

## Brett Leake on caregiving and accepting help

A man with a uniquely unsentimental and humorous perspective spoke about being both a caregiver and a patient at TMA's Annual Patient Conference. Brett Leake, who has a progressively disabling genetic muscle disease, was a caregiver for his father, Francis, who had the same disease. Brett works as a standup comedian, and has appeared on Jay Leno as well as at hundreds of comedy clubs and programs all over the U.S. More recently, he offers programs for non-profits and corporations seeking inspiration and motivation. Leake presented two sessions at TMA's 2012 Annual Patient Conference, with both patients and caregivers responding enthusiastically to his ability to find humor, dignity and compassion in his description of both roles.

Leake said he learned a lot about independence and maintaining dignity from his father, who endlessly tinkered to solve the problems he faced every day, and to continue doing what he loved.

The efforts of Leake's family to sustain their father at his farm near Richmond, Virginia while still allowing him as much independence as possible were rewarded publicly with the 2008 Governor's Caregiver Recognition Award.



Brett Leake

### Thoughts on caregiving

After several unrelated illnesses left Francis unable to stay alone, Brett managed his care, a difficult task for someone who was also growing

increasingly disabled and making his living on the road. Brett learned everything he could about what assistance was available for his father, and discovered the discrepancy between what Medicaid offers for long-term care in a residential institution versus in-home care. The importance of his natural surroundings to his father inspired the family to keep him in his home, with Brett in residence when he was not traveling.

Brett found some valuable connections that helped him in this role:

#### ■ A knowledgeable pharmacist.

The Leake family had an acquaintance who was a pharmacist, and made it a point to seek help often. Anyone who has had experience with multiple medications knows that drug reactions and interactions are often neglected in the prescription process. As the caregivers he'd hired for his father called with questions, Brett was able to answer them in a timely way, with a quick call to the helpful pharmacist.

■ **A good handyman.** As both father and son became less able to get around, the gadgets and mobility devices that kept them independent

became more important. Brett found a talented handyman who was able to make adjustments and repairs to everything from wheelchairs to sliding doors.

■ **A reliable agency.** It's a huge relief to know that caregivers will show up on time and do what's required. The Leake family searched until they found the right service for them.

■ **A clear understanding of what's needed.** The family thought about the quality of life for their father as well as his basic needs. He needed to spend time outside, and he needed to have food in the birdfeeders for his beloved songbirds. As it turned out, Brett Leake said, the caregivers formed deep connections with his father and enjoyed their time together.

### The son's journey

Like his father, Brett was determined to stay independent as long as possible. For many reasons, he did not want to use a wheelchair in public, and he also fought the idea of sitting on a stool to perform. (After all, he is a "standup" comedian.) When he finally accepted the need for a wheelchair he found it gave him greater freedom and allowed him to travel safely.

After successfully negotiating obstacles to handicapped travel all over the world, Brett looked for a

*See Caregiving, page 11*

Published by: TMA, Inc.

## THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600  
Alexandria, VA 22314

P: 800-821-7356 E: [tma@myositis.org](mailto:tma@myositis.org)  
F: 703-535-6752 W: [www.myositis.org](http://www.myositis.org)

Executive Director: Bob Goldberg  
Editor: Theresa Reynolds Curry

### BOARD OF DIRECTORS

Augie DeAugustinis, Chair  
Peter Della-Croce, Vice-Chair  
Craig W. Patterson, Treasurer  
Renee Lantner, Secretary  
Marianne K. Moyer, Immediate Past Chair  
Terry D. Anderson  
Doreen Cahoon  
James Kahl  
William Prall  
Graham Rogers  
David A. Rudig  
Janet Schuler  
John C. Suttle  
Pat Zenner

### MEDICAL ADVISORY BOARD

Kanneboyina Nagaraju, DVM, PhD, Chair  
David F. Fiorentino, M.D., PhD, Vice Chair  
Alan Pestronk, M.D., Research Chair  
Lisa Christopher-Stine, M.D., Nominating Chair  
Dana P. Ascherman, M.D.  
Christina Charles-Schoeman, M.D.  
Robert Cooper, M.D.  
Brian M. Feldman, M.D.  
Mark Gourley, M.D.  
Steven Greenberg, M.D.  
Adam M. Huber, M.D.  
Todd Levine, M.D.  
Susan Maillard MSC, MCSP, SRP  
Andrew Mammen, M.D, PhD  
Tahseen Mozaffar, M.D.  
Chester V. Oddis, M.D.  
Zarife Sahenk, M.D.  
Rup Tandan, M.D, MRCP  
Jiri Vencovsky, M.D.  
Steven Ytterberg, M.D.

### STAFF

Theresa Curry, *Communications Manager*  
Bob Goldberg, *Executive Director*  
Aisha Morrow, *Operations Manager*  
Charlia Sanchez, *Member Services Coordinator*

MAA Founder: Betty Curry

## Patient Perspective

### Letting go of vanity

By Andrea Taylor Langworthy

*Andrea lives in MN, leads the myositis support group, and writes a column for the Rosemount "Town Pages."*

While talking on the telephone with a friend years ago, I walked into a closet and stumbled on a pile of clothes. As I flailed my arms for balance, the telephone flew out of my hand and landed on the floor at the same time I did.

"I'm okay," I hollered, "but I will have to call you later."

It is hard to believe, but I still resisted using a cane. A few days later, that same friend, an able-bodied woman 10 years younger than I, said, "A cane would be fun. I'd decorate it for every holiday and wrap lights around it at Christmas." I used a curse word, then suggested she break a leg (as in short for "good luck") so she would have her chance.

"I will use a cane at the pool but will not be caught dead with one anywhere else," I told her, as I had many times before.

Lunch with a friend I hadn't seen in years added a new dimension to the cane issue. When I arrived at the restaurant, she was sitting on a couch in the lobby. She looked regal in gray wool pants and a black turtleneck sweater. A handsome dark wood cane with a charcoal pearl-like handle rested next to her. I knew she had health issues but never realized it required her to need assistance. I watched as the tool enabled her to gracefully get up from the sofa. "Had it been a difficult adjustment, emotionally?" I asked.

"No," she answered. "I wouldn't be able to leave the house without it."

She told me about the Walking Store, where they had cut her cane to size. That they have every style you

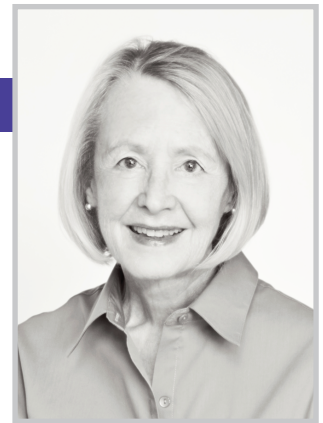
can imagine. Ah! A cane as a fashion accessory, I thought, wondering if I could find one as snappy-looking as hers.

The following Sunday, we drove to the mall. I bought a black model with a curved, sterling silver handle. And another the color of pecans with a tortoise shell grip trimmed in gold. My thought, eventually, was to match them to black or brown shoes; silver or gold earrings. My husband, my human cane, carried them to the car as I held onto his arm, and placed the bag in the trunk, where it stayed for weeks.

Until a shopping trip I took to an Eddie Bauer store with a friend. She went to the cash register to return something. I went hunting for Navy blue chinos. As I stepped back from a wall of pants, I bumped into a small step stool on wheels. I flew into the air and then, to the floor, taking a circular display of flat-front khaki pants down with me.

From that vantage point, I deliberated my options: staying steady with the aid of a cane or being sprawled out on the floor of a retail establishment worrying what part of my underclothing showed.

It was not the first time I had been on a floor looking like an upside down turtle but I decided it would be my last public appearance in that position. My statement about not being caught dead with a cane came to mind. I looked heavenward and said, "Okay, if it's about the cane, thanks, I get the message. You can move on to someone else now."





## It's complicated: Myositis affects more than muscle and skin

*Drs. Chet Oddis and Lisa Christopher-Stine met with a large group of myositis patients at the TMA Annual Patient Conference. Their mission: to explain the whole-body manifestations of myositis. Their session is summarized below.*

As though weakened muscles and itchy rashes are not enough, myositis patients should be aware that the disease can affect their lungs and heart, and other less common targets as well.

The presence of the anti-Jo-1 autoantibody, or anti-synthetase syndrome, is an important marker for predicting disease course and possible complications. Anti-synthetase syndrome can affect the lungs (as interstitial lung disease) and the joints (as arthritis). So far, the presence of the Jo-1 autoantibodies is a reliable diagnostic tool for myositis, since it has been identified only in myositis patients. The systemic implications are so important, said Dr. Lisa Christopher-Stine, that physicians often classify their patients according to its presence, with the distinction between polymyositis and dermatomyositis becoming less important.

Some symptoms that lead physicians to suspect anti-Jo-1 antibody:

- Raynaud's phenomenon,
- interstitial lung disease,
- arthritis,
- skin rash different from that seen in dermatomyositis,
- fever.

Often these patients have a fairly mild form of myositis, Dr. Oddis said, so the main problem is the lung disease. Both Christopher-Stine and Oddis believe that this syndrome and the early stages of ILD are under-reported. They estimate the presence of this difficult-to-treat lung disease

in about a third of myositis patients.

That's not to say that all myositis patients with difficulty breathing have ILD, Dr. Oddis said: shortness of breath can also be due to the underlying inflammation, lung problems caused by aspiration (due to weakened swallowing muscles) and, more rarely, heart involvement.

Drs. Oddis and Christopher-Stine answered questions from those at the session, paraphrased below:

**Every time I see my physician, he does a lot of blood work. Is he trying to see if I have developed the anti-Jo-1 antibody, or if it has gotten worse?**

This test -- for myositis-specific and myositis-associated antibodies -- is not done in-house, except in a few laboratories associated with large hospitals. It is only necessary for your doctor to test it once. It's something you always have, and it doesn't change, even if the disease improves or grows worse. Most likely, if you're on methotrexate or a number of other drugs, he's testing liver function or the level of inflammation in your blood.

**I am diagnosed with polymyositis by biopsy, but my CK doesn't seem to be affected: it's normal or nearly normal, and I have very little weakness. However, I am short of breath. I don't think I have ever had an MSA test. Should I ask to have one?**

You are exactly the type of patient who should have the test. We worry about people like you because, without the ability to measure inflammation, we lose one marker to see how you are doing. See if your doctor has tested you, and if not, ask for one. It will take a while but will be very helpful in knowing what to expect.

**I have persistent and sometimes severe stomach problems. Could this be related to my PM?**

Although some children have terrible gastric problems with juvenile forms of myositis, they are very unusual in adults. There's a temptation to blame everything on the disease, when it could be another autoimmune disease like irritable bowel syndrome, or celiac disease, or the medications, or pancreatitis. Keep searching for a diagnosis.

**I have DM and have been tested for anti-Jo-1-antibodies, and am negative. I am so fearful that I will develop the antisynthetase syndrome. Should I ask my doctor to test me regularly?**

If you do not have the syndrome, you will not develop it in the future.

**I have PM and am doing well, as far as I know, without any lung complications. I have regular check-ups. Should I be concerned about the increased possibility of heart disease, and get checked more often?**

Although the risk of cardiac disease is elevated in myositis patients, it is still not very common. Continue with normal check-ups and immediately report any symptoms.

**I have PM, and then later another doctor diagnosed me with DM. I am not sure what I have. Is it important to differentiate? I have been tested and don't have anti-Jo-1 antibodies.**

PM is sometimes a "wastebasket" diagnosis, where physicians classify anyone with myositis and without a rash. Of those originally diagnosed with PM, 10 percent later get a rash and the diagnosis is changed; 15 percent are found to have adult-onset muscular dystrophy, and of those 10 percent are found to have a statin-related myopathy. So it's not surprising that the appearance of a rash changed your diagnosis to a more precise one.



## "Work-arounds" solve day-to-day problems

TMA members have plenty of ideas for overcoming day-to-day difficulties without spending a fortune. Make it a habit to check the "Community Forum" tab from TMA's "Community" home page for all kinds of advice from those who know best. Thanks to all those who contributed, below, in their own words.

**To get up from a hospital bed** easily, comfortably and safely, I sit up on the edge and put my butt over the "knee" hinge, then use the power control to raise the leg area. That raises me up higher and I can just slide off on my feet - works really well and it's easy!

**When I became too weak** to use this method, I made a frame for my hospital bed. It's essentially a 3/4" sheet of plywood that the bed sits on. The plywood extends about 18 inches beyond the side of the bed, and I added a four-foot-high railing or fence, screwed to the outer edge, made from 1x3" pine, screwed down and braced for strength. At floor level I laid a horizontal 1x3" board. I sit on the edge of the bed and brace my feet against the horizontal rail. Then, using one hand on the bed and the other on the fence, I can lock my knees and stand. The fence is a great safety item for moving "around the corner" to my wheelchair. I'm quite tall so had to elevate the bed about 4 inches. An easy modification, since I'm a mechanical engineer, and my wife is rapidly becoming a construction engineer. She did all the carpentry.

**When I have trouble getting my feet and legs into bed or the car,** I use a cloth belt (unbuckled), loop it under my foot, pull my leg into bed or car, let go of one end, and pull the belt out for next time.

**To make carrying heavier objects possible,** I carry a plastic gro-

cery bag folded up in my pocket. When I need to carry something, I put it in the bag, then put my hand through the handle holes so that the handles wrap around the back of my wrist, but the bag is by the palm of my hand. I gather the bag between the thumb and index finger to keep it steady and prevent it sliding off. The weight is carried on the wrist, not the fingers, so I won't drop it.

**When I can't lift my foot into the car, or onto the bed,** I flip my cane handle-down and use the grip to hook under my foot. Then using the shaft of the cane, I can use both hands to pull my foot up into the car or onto the bed.

**When getting onto the front porch and into the front door became nearly impossible,** my wife solved the problem at no cost. She took 8 x 16 x 1.5 concrete pavers out of the garden and built a 32-inch deep x 48 inch-wide x 3-inch-high midway platform step. Since the storm door swings out over the platform, and the house door swings into the house on the same side of the jamb, she "off centered" the platform so that entering and exiting the door would be easier. She crisscrossed the pavers to tie them in and put our door mat on top. It is secure, good looking, and very functional. The concrete pavers blend in with the color of the concrete porch. We have had visitors come and not even notice that there was a midway platform step.

She built a similar "off center" midway platform step from the sidewalk to the porch. It is 32 inches x 32 inches x 3 inches. The concrete pavers can be further secured with a concrete adhesive. Whether or not the adhesive is used, the pavers are movable to allow for changes in the future. The pavers had been in the garden for

more than 30 years, so we cleaned them up before we used them.

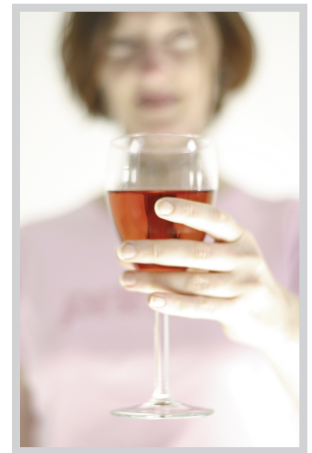
**When I became unable to type with my left hand,** and found speech-to-type software too

expensive, I discovered that Microsoft Windows (all versions) has built-in, native, alternate keyboard layouts for right hand only, left hand only, and standard two-hand keyboards that are much more ergonomic and comfortable to use. I'm typing with the right-hand only version. It took me less than a month to get comfortable with where the letters are on the different layout. My typing speed and accuracy is way better than one-handing the old Qwerty board and best of all - it cost me nothing but the effort to get used to it! To help learn the new layout, I bought a set of transparent, self adhesive stickers for the key caps for \$2.99 on the internet and applied them to my keyboard.

If you have Windows you probably have their speech recognition software. It is quite comprehensive, and although I've heard good things about "Dragon" I suspect the Microsoft version is very close.

From the "Start" menu (lower left corner of screen), Go to "All Programs" then go to "accessories" then go to "ease of access."

**When ordinary drinking glasses became too heavy for me to lift,** even with two hands, a stemmed wine glass was my answer. I slip my hand



*A lightweight wine glass makes holding your drink easy and fancy!*

under the bowl of the glass, with the stem between my middle and ring fingers, and cup the bowl in the palm of my hand. This works great for juice, water, ice tea, or my evening glass of chateau cardboardeaux.

**When I began to have trouble opening "child proof" caps on medicine bottles.** I talked to my pharmacist about it and he noted in the computer that I should always have the snap-on tops.

**When I had trouble** with the 1/4" knobs on pole lights, I took a small piece of 1/4" thick wood, drilled the appropriate size hole in the wood, cut to around 1' long or 1" around, and was able to use this as a switch.

**You can also buy a sort of extension cord with a switch on it.** It is a remote control for lamps and things. There are also more hi-tech solutions

like the "clap on clap off" lights. There are also lamps that turn on and off if you just touch the base.

**When vacuuming became too hard,** I bought a Roomba iRobot vacuum. Yes, it's pricey and noisy, but it works beautifully on hardwood and stone tile floors. You do need to be able to pick it up to clean debris out of the bin, and you might need someone with better balance to help with that. It's saving me so much energy over formerly spending hours on my feet, having to balance, with the big vacuum cleaner. Every now and then iRobot does push a door closed, gets stuck in a room and stops, once under the bed! With the door propped open so it doesn't get trapped, it goes back to its dock all by itself. It charges up, then with a timer it goes out on its next scheduled rounds all by itself. If you have an alarm system, it's low to the ground so it doesn't set off the motion detector.

**If I'm down on the floor due to a fall,** I've been known to go on hands and knees to the stairs. I go up several steps until I can straighten my leg with my foot on the floor and using the step and handrails push myself upright on my feet.

**To open jars, the Kuhn gripper hasn't failed me yet.** For some jars it does take some "body English" to get going, but so far I've not been locked out of any jars I wanted to open.

**When opening soda bottles,** often pliers slip. Wrap a rubber band around the cap, preferably the fat kind that come on veggies from the produce section. This gives the pliers something to grip!

*Have questions, or want pictures or further information on any of these "work-arounds"? Post your questions on the Community Forum on TMA's website at [www.myositis.org](http://www.myositis.org).*



## More ideas

In addition to the wonderful conversation on ingenious "workarounds" in the thread on TMA's Community Forum, many of you have emailed suggestions directly to TMA.

**When cooking pots are too heavy** to lift from the stove, you can cook vegetables in wire mesh baskets. Use a mesh basket with a handle, put it in the saucepan and fill it with the vegetables to be simmered. When cooked, the basket and vegetables are lifted out and the water remains in the saucepan, avoiding the need to lift heavy pans full of boiling water.

**Another way to avoid lifting heavy saucepans** is to place the pan on the burner with the food, then use a plastic jug to add water to the pan. When the food is cooked, use a plastic slotted spoon to lift the food out of the pan into a lightweight serving bowl or straight onto your plate. When the pan and remaining water are cold, it will be safer to carry them to the sink. If you think you would benefit from lighter pots, you can find them at camping shops catering to backpackers.

**If you become fatigued** when you stand at a bathroom sink or when you stand to prepare food in the kitchen, the use of a "perching" stool may make the activity more manageable. A perching stool allows you to lean back safely in a semi-standing position. Perching stools have a sloping

seat and are suitable for people who can take a little bit of weight on their legs. Because of the semi-standing position, you'll need less leg room, which allows you to get closer to work surfaces.

**If a weak grip prevents you from holding your cups** or mugs, you may wish to buy cups with larger handles so you can get your fingers through the handles to more easily support the weight of the cup. Another suggestion is to buy a cup with two large handles so you can use both hands. Lighter cups are available with alternative grip designs in plastic or ceramic materials.

**Using a drinking straw** is an alternative to holding a cup. For someone with reduced suction, a straw with a one-way valve prevents the liquid from flowing back down the straw.

**If you find it impossible to pour hot water** from a kettle or a drink from a pitcher, you may find it easier to use a lightweight travel kettle. Travel kettles are available from camping stores and are significantly lighter than standard kettles.

**If the kettle is too heavy** for you to tip it forward to pour, you may find that a kettle tipper takes away the need to lift the kettle when pouring. Kettle tippers are available for teapots and pitchers.



## Powering up: Members discuss logistics of move to power chairs

Many TMA members use power wheelchairs and find they have greatly increased their mobility. They're covered, at least partially, by Medicare, but the approval can be a lengthy process at times, summarized below:

- Your doctor submits a written order stipulating your need for a wheelchair or scooter. You must have difficulty moving around inside your own home; it must be after a face-to-face exam; and your doctor must believe you are too weak to use a manual device, and that you can operate a power chair safely.

- Generally, Medicare will pay 80% of the Medicare-approved amount, after you have met the Part B deductible. You pay 20% of the Medicare-approved amount.

- You may need to get your power wheelchair or scooter from specific suppliers approved by Medicare. Visit [www.medicare.gov/supplier](http://www.medicare.gov/supplier) or call 1-800-MEDICARE (1-800-633-4227) for more information. TTY users should call 1-877-486-2048.

- If you don't need a power wheelchair or scooter on a long-term basis, you may want to rent the equipment to lower your costs. Talk to your supplier to find out more about this option. Some wheelchairs must be rented first, even if you eventually plan to buy them.

Here's how the process worked for one IBM caregiver. She looked for and got vendor suggestions for a power wheelchair for her husband, an IBM patient, and her vendor helped guide her through the process. Her doctor gave her a prescription for a power chair evaluation, and had the doctor's office fax it to the vendor. The vendor made arrangements for the physical evaluation at the hospital in their town.

The evaluation was done by a physical and occupational therapist, along with a vendor representative who brought several chairs and also attended the evaluation. "This was the best evaluation of strength he ever had," the caregiver said. "They really knew what they were doing."

Following that, they had another face-to-face evaluation with their doctor, and he filled out a questionnaire. They were pleasantly surprised to get approval quickly.

This doesn't solve every problem, Earl Klein points out: "Many of us are surprised to discover that, even with Medicare or private insurance, out-of-pocket costs when purchasing a new power wheelchair often exceed \$5,000. Out-of-pocket costs result from deductibles and features like an elevating seat, which is not covered by insurance."

Earl makes a case for buying a used wheelchair,

next page. He is a former TMA board member and an IBM patient.

See Earl's advice, facing page.



Earl Klein found several used power chairs.

### Points for powering safely

*The National Institute for Rehabilitation Engineering has made a thorough analysis of safety features for power wheelchairs, summarized below. For the full analysis, go to [www.abledata.com](http://www.abledata.com).*

- Mechanical brakes that can be set or released by the user are necessary, and especially essential for outdoor wheelchair use. They must be operable when moving to brake, stop and lock the chair. It must also be possible for the user to manually lock or to release the mechanical brake when stopped. For those unable to move a lever, it is feasible to use standard mechanical brakes that are set, locked and unlocked by small user-controllable electric motors.

- Front-wheel configurations are very important for user safety. Power wheelchairs for outdoor use should always have powered large wheels in front, never free-swinging casters. Indoor wheelchairs with front casters are safe for outdoor use only on flat, level surfaces. They are at risk on sidewalks and totally unsafe on grass and soil. Wheelchairs with front casters are designed for indoor use because they offer better indoor maneuverability.

- User arm stabilization should be considered for those with impaired arm and hand function. An orthotic elbow or forearm support can be installed on the wheelchair to support the hand used to operate the wheelchair's controls.

# Member Tips

## The case for buying a used power wheelchair

By Earl Klein

I classify power wheelchairs broadly as “standard” and “complex” (or “rehab”).

■ Traversing inclines. Always steer up or down an incline, never across, because the wheelchair is likely to fall over sideways. For wheelchairs with casters in front, avoid areas in the pavement or path that tilt to one side to avoid having the wheelchair roll off the path and over an embankment.

■ Avoid obstacles such as stones, cracks and curbs to prevent sudden deflection of the wheelchair to one side.

■ Batteries must be fully charged before leaving home to avoid being stranded outdoors in a power wheelchair with dead batteries. Periodically, the batteries should be checked by a technician for proper fluid levels and for remaining charge capacities.

■ Always have a cell phone for safety. People with impaired hand dexterity can have a modified cell phone attached to the wheelchair. If you cannot afford monthly cell phone fees, then get a “911-only” cell phone with no monthly charges. Cell phones should be wired to work from both internal battery and wheelchair battery.

■ Periodic maintenance is absolutely necessary to maintain the safety of any power wheelchair. We recommend daily minor and weekly major inspections by the user. We also recommend a professional inspection at least once every three months for most users, and as often as once a month for very active or severely disabled users. If tires are air-inflated, air pressure should be checked before each day's use. Solid tires should be visually inspected for breaks. For safety, legal and financial reasons, it is recommended that all power wheelchair service be provided by the seller, by the manufacturer, or by a local mechanic who is designated as a manufacturer's representative.

■ Standard power wheelchairs, such as Invacare Pronto and Pride Jazzy, have captain's chair seating and limited options. They are sold by local mobility dealers as well as nationally promoted companies such as The Scooter Store. The retail price might range from \$2500 to \$6000.

■ Complex power wheelchairs are customized to meet the individual needs of paraplegics and persons with neurological diseases such as IBM. Complex power chairs, such as Invacare FDX, Permobil and Pride Quantum, accommodate a custom seat cushion, custom seat size and other features such as power elevating seat, reclining seat back, seat tilt, and power leg rests. The retail price might range from \$15,000 to \$35,000 or more.

Purchasing a used wheelchair can be a cost effective alternative for solving mobility needs. Previously owned standard power chairs can be purchased for \$500 to \$1500. Complex chairs can be purchased for \$1500 to \$5000.

In most cases, the power wheelchair user will have passed away, and a family member will be selling the wheelchair. These are sad situations, but the family member is usually relieved to be closing another chapter in a difficult situation.

I have purchased three Permobil power chairs: a two month old C300 model for \$1500 and two C500's, each less than 6 months old, for \$3500 each. All were equipped with power elevating seat, power recline, power tilt and power leg rests.

Do your research before searching for a used power wheelchair. Talk with friends who have power chairs to

learn what they like and don't like. Visit local mobility centers to learn about brands and features, gather brochures and visit manufacturer websites. Check the TMA Community forums for member opinions. Develop a list of features and specifications you require, and use this as your shopping list. My personal philosophy is to buy a power wheelchair with the capabilities I will need in the future, not just in the present.

My checklist of “must have's” includes excellent seating system to support declining trunk and buttocks strength, variable seating positions to relieve pressure points, power leg rests and tilt to reduce problems with edema, and powerful motors, wide wheelbase and large batteries to accommodate my desire to be outdoors on hilly and unpaved surfaces.

The 2011 Permobil C500S which I purchased most recently (see photo) meets all these requirements. Fortunately, my single level home has wide doorways and hallways to accommodate the wheelchair. As my condition progresses, I am confident that the wheelchair will continue to serve me well. Your list will be different from mine, but this gives you some idea of issues to consider.

### Sources

Craigslist is probably the best source for used wheelchairs. Classified listings in your local newspaper are another source. Check Craigslist and classifieds once a week in nearby metro areas. Limit your selections to newer and lightly used, and make sure that your specifications are met. Be patient. It might take weeks or months to find the right power chair for you. Be sure to test drive and consider having a local dealer check out the chair

*See Used chairs, page 11*

## Knowledge and planning make travel possible for those with disabilities

It has happened to many of you. You make a hotel reservation online, requesting an accessible room. When you actually show up, there are no handicapped rooms available.

This is a common problem, says Rosenda Calloway, who spoke at TMA's Annual Patient Conference. The hotel may have accommodated another person with a disability who decided to stay later.

"Or," she said in a later interview, "you may have 'requested' a handicapped-accessible room. This does not constitute a guarantee that you will get the room." She advises patients to either work through a travel agent experienced in disability accommodations or call the hotel directly, making sure you speak to someone in administration, and asking for confirmation that you will actually get an accessible room. In either case, there will be no additional fee, and you'll have some confidence that there won't be any surprises when you arrive. She also suggests confirming the availability of the room a day or two before arriving.

If a handicap accessible room is not available, she suggests, find the manager and ask for an accessible room at a comparable hotel, at the same price. Even if you eventually get the room you originally asked for, Calloway advises people to let their voices be heard. "You're your own best advocate," she says. "Call or write after you return home and let everyone know where there were problems or where you were pleased with the service."

Other pointers from Calloway, a veteran agent who became interested in the needs of people with disabilities because of a sister who must travel in a wheelchair:

■ **When flying alone**, you have the right to ask an attendant to help you get to the bathroom. For more infor-

mation on what you can expect from the airlines, find the Air Carrier Access Act and become familiar with it. ([www.disabilitytravel.com](http://www.disabilitytravel.com))

■ **When going on a cruise**, let the special service department of the cruise line know what is needed for your comfort. Sometimes, it's simply a matter of adding a mattress to the bed to give it more height. "Make sure to specify in detail the accommodations you need," Calloway said. The cruise is a favorite mode of travel for people with disabilities because they do try to accommodate people with special needs and will not release their accessible staterooms to people without disabilities until minutes before they sail. "Also," says Calloway, "if there are any ports that aren't accessible, cruises generally provide plenty to do onboard."

■ **Working with a travel agent** is often the best and simplest way to ensure your ability to enjoy all parts of your trip. Find a reputable agency that doesn't add a fee (all agencies add a fee for airline reservations, some more than others.) And while working with your agent, advises Calloway, you will need to be very specific in order for the agent to help you. For instance, whether working with an agent or directly with the service department, measure the width of your wheelchair to ensure you can get into and out of every room where you will need to go. When reservations are made for a hotel, always request the ground floor and not the first floor because many European hotels designate their second floor as their first floor because the first floor does not have rooms.

And, says Calloway, if you find yourself in a restaurant or home where you cannot maneuver your wheelchair due to narrow aisles or doorways, request a rolling office

chair if they have one available and you can be wheeled into the restaurant and to your table in an office chair.

### Try the train

Amtrak ([www.amtrak.com](http://www.amtrak.com)) provides assistance to passengers in wheelchairs as follow:

■ **High Platforms.** Amtrak assists you across the gap between the platform and the train by using a bridge plate.

■ **Low-Level Platforms.** Amtrak provides station-based mobile lifts.

■ **Bi-Level Trains.** Amtrak provide a ramp or station-based mobile lift to get you to the lower level of the train.

Whether you stay in your wheelchair or transfer to a seat, Amtrak provides room in coach, business class and first class cars.

Because of the rolling motion of the train, you may want to remain seated until your destination, keeping your brakes applied while the train is in motion.

If you choose to transfer to an accessible seat, you may stow your wheelchair nearby, or onboard. The conductors will assist you with stowing your wheelchair.

Amtrak trains accommodate most wheeled mobility devices with these guidelines:

■ **Dimensions.** The device should not exceed 30 inches wide and 48 inches long, and should have at least two inches of ground clearance.

■ **Weight.** The weight limit for an occupied wheeled mobility device is 600 pounds.

■ **Manual and battery powered.** Amtrak permits both manually operated and battery powered mobility devices that meet the above specifications.





# Travel Tips

## Handicapped accessible: just a phrase

By Mary Jane DeLauder

*TMA member Mary Jane DeLauder, who has IBM, has traveled all over the world, most recently in a wheelchair. She also has some advice for travelers, from hard-won experience, in her own words.*

Remember, "handicapped accessible" is just a phrase! For us, it means we need to clarify. And clarifying before you go is the secret to successful and stress-free travel.

It's called "think ahead and communicate." Call the motel or hotel or cruise director; tell them you have challenges. Explain your challenges. Ask the questions that cause you anxiety:

- What is the height of the commode?
- Is there a walk-in shower?
- Are there steps?
- How high is the bed?
- Can you use risers or is it a platform bed?
- Can the bus kneel? Does it have a lift?
- Can you handle me on this tour?

Carry a riser for the commode. Carry blocks for the bed if they say it will work. Take portable grab bars but know that they may not stick to textured walls, so be care-

ful. Take a half-step for boarding buses.

I take my own wheelchair on airlines and have so far been very happy with the care. I also carry my uplift to make it easier rising from the airline seat. One time in a small aircraft, they used a forklift type machine to get me in the doorway, since I could not walk the steep stairs. It was embarrassing, but we all had a good laugh and it worked!

Trip Advisor is helpful when choosing hotels, since you can ask questions of the reviewers. "Cruise Critic" has boards for asking questions about specific cruise lines.

If you are planning a cruise, ask about "tender operations." Some cruise lines will not transport you if in a wheelchair.

We were fortunate to use Crystal Cruises and they were willing and able to help. When booking tours, we make sure to sit down with the tour desk and clarify "go" and "no go" situations.

If you know you are going to be in a location where commodes are going to be difficult, take a TravelJohn with you: <http://www.traveljohn.com/1-1.php>.

Anticipation of the unknown is a very unhappy and stressful way to start your new adventure. Ask questions! Get answers! Don't be shy!

Know what you are up against and what you need in the way of help.



## Chairs in the air

*From the Society of Professional Travel and Hospitality ([www.sath.org](http://www.sath.org))*

Normally you can use your own wheelchair as far as the boarding point of the aircraft, where you will transfer to a special aisle chair. If you are able to walk a short distance, you should request a seat near the entrance doors. Your wheelchair will then be stored conveniently for immediate availability on arrival. The airline will probably want to preboard you, so be early at the airport. You, however, have the choice not to preboard.

Those who have wheelchairs with wet acid batteries should check with the airline, as a leaking battery inflight can be dangerous. It will be

necessary for baggage handlers to remove the battery and place it in a special container. This requires the passenger to be at the airport at least 3 hours before departure.

Most modern power-operated wheelchairs have some form of safety battery so they can be carried without risk of damage to the aircraft. However, it will be necessary for baggage handlers to disconnect the leads from the terminal and to cap them to avoid shorting. This may take some time, so you will have to preboard. It may be necessary to transfer you to a special



aisle wheelchair in the air terminal, and there may equally be a delay on arrival before your chair is available.

The airlines are responsible for ensuring that your battery is reconnected and that your chair is working on arrival at your destination. Electric scooters can also be transported without problems; their battery requirements are the same as for wheelchairs.

As a precaution against loss or damage, always remove all detachable parts before your wheelchair is stored, and label the chair with your name and address and destination airport.



## Food to suppress inflammation, elevate mood

*TMA Board Member Dr. Renee Lantner; herself a DM patient and a practicing immunologist, spoke on nutrition at TMA's Annual Patient Conference. Dr. Lantner makes reference to the work of Rose Mary Istre, also a DM patient, who conducted a small study of myositis patients. More information on both is available in the Conference coverage section of TMA's website at [www.myositis.org](http://www.myositis.org).*

Healthy food, moderate portions, enjoyable meals: "We all kind of know what we're supposed to do," Dr. Lantner said. First we need to eat healthy in general, then we need to keep in mind the nutritional demands presented by chronic disease, then we need to be aware of issues specific to myositis.

The "moderate portions" part of a healthy diet is where some of us run into trouble, she said. The protein portion of our meal should be about the size of a playing card; a helping of pasta about half the size of a softball.

There's another factor, Dr. Lantner said, that we tend to ignore: "I often eat alone," she said, "and that's not because my family doesn't like me." Like many people with busy lives, her family is often scattered at lunch time. "Still, I always try to make it presentable, even if it's just me."

There are several reasons for this, she said. Sometimes, especially in people with active disease, certain foods are not very appealing, because of a variety of issues from swallowing to digestion. Yet the disease makes it even more important than ever to eat very well, to take the time to prepare something that appeals to you, make it as attractive as possible, and take

some time to enjoy eating it.

There are ample reasons for following an anti-inflammatory diet besides myositis, she said: Inflammation is implicated in everything from chronic pain to Alzheimer's disease, including cancer, heart disease, asthma, and other autoimmune conditions.

"We can't pick our genes," Dr. Lantner said.

"And for most of us, there are few things that we can control." So diet, at least, is something that we can choose for ourselves.



### Supplements vs. food

Antioxidants -- the key components in food that prevent aging and inflammation -- are found in plant-based food and in commercial supplements, but "Supplements are no replacement for whole foods," she said. That's because foods are not just vitamins and fiber. They have all kinds of components that we just don't know about yet, so we can't extract key anti-inflammatory elements from the food that contains them. She cited a study of athletes who got all kinds of oxidative support from supplements and actually did worse than those who ate normal food.

### Vegetables and fruits

Almost all fruits and vegetables have something to contribute to a healthy diet, Dr. Lantner said, but corn and white potatoes are probably an exception, both with a high glycemic load (a tendency to increase hunger rather than satisfy it.) Besides, she said,

corn, soy and cottonseed in this country are likely to be genetically modified unless they are labeled organic. "There's probably nothing really good about corn."

Fruits have a lot of good properties, she said, but are also high in sugar: "one's a serving, two are dessert." She compared having an orange, with lots of fiber and vitamins along with the sugar, to having a glass of juice: "if you've ever squeezed oranges for juice, you've seen how the peels just mount up." It takes a lot to make just a little bit of juice. The fruit is better.

### Those evil carbs

"We all love carbs," she said. "They're so evil sometimes, though." Dr. Lantner said that eliminating sugar (one of the "evil" carbs) from your diet can be productive: "Sugar can be addictive, but if you try not having it, the craving will go away." Bottom line on carbs: "Stay away from processed foods -- if you can't pronounce it, don't eat it." And "fight the white," choosing whole grains rather than refined.

### Fats: friend or foe?

It used to be that the population had about an equal intake of both Omega-6 and Omega-3 type fats, Dr. Lantner said: "Now we're getting more like 15 parts of Omega 6 type fats to one part Omega-3." This proportion is pro-inflammatory, she said. (Omega-6 fats are those found in corn, cottonseed, grapeseed, peanut, safflower, soy, and sunflower oils).

Omega-3 fats, found in coldwater fish, leafy greens (yes, vegetables do have small amounts of fat), walnuts and flax, are anti-inflammatory, and decrease the production of TNF

alpha, a significant player in inflammation. "So these good fats can actually increase the effects of anti-TNF alpha drugs," Dr. Lantner said. She also mentioned eggs from chickens fed Omega-3 acids, chia seeds and purslane, a common weed.

Find a photo of purslane, along with the Dr. Lantner' slide presentation, at [www.myositis.org](http://www.myositis.org), under "2012 Annual Patient Conference."

During her presentation, Dr. Lantner summarized the work of Rose Mary Istre, also a DM patient, who had done a small study of what happened when a group of myositis patients followed an anti-inflammatory diet. The diet followed in this study was essentially the same as that recommended by Dr. Lantner: good fats, lots of colorful fruits and vegetables.

Istre's work included examining the emotional well being of the myositis patients she followed. Her hypothesis was (that) "an anti-inflammatory diet would have an effect on the inflammatory process in myositis patients, leading to an increase in muscle strength and a decrease in depression, resulting in an improvement in patient functioning."

The 17 participants, 14 female and 3 male, between the ages of 26 and 72, were randomly assigned to one of two diets, either what she called an "independent variable" diet, where participants chose what they normally might eat; and the experimental anti-inflammatory diet.

Those on the anti-inflammatory diet ate five fish meals each week, choosing high-fat, coldwater fish like tuna and salmon and being careful to fix them in a way that did not involve frying. Other meals could include lean protein, going easy on the beef, and vegetables and fruits high in antioxidants, like spinach, broccoli, berries and melon. They also ate whole grains and nuts, avoiding "white" carbohydrates, junk foods, soft drinks and cold cereals.

At the conclusion of the study the anti-inflammatory diet group had improved both strength and mood, significantly in some cases. Since no risk or expense is involved in following an anti-inflammatory diet, Istre called for more study.

Dr. Lantner generally advises myositis patients to get their nourishment from whole foods rather than supplements. However, she said, in her research there were some things that stood out:

- Vitamin D - People with autoimmune disease tend to be low in this vitamin. She advises myositis patients to have their level of Vitamin D tested. Those on steroids have a greater demand for this vitamin.

- Folic acid -- a must for anyone on methotrexate.

- Gluten intolerance - Try a gluten-free trial, since a higher than normal percentage of myositis patients have celiac disease.

- Creatine - might be helpful for DM and PM patients.

- Organic food - Consider eating organic, since we don't know the exact role of genetically-modified organisms and pesticides in autoimmune disease. Learn the "dirty dozen" (those foods most likely to be saturated with pesticides) so you can at least buy these from organic sources.

- Chocolate! Buy dark chocolate for an antioxidant boost.

- Cucurmin - Ingredient in curry, turmeric. Shows promise, but in huge amounts. Must be eaten with piperine (black pepper). Look for more news ahead.

- Coenzyme Q-10 - also shows promise but its role in myositis is unclear.

*Find Dr. Lantner's Conference presentation at [www.myositis.org](http://www.myositis.org).*



## Used chairs, from page 7.

before you commit to buy. Repairs are costly, so you want to purchase a power wheelchair in good condition.

eBay has many wheelchair listings, but most will not be local. It will be difficult for you to inspect the wheelchair and you will need to arrange and pay for transportation through one of several providers. At a minimum, eBay will give you an idea of which power wheelchairs are on the market, and their price.

Your patience and hard work will be rewarded with a power wheelchair which will serve you well over time.



## Caregiving, from cover.

wheelchair that would allow him to stand up. Here's how he describes his choice:

"I wanted a standing wheelchair because I've always liked the feeling of being on my feet – the way tight ligaments in a few minutes begin to relax, the sense that blood is pounding and returning up my leg with renewed vigor, the way I retain some dexterity as my feet flatten and I twist my torso back and forth."

Some of those who were at the Conference asked about Brett's wheelchair. "My standing wheelchair is a Levo Combi," he said. Although they cost about \$30,000 new, he was able to find a used demonstrator for half price. He recommends a couple of sites for those wanting to buy used standing wheelchairs:

- Marc's Mobility, [www.marcsmobility.com](http://www.marcsmobility.com).

- Disabled Trader, [www.disabled-trader.com](http://www.disabled-trader.com).

Find Brett Leake online at [www.BrettLeake.com](http://www.BrettLeake.com).





# THE OUTLOOK

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

For the inflammatory myopathies

## Myositis and Muscle Regeneration Study

Researchers at the University of Kentucky, College of Medicine, College of Health Sciences and College of Public Health are conducting a research study to examine muscle regeneration in individuals with idiopathic inflammatory myositis (IIM). Inflammation often occurs in the muscles of patients. While inflammation causes muscle damage, it can also promote muscle regeneration.

By conducting this research study, we hope to learn how:

- 1- inflammation helps muscle regeneration;
- 2- medications used to treat IIM affect muscle regeneration; and
- 3- muscle regeneration relates to the course of the disease.

You may be eligible for this research study if you:

- are 18 years or older; and
- have been diagnosed or are suspected to have myositis.

Participants will be compensated for their time.

Contact Research Coordinator:  
Douglas Long

Email: [delong2@uky.edu](mailto:delong2@uky.edu)  
Phone: 859-323-5438