better than what they were pre-tm.

No one knows if I will ever be 100% again, but absolute perfection never really was my thing anyway. Imagine having to live up to that! I will never stop trying to get better. I still have those bills hanging over my head and no longer being able to work full time surely doesn't help. But life goes on and it goes on for all of us. We may as well smile while we are here.

I purchased this plaque after I got tm and I believe in it as much as I believe in breathing… "I get up. I walk. I fall down. Meanwhile, I keep dancing.…"

If I can help just one person deal with the hand they have been dealt, it is worth it. I am hoping to start a local support group for fellow tm'ers living in New Hampshire. I can be reached

on line at cutch4@aol.com or by telephone at (603) 332-9380.

Life is not measured by the number of breaths we take, but by the moments that take our breath away!

Life is not meant to be a journey to the grave, only to arrive in a pretty and preserved body, but to skid in broadside, thoroughly used up, proclaiming, "Wow! What a ride!"

With Love,
Suzanne McCutcheon

Glasgow, Scotland

Meeting with Dr. Douglas Kerr, 17th October 2007

What a privilege to have Professor Doug Kerr come to Scotland to meet up with TM Scotland Support Group. We had been excited about the meeting since Doug took up our invitation in the summer and we met up at the Ramada Hotel next to Glasgow Airport.

The group was started in 2003 and now has 40 members, 25 of whom attended the meeting with Doug. Represented were members diagnosed with TM, recurrent TM, Devics and ADEM, ages ranging from 3 years upwards.

Some of the group had dinner with Doug the previous evening including Margaret (Group Leader) who Doug re-diagnosed with a variant of Devic's (LETM) and wrote a letter to her neurologist. Margaret insisted the members let Doug do his whole presentation before lunch (from 11:30 until just after 1:00) with no questions (only a few). This allowed him to expand a lot more on several things (slides in his presentation that he never got time to do in London). For example, he could explain the 6 criteria he uses to distinguish Recurrent TM. If all 6 are negative, the risk of recurrence is less than 1%. If all 6 are positive the risk is over 70%. Normally, if there is no second attack within two years, JH would consider the TM monophasic not recurrent. In Dr. Kerr's opinion, MRI's should be repeated every 3-6 months for patients at risk of recurrence or at risk of MS. He said that 80% of MS relapses are clinically silent and can only be detected on MRI.

He also talked about the experimental use of thalidomide and statins to break the chain reaction that is now known to cause TM. JH is going to publish a paper shortly on the successful use of thalidomide for two patients who failed to respond to steroids over a period of a month. He went through a new paper they are going to publish soon (on the web for GPs) on how to treat acute TM (a sort of treatment decision tree), based on 122 cases which fail to respond to steroids and also have high IL-6. JH is much more aggressive than UK neuros, making liberal use of plasma exchange (PLEX) and cyclophosphamide. The choice is based on the degree of disability at onset and the presence or absence of 'systemic' autoimmune symptoms, i.e., rash, swollen glands, fevers.

Then he gave us a much longer explanation regarding stem cells. The Central Nervous System (CNS) was previously thought to be one of the few parts of the body lacking stem cells, but this is now proved to be incorrect. Your OWN stem cells (endogenous) in CNS are INCREASED by exercise (the biggest factor!) and DECREASED by stress, injury, sleep loss, depression. Doug then went through the two types of stem cell transplants JH is working on (1) Glial Restricted Precursor (GRP) cells to create new myelin and (2) the earlier experiment in rats to use embryonic stem cells to create new motor neurons to replace those damaged by TM. The GRP human trial (1) may be approved by the American government FDA in 2008 or more likely 2009. The embryonic stem cell transplant (2) is now being replicated in large mammals (pigs), prior to human trials. The first experiment may be in babies with spinal muscular atrophy (SMA) and may be approved in 2010 or 2011. Doug is careful to point out that even when stem cells work to produce new myelin and neurons; it is still a long road back for the brain to learn to use them via physio and exercise.

Other questions came regarding persistent pain and possible remedies, and Sjogren's Syndrome and other rheumatological conditions. Campbell asked about the cognitive problems associated with ADEM, mainly short term memory loss. Doug mentioned that IL-6 caused cognitive problems in rats, and rats took about 12 months to recover. In human terms, this is equivalent to 4 years, so he would estimate these problems could take 4 years to recover in humans. There was a brief discussion of TM in infants. Doug mentioned that infants ***never*** recur, and in many cases their recovery takes much longer than adults, so parents should never give up hope of further recovery and physio needs to be continued, too. I asked a question regarding JH use of 4-AP, fampridine, a drug to improve nerve conduction which I think I am going to try out. Doug was very supportive and explained that he had tried it on 60-70 patients with 30% showing significant functional improvement.

On a separate topic, Dr. Kerr mentioned that JH was soon to publish an aggressive new treatment for MS that may result in sustained remissions for some. JH took a large number of MS patients and treated them with a large dose of cyclophosphamide, a chemotherapy drug, to 'reset' their immune systems. Four years later, two thirds of the patients have had no MS relapses, though some of the patients

who did not relapse still had the development of new brain lesions.

Asked if Prof Angela Vincent treated any patients and Doug said he didn't know. But, he said, she is regarded so highly at the Radcliffe that if she said TM patients ought to be treated more aggressively, then there would be neurologists there ready to listen. So Doug urged us to follow up with Prof Vincent, as well as Anu Jacob, to try to define best practice in diagnosing TM (and Recurrent TM) and in treating TM.

Each member had their questions answered by Doug, but the meeting sadly came to an end after 4:00 pm to allow Doug to get his onward flight. Everyone agreed that it had been an unforgettable experience and a delight to get so much information first hand from Doug. Sandy Smith gave a vote of grateful thanks and presented Doug with a wooden clock he had hand carved as a gift from the Group. Blair gave him a bottle of Scotch whisky and the Group gave Margaret Shearer a lovely bouquet of flowers. All the questions made to Doug at the meeting and his answers can be found on the Scotland Group webpage on the TMA website.

South Africa

8 October 2007

Hi everyone,

October 2007 was transverse myelitis **PARTY TIME** in Cape Town and Pretoria!

Friends of Andre Venter decided to organise two huge TM awareness events. One function was held in Cape Town and another in Pretoria. **A.J. Smith** and **Susann Myburgh** put a lot of time, effort and planning into these events. Their main aim was to create awareness of TM and to raise money for TM patients in SA by auctioning rugby memorabilia.

Jenny attended the Cape Town function and Mart attended the Pretoria function.

WOW! These evenings were truly unforgettable.

Tables were sponsored by various companies and, of course, a delicious three course meal was included. Andre Markgraaff was a guest speaker at the Cape Town function and Hennie Kriel spoke at the Pretoria function.

By selling beautiful rugby memorabilia, a basic fund for financially needy TM patients in South Africa was set up.

Considering the fact that Andre is already working in the financial field, he volunteered to be the fund manager. Andre is financially secure and he won't personally benefit from this fund. As soon as we have clarity, we'll inform you about the total amount of money that was raised and also how this fund will work. Please watch this space!

As we all know by now, Andre was a Springbok rugby player. In fact, he played 66 test matches for South Africa! At some stage he was rated the *best flanker in the world*. Since July 2006 Andre has been wheel chair bound because of TM. Andre was the main speaker at both of the events. He shared his TM story with us and he described the devastating effect that TM had on his life since he was 36.

Tears were running and once again we all realised what an extremely challenging disease TM is. Fortunately Andre's positive attitude clearly shone through and he explained that he will not allow TM to break him. He had a standing ovation after he read a poem called "Slow Dance" that was written by a young girl in a New York hospital who was diagnosed with terminal cancer:

Slow Dance

Have you ever watched kids
On a merry-go-round?
Or listened to the rain
Slapping on the ground?
Ever followed a butterfly's erratic flight?
Or gazed at the sun into the fading night?
You'd better slow down.
Don't dance so fast.
Time is short.
The music won't last.

Do you run through each day
On the fly?
When you ask "How are you?"
Do you hear the reply?
When the day is done
Do you lie in your bed
With the next hundred chores
Running through your head?
You'd better slow down
Don't dance so fast.
Time is short.
The music won't last.

Ever told your child,
We'll do it tomorrow?
And in your haste,
Not see his sorrow?
Ever lost touch,
Let a good friendship die
Cause you never had time
To call and say "Hi"?
You'd better slow down.
Don't dance so fast.
Time is short.
The music won't last.

When you run so fast to get somewhere
You miss half the fun of getting there.
When you worry and hurry through your day,
It is like an unopened gift....
Thrown away.
Life is not a race.
Do take it slower
Hear the music
Before the song is over…

We would like to ask our members to *please* write a thank you note to Andre Venter, Susann Myburgh and A.J. Venter for their efforts to create TM awareness and for the fundraisers.

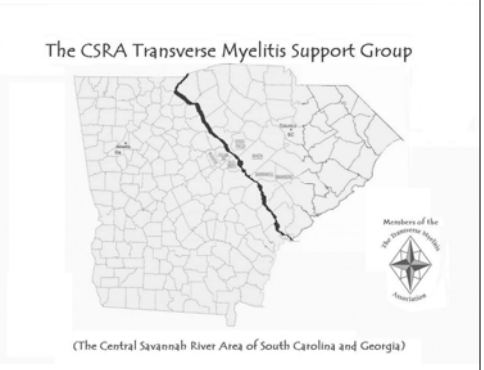
Without them, we would not have a basic fund to help our TM community in the future.

Their email addresses are:

Andre Venter:
andrev@itec-bloem.co.za
Susann Myburgh: susann@almm.co.za

Lots of love and hope to all of you,

Mart (martuys@iburst.co.za) and Jenny (moss25@mweb.co.za)



Central Savannah River Area of South Carolina and Georgia

Hello, my name is Vicki McKie. I live in South Carolina, in the Central Savannah River Area. The CSRA is a metropolitan area encompassing five counties within the states of South Carolina and Georgia. All five counties in the area border the Savannah River.

I was recently diagnosed (March 2008) with Transverse Myelitis and am still adjusting to this "new normal." I am interested in starting a local support group in our area. Within the past week, I found three other women in my area with TM and we will soon be having a "Meet and Greet" just to get to know each other, share information, and get organized.

I hope to begin holding regular meetings with educational presentations. Anyone from South Carolina and Georgia with TM, ADEM, NMO or ON, family members, care-givers, doctors, medical and support team is invited to join our support meetings. I will be posting a meeting schedule as soon as we are established. We will also offer online support through message forums here on the website for those who cannot drive to the CSRA. If you are interested in more information about our support group, please contact Vicki by email at: mamamckie@hotmail.com; or call my home phone: (803)278-4819.

Our mission is to provide fellowship and support through sharing our common experiences, to provide educational information, and to open the doors of communication between patients and the medical community.

Cities and Towns included in the CSRA:

Aiken County, SC: Aiken, North Augusta, Beech Island, Belvedere, Burnettown, Clearwater, Gloverville, Graniteville, Jackson, Monetta, New Ellenton, Perry, Salley, Wagener, Windsor

Edgefield County, SC: Edgefield, Johnston, Murphy's Estates, Trenton

Richmond County, GA: Augusta, Hephzibah, Blythe

Columbia County, GA: Evans, Martinez, Grovetown, Harlem, Appling

McDuffie County, GA: Dearing and Thomson

Within the CSRA we have a large medical community with several hospitals including:
University Health Care System, Augusta, GA
http://www.universityhealth.org/

Medical College of Georgia, Augusta, GA
http://www.mcg.edu/

Trinity Hospital, Augusta, GA
http://www.trinityofaugusta.com/default

The Charlie Norwood V.A. Hospital, Augusta, GA
http://www1.va.gov/augustaga/

Eisenhower Army Medical Center, Fort Gordon, Georgia
http://www.ddeamc.amedd.army.mil/

Doctor's Hospital, Martinez, GA
http://www.doctors-hospital.net/

Aiken Regional Hospital, Aiken, SC
http://www.aikenregional.com/index.php?

Vicki McKie
731 Republican Road
Clarks Hill, SC 29821
(803)278-4819
mamamckie@hotmail.com (all lower case)

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

Dr. Douglas Kerr Presents to the UK TM Society Members in London

Dr. Doug Kerr from Johns Hopkins very kindly agreed to come speak to UK TM Society members in London in October. Over 150 members, family and friends crowded in to hear Dr. Kerr and our other speakers, at our first-ever UK TM Conference. Then Dr. Kerr followed up with a second solo meeting at the Scotland TM Support Group in Glasgow, en route to speak at a stem cell conference in Leipzig Germany.

For the London Conference, we were very pleased to have visitors from Ireland, Italy and Romania in addition to British members. We had excellent presentations by Prof. Angela Vincent from Oxford University, Dr. Diane Playford from Queens Square London, and Tony Murphy from the Walton Centre Liverpool. The main emphasis was on Questions and Answers addressed to all the speakers, but mainly Dr. Kerr, who even gave up his lunch hour to see a little girl from Birmingham and to answer private questions from members who queued to speak to him.

Members who were unable to attend the meetings can access the presentation slides and especially the Q&A documents at www.myelitis.org.uk and also at www.myelitis.org.uk/scotland/kerr.htm.

The UK TMS Committee of eight members put in four months of preparation to organise the Conference brochure, venue and audiovisual facilities, catering, finance and bookings, hotel information for visitors, timetable, chairman, literature and a team of twenty volunteers on the day. Several members have written to describe the event as 'inspiring' – not only for the excellent speakers, but also for the chance to meet others with TM, some for the first time ever.

Lew Gray
UK TM Society
lewgray@blueyonder.co.uk

The T M A Equipment Exchange

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

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

Thank you for your support,
Darian Vietzke

T M A Equipment Exchange Instruction Sheet

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

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

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

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

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

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

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

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 RESTORE 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 http://www.myelitis.org/multimedia.htm into your web browser.

The TMA Newsletter and Journal Archives

The TMA announced a new publication schedule and format for our newsletters and journals. We will publish a newsletter each fall and spring, and a more extensive journal will be published once 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

Important Reminder About The Transverse Myelitis Association Membership Directory

In order to receive a TMA membership directory, you must be willing to have your name and contact information listed. Those who have designated that they do not want to be listed in the directory will no longer receive one. The purpose of the directory is to assist our members in finding each

other in their local communities, states and countries. As our membership is small and widely scattered around the globe, the directory serves as a way to facilitate the local or regional sharing of information and support. The value of this directory is commensurate with the numbers of our members who are willing to participate in our support network.

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

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

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

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

Help Wanted: Keeping Our Membership Information Accurate

By doing something as simple as keeping your information accurate in our records, you are helping to save the TMA money; funds that can be used for research or to support symposia or the TMA Kid's Camp. The TMA uses a bulk postage rate for our mailings which results in considerable cost savings. Unfortunately, with this method of mailing, we are not notified when an envelope is not delivered due to a bad address without incurring additional costs.

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

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

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

Contacting the TMA by Email

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

Fundraising and Awareness

Helping to Fund the Work of Your TMA

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

GoodSearch

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

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

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

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

Donate your cell phones

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

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:
http://www.readingforrachel.org.
All funds received by The Transverse Myelitis Association for the Reading for Rachel Program are used exclusively for research to better understand TM, to find treatments for the symptoms of TM, and to ultimately find a

cure. If you are interested in starting the Reading for Rachel program in your school, you can also contact Cathy Dorocak, Rachel's Mom and International Chair of the Reading for Rachel Program: cathy@readingforrachel.org; (440)572-5574.

Donations using Paypal

International members, as well as those in the United States, can make donations to the TMA using PayPal. You can donate online with PayPal using your checking account or credit card. You can also use a credit card to donate through PayPal even if you are not a member. PayPal will show you the current exchange rate, the equivalent amount in your primary currency (if not US Dollars) and handle the conversion for you. Please visit http://www.myelitis.org/donations.htm for more details.

Donations by Check

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

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

Thank you!

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

You can make secure donations online with Google Checkout using any credit, debit, or gift card with the following logos: Visa, MasterCard, American Express, and Discover. TMA will receive 100% of your donation using Google Checkout until 2009. Go to http://myelitis.org/donations.htm, enter the amount you want to donate; then click the blue Donate button. You will be taken to the Google Checkout page.

We greatly appreciate your support!

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

Sandy and Margaret Smith are members of The Transverse Myelitis Association from Pittenweem, Fife, Scotland. They are also active members of the Scotland Support Group led by Margaret Shearer. Sandy has TM.

Margaret is an artist. Margaret has created beautiful paintings of landscapes and flowers. She has donated this artwork to the TMA and we are very pleased and proud to be able to offer you these beautiful pieces through Café Press. We urge you to consider using these wonderful paintings as your regular cards for the holiday season, for thank you and everyday notes or for any purpose.

The proceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. The officers and board members of the TMA are volunteers; they receive no compensation of any kind for their work. There are no employees in the TMA. There are no offices; the officers work out of their homes. In order to facilitate access to support and information, the TMA does not assess membership fees. As TM is a rare condition and our membership is small, it is extremely difficult to raise funds for our cause. We work most diligently to focus our resources on the direct services to our members.

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

http://www.cafepress.com/tmagifts

Honor the Children in Our Community and Support the TMA

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

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

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

http://www.cafepress.com/tmagifts

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Where in the world are the TMA Wristbands?

As part of the TM Awareness campaign, we are collecting photos of people from around the world wearing the signature blue TMA wristbands. If you would like to send us a photograph of you, your family, or friends we would love to have it for our collection. Here's is what we would like for you to do. Please have a photograph taken of you or a family member and be sure that the wristband is clearly visible in the frame. Tell us who you are and identify where the photograph was taken. If you live by, or will be traveling to, a famous landmark, it would be great to include these places in the photograph. When you take the photograph, please be sure that the landmark appears in the background. We encourage you to be creative! Any background will do; we would love to see you wearing the wristband in the photograph. We will be posting many of your submittals on our website. TM touches lives all over the globe and this is a simple, tangible way to show we are all connected. To submit a photo, e-mail it to wristbands@myelitis.org

We can't wait to see you!

A Special Thank You!

I wanted to extend a very special thank you to Shannon Mada. Shannon provided a great deal of assistance to me in reviewing and editing all of the articles in this Journal. And, of course, there's a story…. Shannon and her husband, Tirtak, are very close friends of Pauline's and my children. Aaron and Tirtak went through graduate school together. A few years ago, Shannon's father got TM. It was a horrible time for them, but I was glad that they had a TMA; I know the information and support helped their family. The work Shannon is doing for the TMA derives from her love for her father. You are such a mench, Shannon!

The Transverse Myelitis Association 2006 and 2007 Statements of Financial Activities

(in US Dollars)
Paula Lazzeri

The following tables present The Transverse Myelitis Association Annual Financial Reports for 2006 and 2007. The TMA (General) Fund column presents all funds received and expended directly by TMA as recorded in the Association's financial account. The Total Donations and Expenses to Benefit TMA column is presented to help convey the total costs of providing TMA member services during 2006 and 2007. This column includes funds/activities reported in the TMA (General) Fund, as well as non-reimbursed expenses paid by members of the Board of Directors. These non-reimbursed expenses also are shown as Donations made by Board of Directors under Revenues. The Donations made by Board of Directors line item presents the amount of funds spent by members of the Board of Directors that were not reimbursed by the TMA (General) Fund.

The Transverse Myelitis Association 2006 Statement of Financial Activities (in US Dollars)

INCOME	TMA Funds	Total Donations and Expenses to Benefit TMA
Amazon.com Commissions	44	44
CafePress Commissions	36	36
Donations made by Board of Directors	0	5365
Endowment Donations	1,596	1,596
Endowment Interest	234	234
General Donations	94,765	94,765
iGive.com Commissions	127	127
Interest	3,256	3,256
Recycling Commissions	2,892	2,892
Research Donations	8,525	8,525
Support Group Donations	706	706
Wristband Fundraiser	4,177	4,177
TOTAL INCOME	**116,358**	**121,723**
EXPENSES		
2006 Symposium	51,713	51,713
Bank Fees	120	120
Children's Camp Expenses	52,416	52,416
Domain/Web-site/Webhosting	1,053	1,053
Internet Service Provider	0	929
JH Research Coordinator Grant	8,750	8,750
Membership Fees	0	60
Mileage and Parking	0	83
Office Supplies	0	1,045
Postage	11,827	12,502
Printing	29,111	29,144
Secretary of State Registrations/Annual Reports	220	220
Software/Computer/Projector	1,197	1,386
Support Group Expenses	125	175
Telephone	0	856
Travel Expenses	0	1,446
TOTAL EXPENSES	**156,533**	**161,898**
Net Loss	**-40,175**	**-40,175**

Transverse Myelitis Association 2006 Statement of TMA Account Balances

Children's Camp	363
Endowment Fund	11,603
Endowment Interest	903
Operating Fund	134,756
Research Fund	126,478
Support Group Fund	976

The Transverse Myelitis Association 2007 Statement of Financial Activities (in US Dollars)

INCOME	TMA Funds	Total Donations and Expenses to Benefit TMA
Amazon.com Commissions	435	435
CafePress Commissions	25	25
Children's Camps	10,950	10,950
Donations made by Board of Directors	0	9,948
Endowment Interest	320	320
General Donations	74,801	74,801
iGive.com Commissions	143	143
Interest	2,728	2,728
Mission Fish.com Commissions	95	95
Paypal/NFG	14,021	14,021
Recycling Commission	1,489	1,489
Research Donations	7,864	7,864
Support Group Donations	378	378
Wristband Fundraiser	442	442
TOTAL INCOME	**113,691**	**123,639**
EXPENSES		
ACP Support	35,000	35,000
Bank Fees	75	75
Children's Camp Expenses	3,414	3,414
Domain/Web-site/Webhosting	45,391	45,391
Internet Service Provider	0	929
JH Research Coordinator Position	19,016	19,016
Membership Fees	0	110
Mileage and Parking	0	76
Office Supplies	0	811
Postage	7,395	8,064
Printing	0	31
Secretary of State Registrations/Annual Reports	220	220
Software/Computer/Projector	1,916	4,265
Telephone	0	1,812
Travel Expenses	0	3,161
	112,428	**122,376**
Net Income/Loss	**1,263**	**1,263**

Transverse Myelitis Association 2007 Statement of TMA Account Balances

Children's Camp	11,313
Endowment Fund	11,603
Endowment Interest	1,223
Operating Fund	167,200
Research Fund	80,326
Support Group Fund	1,354

The Transverse Myelitis Association 2006 and 2007 Donors

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer the services to our membership; they also make possible the expansion of services to our existing and future members. The following persons and organizations made donations to The Transverse Myelitis Association in 2006 and 2007. The donations made by members of the Board of Directors include non-reimbursed expenses.

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