FanFare: TMA finds friend in supermodel, Fabio

Fabio, the model and actor who has graced thousands of romance novel covers, is one of the most recognizable celebrities in the world. His imposing presence is so distinct that when he appears in films and on television, he’s usually called upon to play himself. He’s a good friend of The Myositis Association and, in March, was the big draw for a fundraiser for TMA’s southwest Florida support group.

Fabio, a motorcycle enthusiast and collector, led off a poker run, greeted fans, posed for photos, and ate dinner with five lucky high bidders.

“He had a number of difficulties and delays traveling for this appearance and a lot of demands on his time and energy,” said TMA Executive Director Bob Goldberg. “He never complained, never appeared tired. He was the exact opposite of the image of the demanding, pampered celebrity.” Marianne Moyer, one of the organizers of the Florida group and who helped plan the fundraiser, said the first bid for dinner with Fabio came in at $500.

Possibly the most successful male model of all time, Fabio is known worldwide by his first name, and never fails to show gratitude for the good things in his life. "I wish I could say I worked very hard to become successful," he said, "but that would be hypocritical. The truth is I was very lucky, and my opportunities just came to me. I can’t take credit, and I am very thankful.”

Born Fabio Lanzoni in Milan, he was a child – and later a man – with deep faith: "I would say blind faith," he said. Although he didn't have any idea how his life would eventually work out, he was certain that he would end up in America. “That was something I knew even as a little kid,” he said. He was born into a close-knit family and his size and strength were valuable to him as a teenage athlete. After a tour in the Italian army, he came to New York and almost instantly was signed as a model by the city’s most prestigious agency. His career took off and expanded to include fashion modeling, television appearances, film and comedy spots. He’s also written romance novels, promoted healthy living, hosted a reality show and sponsored a clothing line. He’s appeared on David Letterman and Jay Leno shows doing good-natured spoofs of his own international image as a hunk. He said he enjoys comedy spots that poke fun at his enormous popularity as a romantic idol, and he isn’t afraid of aging.

He now lives near Los Angeles when he’s not traveling. This month, he’ll be featured as the centerpiece for an extensive international ad campaign, so watch for him on television and in magazines.

Fabio has helped The Myositis Association in other ways, recognizing that celebrities can draw attention to worthwhile causes. Many celebrities choose huge organizations to promote, thinking the exposure will also advance their public image, he said, but he sees it differently: "It's really the small organizations that need more attention.” He hopes that any publicity myositis receives from his efforts will draw the attention of pharmaceutical companies.

“They’re just not interested in spending a lot of money on diseases as rare as myositis,” he said, “Anything we can do to publicize this disease will help.” He has another reason for wanting to play a part in educating his international audience about myositis: “I just know there are people, lots of people out there who haven’t been diagnosed and are searching for answers,” he said. “Or they may be misdiagnosed, taking drugs that don’t help and possibly may hurt them. I always have the hope that they’ll get more information and continue to seek the right diagnosis.”

Fabio became interested in myositis when a family friend began suffering from weakened muscles and impaired swallowing. He was a very close fan.

Continued, page 2.
Fabio, cont’d from cover

friend, Fabio said, one he’d known all his life. “It was just awful to see what was happening to him,” he said. “We’d be at dinner and he’d have to chew each bite for several minutes, swallowing was so hard for him.” Although his friend went for years without knowing what was wrong, he finally made a trip to New York and got a diagnosis of inclusion-body myositis. “He’s become weaker and weaker over time,” Fabio said, “and I wanted to do something for people like him.”

Fabio himself is a strong proponent of healthy living, and eats carefully and exercises often. “You know, we can’t trade ourselves in like a washer or toaster,” he said. “We just get one body and we’ve got to take care of it.” Now 51, Fabio finds he can do everything he once did as a much younger man. “I have friends my age and they’re starting to complain about aches and pains in their muscles and bones. That hasn’t happened to me, but I work very hard at being healthy.”

Strength and vitality are essential for Fabio’s career portraying a powerful romantic hero as well as his general well-being. He said his good health makes him even more aware of the challenges faced by people with myositis: “Everything I take for granted is a daily struggle for them. I want to do whatever I can to put an end to this terrible disease.”

Support Center

Local updates

The New Jersey Support Group met June 2 at The Kessler Institute for Rehabilitation with 11 members in attendance. Accredo sponsored the lunch for the group, with food from Panera Bread. Linda Iferika was introduced as the group’s co-leader.

The Georgia Support Group held its annual barbeque fundraiser on June 11. Members were joined by many friends, family and supporters. The barbeque and fundraiser is becoming a favorite with family and friends, since they all love good food and supporting a great cause.

The Connecticut Support Group held “Bowling for Myositis” a bowlathon, on June 12. The afternoon event was a wonderful time for family, friends and support group members to get together for a common cause. The group held a 50/50 raffle and had many great prizes as well.

The Southwest Florida Support Group met in late May, with several topics of discussion: “How to travel with myositis (or any other disability)”; “How to plan for a trip,” which included flying, lodging, sight-seeing, etc. The group had lunch sponsored by ArkRay, a diabetes equipment supplier, and heard a presentation on diabetes.

The Houston Support Group is again participating in the Kroger grocery store fundraiser. Customers have their Kroger rewards cards scanned during check-out and TMA receives donated funds from Kroger. If you live in an area with a Kroger, let TMA know so we can get you involved in this easy fundraiser.

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MAA Founder: Betty Curry
New program offers help for managing chronic disease

Joyce Cramer is a trainer for chronic disease self-management programs for several eastern states. She’s gone through extensive training herself, but a great deal of her knowledge, as well as her inspiration, comes from tragic personal lessons.

Cramer has had a couple of close family members who died prematurely – and, she thinks, perhaps needlessly – of complications from chronic diseases – diabetes, high blood pressure and rheumatoid arthritis. “There were all kinds of factors influencing their health,” she said. “They were always taking care of someone else, for one thing.” The simple adjustments to diet, daily activity, rest and appropriate medications that might have helped them got lost in a daily life that was often too busy.

In contrast, Cramer mentions her brother, who also has rheumatoid arthritis but controls it with strict attention to the guidelines for managing his disease.

Chronic disease is the target of a host of cost-cutting strategies as the aging population begins to push health care costs up; and understandably so. Chronic disease kills more people than any other cause. The Centers for Disease Control provide recent statistics:

- Seven of 10 deaths among Americans each year are from chronic diseases.
- In 2005, 133 million Americans – almost one of every two adults – had at least one chronic illness.
- One in every three adults is obese and almost one in five children between the ages of 6 and 19 is obese, according to the Centers’ growth charts. Researchers have found that obesity not only contributes to what’s commonly called metabolic syndrome – diabetes and hypertension – but greatly hastens disability in people with muscle and bone diseases.
- About one-fourth of people with chronic conditions have one or more daily activity limitations.

Geneva Brown, a polymyositis patient, controls her disease with appropriate medications, but finds that the pain is often debilitating. She’s learned that educating herself has been a big key to an improved life.

“For instance, if I wake up and the pain level is already at a ‘nine,’ I know that I need to make myself move around as soon as I can, even though I may not feel like it, since the pain makes it hard,” she said. (People with chronic pain are often taught to assess their pain by rating it on a scale of one to 10, with 10 being the highest level.)

Brown also knows that she must control her weight, get proper rest, and take medications as prescribed. “Sometimes I can even manage to dance a little,” she said. “That used to be my favorite thing.”

Brown took advantage of several classes on managing chronic disease that were offered to her in Maine, where she was first diagnosed. “It’s a shock at first, and then depressing, when your life is changed so much,” she said. “I learned to ask myself, ‘if I can’t do this, then what can I do?’” She always tries to find something to occupy herself, and is active in her church. “I learned that if I felt like crying, to cry and then to go on.”

The classes Brown took explored practical ways that people with chronic disease can make changes that benefit their lives and their health.

Classes are based on research conducted with a thousand people over three years at Stanford University. Researchers found that people who learn disease self-management in this type of intensive, collaborative way gain confidence that they can live a full life and show significant improvements in getting exercise, managing their symptoms, communicating with their doctors, improving their overall health and energy, and maintaining a rewarding social life. Compared to people without the training, they also were less distressed and spent fewer days in the hospital.

Subjects covered in these Stanford-sanctioned workshops are managing frustration, fatigue, pain and isolation; exercise for maintaining and improving strength, flexibility, and endurance; use of medications; communicating effectively with family, friends, and health professionals; nutrition; and how to evaluate new treatments.

April Holmes, who coordinates prevention programs for older adults for the Virginia Department of the Aging, says collaboration is a key factor. “People set goals – realistic ones – every week. If they seem to be stuck in their progress, the group brainstorm for solutions. So we’re taking advantage of the group knowledge as well as what we’ve learned in research.”

It only makes sense that this self-management program is effective, Holmes said: “When you think about it, who manages your disease? You’re only with your doctor a tiny fraction of your time. In the end, it has to be you.”

There will be a session introducing the Stanford disease self-management program at TMA’s Annual Patient Conference.

To find a program near you, go to http://patienteducation.stanford.edu/organ/cdsites.html
Dr. Tahseen Mozaffar was featured in a live online discussion about the use of IVIG in myositis treatment. Dr. Mozaffar is a neurologist, an associate professor of neurology at the University of California Irvine School of Medicine, and he directs the neuromuscular program at the UCI School of Medicine. He is also the director of the UCI-MDA ALS and Neuromuscular Center. He is a member of TMA’s medical advisory board, and will speak at TMA’s Annual Patient Conference in September.

The following is edited for length and clarity. Find the whole transcript at www.myositis.org.

**I was diagnosed by biopsy with DM, but I have no rash. I’ve been on IVIG for 12 months, nine months with one provider and three months with another. My question is, since I moved and started with the new provider, I’ve experienced massive headaches and high fevers during the infusions. I never had this with the past provider. I know each batch is different but could a buffer in this brand of IVIG be causing my problems?**

**Dr. Mozaffar:** It sounds like you are receiving too much IVIG. The symptoms of headaches and fevers are not unusual for IVIG infusions; they usually respond to slowing down the rate of infusion. However, you may want to make sure that IVIG is not causing a chemical meningitis, a rare complication, that would require a lumbar puncture "spinal" tap for diagnosis.

**I have either PM or IBM. A few years ago, I had an IVIG series during two years. I felt it helped me to feel tremendously stronger in the long run. My rheumatologist felt that it was not successful since my CPK did not go down and stay down. He has never recommended it again. Is CPK the only measure of IVIG success?**

**Dr. Mozaffar:** CPK is not the only measure of success. Your symptoms, but more importantly your strength measurements, should be the measure of success. If you benefitted, and there is a reproducible measurement of it, then I don't care what happened to the CPK.

**I am currently on Cellcept and IVIG and symptom-free. I have DM. Eventually I would like to be off both medications, weaning off Cellcept and then IVIG, as I think Cellcept has more risks associated with side effects. In my opinion, I should try to reach remission without suppressing my immune system. I have not experienced any negative side effects with either treatment. What are your thoughts?**

**Dr. Mozaffar:** If you decide to try to get off the medications, it has to be a mutual decision between you and your physician. You should not try to do this yourself. It can be done, but there are risks and therefore your treating physician has to be the one to initiate it and monitor it.

**I was diagnosed with IBM in 2002. As part of my earliest treatment I had more than 30 IVIG treatments. I did not notice any measurable improvement during or after the conclusion of treatment. In the subsequent eight plus years I have grown progressively weaker. Is there any reason to believe that renewed IVIG treatments, at this time, would be of any benefit?**

**Dr. Mozaffar:** No, as I said in the earlier question, IVIG does not have a great track record in IBM. We do offer it to patients, but if it does not work we stop and there is no reason to go back to it, if it did not work in the first place.

**I have IBM and tried IVIG for a year at a cost of $12,000 to me. It seemed to help, but is not approved or covered for IBM because it isn’t supposed to help. Could I possibly have a combination of PM and IBM, and is anything being done to get approval and Medicare coverage of IVIG for IBM?**

**Dr. Mozaffar:** You either have PM or IBM and IVIG usually does not work in IBM, and even if it does, the effects are very minimal and short-lived. So unless there was a robust improvement, I am not sure I can support its use much in IBM either.

**I am a 53-year-old male with IBM for the past five years, and am steadily losing muscle. What is the most important thing I should be doing to preserve what muscle I have left?**

**Dr. Mozaffar:** Try to stay active, with emphasis on keeping your muscles active (not necessarily focusing on making them stronger, but just active). Exercise, especially aerobic exercise, including stationary bikes and swimming would help.

**What are the side effects of long-term IVIG therapy?**

**Dr. Mozaffar:** Very little; there is risk of blood clots, and some kidney dysfunction, but overall very little long term consequences.
Alternatives show promise for pain control

Complementary and alternative health practices—including meditation and relaxation techniques; massage and spinal manipulation; yoga, Tai Chi, and acupuncture—show promise in the management of pain, according to research presented at this year’s meeting of the American Pain Society.

In her keynote address, Dr. Josephine Briggs, director of the National Center for Complementary and Alternative Medicine at the National Institutes of Health, said these approaches have become widely used to manage painful conditions, including musculoskeletal pain.

A government survey found 38 percent of U.S. adults and approximately 12 percent of children use some form of complementary and alternative medicine.

Studies in this field include tai chi for fibromyalgia, as well as meditation, yoga and acupuncture for low back pain. Briggs said symptom management is where research can have the greatest impact, and the National Center’s strategic plan calls for a strong evidence base in pain management.

The integration of these complementary therapies with conventional medicine for pain management is already found in a number of military health care settings.

New drugs improve outlook for chronic illness

In the last ten years, more than 300 new medicines have been approved by the U.S. Food and Drug Administration. Better medicines help patients live longer, healthier lives. They are transforming many cancers into treatable conditions and reducing the impact of cardiovascular disease. Many new drugs and combination of drugs provide better lives for those with chronic inflammatory diseases and the side effects of diabetes and osteoporosis caused by treatment with prednisone.

- Diabetes patients treated with medicines are less likely to develop other health problems.
  Hospitalization rates and the number of days spent in the hospital were 23% and 24% lower for those patients who carefully followed treatment guidelines.
- Clinical remission is now possible for patients with severe rheumatoid arthritis.
  A recent study found that patients treated with combination therapy had a 50% chance of complete clinical remission after 52 weeks of treatment.
- Osteoporosis medicines greatly reduce the risk of fractures when taken consistently.
  Patients who take osteoporosis medicines have a 40% lower rate of fractures compared with those who are untreated.

Monitor multiple drugs

The Kaiser Family Foundation reports that prescription drug usage in the United States is continuing to rise. A recent report finds the number of prescriptions filled each year increased by 39% between 1999 and 2009, and the amount of money spent was $234 billion in 2008. The average American fills 12 prescriptions each year.

"Many side effects from drug interactions are exacerbations of known side effects of the single drugs that are made worse by the two drugs together," says Dr. Russ Altman, a professor of bioengineering, genetics and medicine at Stanford University.

Altman says most drugs are tested and approved independently, and it can be difficult to predict the side effects of drug combinations. "It is very hard to find these in advance of release of the drug, because sometimes these effects will only manifest in the context of large numbers of patients," he explains.

"I don't think people really understand the nature of medication; the (drugs) will, by definition, have some toxic, collateral side effects," says Dr. Douglas Bremner, a professor of psychiatry and behavioral sciences at Emory University. His 2008 book "Before You Take that Pill" warned patients of the risks and benefits of some commonly prescribed drugs.

Bremner says medications clearly do a lot of good and are needed in many situations, but warns that when a patient is on too many at once, there are serious questions about whether the therapeutic benefits outweigh the collateral. "When you end up on 12 prescription medications you need to seriously look at what the situation is," he says. "At that point, there's no way of knowing what's causing what anymore."

He recommends patients fill all their prescription medications at one pharmacy, especially if they are receiving treatment from multiple practitioners. "Often the pharmacist is the best point person because they're the last stop before the prescription hits the hand of the patient and are ready to be taken."

Dr. Altman says introducing new medications one at a time can help you recognize side effects and interactions earlier. You can potentially trace them to the most recent drug added.
When Bob Massey – an IBM patient from New Market, Maryland – set out to buy a mini-van designed to transport a power wheelchair, he didn't find much help that was relevant. After months of searching and researching, he was finally able to make a decision and a purchase. "I am hoping that my summary will reduce the search effort for others," he said.

To that end, Massey carefully documented his efforts, excerpted here.

**Sticker shock**

There's no doubt that you will experience this, Massey writes. He found new, converted mini-vans priced from $51,000 to $60,000, before taxes, titles and tags. For this reason, he considered a used mini-van. Even the used vehicles with low mileage are tremendously expensive, though, he said.

To buy a van that fits your needs, you'll need to see it and drive it for yourself. If you're not able to drive to the dealer's lot in your current vehicle, this can be a problem, Massey said. Although dealers are often willing to bring the van to you, you may miss the best deal if you leave the selection up to them. "Since the profit margin for the seller is largest with selling new vans, that's the vehicle they'll select to show you at your home."

It's best, he found out, to have a family member go to local dealers to view the used van inventory, then request that the dealer bring a specific vehicle to your home for you to inspect and test drive. For out-of-state dealers, there is generally a charge for this, Massey said, but it is important, since you will need to practice entering and exiting in your wheelchair to make sure the arrangement will work for you.

As one of his first steps, Massey compiled a list of national dealers, with comments about their specialties:

**AMS (Atlanta, Georgia)**
800-775-8267; www.amsvans.com
National inventory, new and used vans, performs conversions, brochure available upon request.

**Braun Ability**
800-843-5438; www.braunability.com
New, used, conversions, Toyota, Honda, Dodge and Chrysler, brochures depicting all dimensions.

**Freedom Motors**
New, used vans, specialty conversions of Honda Element, Toyota Scion and rear-entry vans.

**Liberty Motor Company**
866-570-6587; www.libertymotorco.com
New, used vans, performs conversions.

**Rolls Vans**
800-956-6668; www.rollsvans.com
New, used vans, performs conversions.

**The Mobility Resource**
www.themobilityresource.com
Vehicle conversions.

**Should you convert or should you buy?**

Depending on the cost and timing, you may want to buy a van now while you're able to drive a conventional vehicle and convert it for wheelchair use later, Massey says. If this is the case, make sure the van has the following:

- Front wheel drive
- A power sliding passenger door
- Less than 50,000 miles

Also, says Massey, check with the dealer to make sure it's possible to convert the van for your later use with a power wheelchair.

**Know the details**

Manufacturers have brochures with guidelines showing you how to convert your van, Massey said. Make sure you have diagrams about the conversion that show all dimensions within the van, including the ramp. You'll also need to know the inside dimensions; entry opening width and height of passenger door; width and length of the ramp; your wheelchair length; and the width and occupied height of your chair. To get the most accurate measure of the wheelchair length, sit in your chair and drive it until your toes touch the wall.

Measure from the furthest back point – for many it will be the back of the back wheels – to the wall. This dimension, Massey said, is critical for determining maneuverability room in the bed of the van. Check the instruction manual to find the ramp angle and slope degree limits of your wheelchair.

**Buy-back arrangements**

Some dealers will offer a guaranteed buy-back agreement for when you decide to sell. Massey said the typical agreement was projected on 12,000 miles of use yearly. After one year, the loss was about 51.5 percent, he said.

**Some options and extras**

- Emergency back-up for battery operated ramps. Massey found one system that included a back-up emergency battery, which can be employed to open the door and activate the ramp for the exiting wheelchair in the event the main battery fails. Another back-up system is a hand crank that operates the ramp in an emergency. Some conversions include both the battery and crank back-up systems.
Kneel modification. Some van conversions for side entry include a “kneel” modification. The van is tailored so it lowers the passenger side a few inches when the automated ramp is extended to street level. The Quantum 6000Z wheelchair manual suggests that it negotiates only a five degree angle (8.7 degree slope). Most of the ramps without “kneel” exceed that specification.

Maintenance. Obviously, it is most convenient to have a conversion unit serviced by someone nearby. Most local dealers do all the servicing and repairs at their dealership. It is also possible to find someone in your state who services the vans sold by a national dealer.

Delivery charges. Most dealers add a delivery charge for transporting a van to your home, but there are some exceptions. Make sure you inquire.

Inspection and testing. Most dealers offer you the opportunity to test drive the vehicle at your home, but you’ll most likely be required to have a signed contract first. If you’re purchasing your van from a distance, Massey suggests you find a CARFAX team to conduct a mechanical inspection of the van before you agree to purchase it. For a fee, they’ll provide a written report before you agree to purchase.

Loaner van. Some dealers will offer you a loaner van to use until your conversion is complete. Check with the dealer to determine if this is the case in your situation.

Performance and ease of use

Massey made a thorough study of some of the steps involved in entering, exiting and parking in different vans. He found some variables that will help you decide which type of van will be the best fit for you:

Parallel parking for side entry vans. This is a major concern, Massey said. Since the passenger sliding door is extended downward to allow for greater height at the point of entry, you’ll always need to allow extra distance from the curb, so the door is not damaged when it opens. For vans that are converted to “kneel,” you also need to avoid activating the ramp extension into the side of the curb. Normally, there is a dashboard switch control to prevent this. The switch has an option that allows the ramp to extend from the slot in a way that positions it to lie on top of the curb. In either case, the height of the curb is a critical issue.

Ramps for side entry conversions. There are a few options for side entry conversions, Massey said, including lowering the floor by 10 or 11 inches from the front of the back row of seats to the rear of the driver-passenger seats. Some lower a greater area of the floor to allow the driver or passenger seat (or both) to be removed quickly to allow the wheelchair to be parked in either space. Passenger side conversions include a manually-operated ramp that folds up after entry and blocks the door exit. There are also battery-operated ramps that automatically fold up or slide into a slot in the floor. They are activated by the opening of the powered side door.

Ramps for tailgate entry. In this type of conversion, a channel is created in the middle of the van floor, on an inclined angle. A ramp is lowered from the bottom of the channel (in the tailgate of the vehicle) to street level. The channel is 31 inches wide. The wheelchair is generally secured in the second row of seats. Because of the channel in the floor, you can’t maneuver the wheelchair inside except to back out the same way you came in. This method has some safety concerns, Massey said, especially if the caregiver is frail.

Wheelchair security restraints. Massey became familiar with three versions of restraints: a ratcheting belt type, generally provided at no extra cost; a floor unit with an automatic retractable strap, which cost about $500; and an E-Z release type with remote release. The E-Z release type includes a floor unit with a V-shaped cut out, mounted to the floor. A special plate, custom-made for each wheelchair type, is fixed to the bottom of the wheelchair. This plate has a “pin” that engages in the V-shaped cut away in the floor unit. The E-Z release quotes were $1800 to $2195, including installation. Some users who have wheelchairs with movable seats, may experience a rocking motion with this type of restraint.

Massey’s van has four floor units with retractable straps for securing the wheelchair (two in front and two in back). He found that the two units in the front, located under the dashboard, are tricky to reach, particularly the one between the driver and passenger side. With a little ingenuity, he modified the way the wheelchair-securing floor units are controlled to reduce the caregiver’s difficulty in reaching and using them. Massey used a 1 ½-inch rod, 20-24 inches long, and an open-ended screw hook with an opening in the hook of at least ¾ inch.

His instructions: Screw the hook into one end of the rod. The wheelchair-securing floor units have a red strap release switch on top of the unit. With a cane, depress the release switch, then use your rod and hook to lift the retractable strap hook upward to place it in the wheelchair receptor that secures the wheelchair. To release the strap, just depress the switch and remove the strap hook from the chair.

Finally, Massey warns that navigating the van’s ramp in a power chair requires extreme caution. The ramp edges are only an inch high, a height that the wheelchair’s motor could easily overrun. Massey avoids using the ramp during wet or snowy weather.
In response to evaluations from TMA's Annual Patient Conference last year, and to comments we've gathered since then, we're adapting this year's Conference sessions. If you go to the agenda online, you'll see a slower pace to the scheduling, allowing more time for people to get to sessions and even linger a bit in the hall to talk.

Once you get to the sessions, you'll see we've changed the format a bit! While some of the sessions will include the traditional power point presentation and handouts, others will be primarily interactive, inspired by your questions.

For the second consecutive year, the Conference includes TMA's Medical Advisory Board, meaning that the world's top myositis experts will be on hand. We've asked them to show up ready to respond to the issues that concern you the most. Some sessions will offer audience participation, as you learn how to exercise on land and in the water; or keep your balance; or manage your disease with your resources.

Since these sessions will be spontaneous, many won't have handouts or other records that we can post on our website. However, we will capture these sessions in photos, interviews, transcripts and recordings, and make them available on TMA's website and in our newsletters, for those who were unable to attend the Conference.

For those who have provided feedback in the past, thank you for your contributions to TMA's 2011 Annual Patient Conference!