

The OutLook

WINTER 2014

Quarterly Newsletter

Dog: Myositis' Best Friend? | pg 8



In the Spotlight: **Research in progress**
Patients and researchers report | pg 3



Executive Director: Bob Goldberg
Editor: Theresa Reynolds Curry

BOARD OF DIRECTORS

Augie DeAugustinis, Chair
Pat Zenner, Vice-Chair
Craig W. Patterson, Treasurer
Renee Lantner, Secretary
Marianne Moyer, Immediate Past Chair
Terry D. Anderson
Dana P. Ascherman, M.D.
Doreen Cahoon
Christopher Dotur
Marvin Lauwasser
William Prall
Dale Scott
Carla Stevenson
John C. Suttle
Robert Wortmann, M.D.

MEDICAL ADVISORY BOARD

Tahseen Mozaffar, M.D., Chair
Dana P. Ascherman, M.D., Vice Chair
Rup Tandan, M.D, MRCP, Research Chair
Chester V. Oddis, M.D., Nominating Chair
Rohit Aggarwal, M.D., M.S.
Helene Alexanderson, Ph.D.
Christina Charles-Schoeman, M.D.
Mazen Dimachkie, M.D., FAAN
Steven Greenberg, M.D.
Susan Maillard, MSC, MCSP, SRP
Andrew Mammen, M.D., PhD
Neil McHugh, M.D.
Margherita Milone, M.D., PhD
Kanneboyina Nagaraju, D.V.M., PhD
Alan Pestronk, M.D.
Ann Reed, M.D.
Zarife Sahenk, M.D.
Jiri Vencovsky, M.D.
Ruth Ann Vleugels, M.D., MPH
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

Corner Office

Dear Friends,

This past summer was a very busy time at TMA as we prepared for the 2014 Annual Patient Conference and focused much attention on creating greater awareness of myositis among the public and physicians. I am very pleased to report that these efforts appear to have been successful and worthwhile. Through funding received from Mallinckrodt Pharmaceuticals (formerly Questcor) as National Sponsor of Myositis Awareness Day, TMA was enabled to mail myositis educational brochures to nearly 2,000 physicians with an interest in myositis. We also sent to them the new TMA publication, *A Physician's Guide to the Inflammatory Myopathies*, and a poster for their office to direct myositis patients to TMA for more information about the disease and where to find a local myositis support group.

For young physicians and medical school students, TMA initiated a new program this summer: *Visiting Professor Series*. This program is intended to educate medical students, interns and residents about myositis. TMA scheduled lectures and grand rounds about myositis which will be presented by members of TMA's Medical Advisory Board. Thirty-three U.S. medical schools asked to be included in this program. That is more than 25% of all U.S. medical schools – a very strong response and level of interest in teaching physicians about this rare disease.

And, TMA's equine celebrity, thoroughbred racehorse Myositis Dan, won a race in Chicago, raced at Churchill Downs, and raced for a purse of \$500,000 at Saratoga Springs, NY this summer. "Dan" continues to bring the word "myositis" to literally millions of people who would otherwise have little reason to ever have heard it before.

TMA also has sent to our support groups thousands of "Cure Myositis" wristbands and is making wristbands available at all community events to spread the word and the need for a cure.

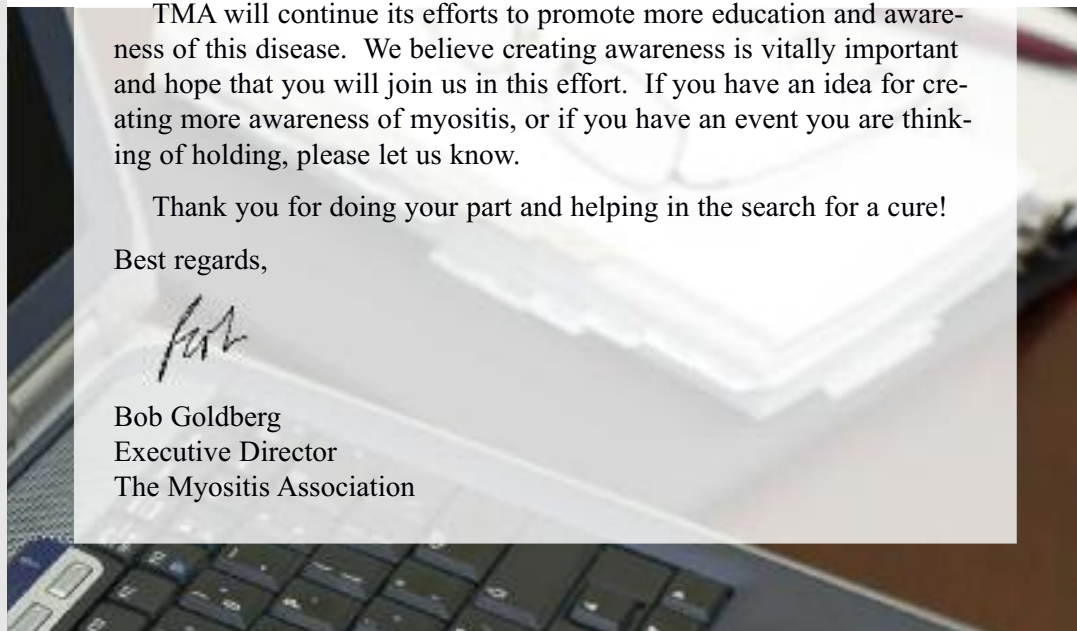
TMA will continue its efforts to promote more education and awareness of this disease. We believe creating awareness is vitally important and hope that you will join us in this effort. If you have an idea for creating more awareness of myositis, or if you have an event you are thinking of holding, please let us know.

Thank you for doing your part and helping in the search for a cure!

Best regards,



Bob Goldberg
Executive Director
The Myositis Association



Research Review

Patients and researchers report on current trials

Trials investigate drugs for PM and DM

Dr. Lisa Christopher-Stine, director of the Johns Hopkins Myositis Center, told TMA members at the 2014 Annual Patient Conference that there's growing interest in myositis research. Some projects in Europe are examining physical activity and the disease process as well as comparing the relative merit of different treatment strategies. European TMA members will find these trials included in the United States database compiled by National Institutes of Health at www.clinicaltrials.gov.

Dr. Christopher-Stine said the US has several active trials:

Novel Drug Delivery of Sodium Thiosulfate for Calcinosis Associated With Adult and Juvenile Dermatomyositis

This is a pilot study to evaluate the use of topical sodium thiosulfate solution in treating superficial calcinosis in juvenile and adult dermatomyositis. Investigators will use laser technology to deliver the medication to the areas of calcinosis. This study, at George Washington University in Washington, DC, is actively recruiting. Call 202-741-6141.

Tocilizumab in the Treatment of Refractory Polymyositis and Dermatomyositis

This multi-center pilot study is to determine if the drug tocilizumab (Actemra) is effective in the treatment of patients with refractory adult polymyositis (PM) and dermatomyosi-

tis (DM). This study, at the University of Pittsburgh, is not yet open for recruitment.

Open Label Proof of Concept Study to Evaluate Efficacy and Safety of Adrenocorticotropic Hormone Gel in Refractory Dermatomyositis or Polymyositis

This study will evaluate the effectiveness of the ACTH Gel (Acthar) in peo-



Find current trials for myositis patients at www.myositis.org.

ple diagnosed with DM/PM. The study doctors want to evaluate whether ACTH Gel will improve symptoms. An FDA-approved treatment for myositis since 1952, Acthar was retained in 2010 by the FDA as a treatment for PM and DM. This study, at the University of Pittsburgh, is actively recruiting. Call Diane Koontz at 412-383-8674 or email dik4@pitt.edu.

A Multi-Center Double-blind, Placebo Controlled, Proof of Concept Study to Evaluate the Efficacy and Tolerability of BAF312 in Patients with Polymyositis

This study will assess the efficacy, safety and tolerability of BAF312

administered orally in patients with clinically active polymyositis who have shown inadequate response to corticosteroids and or DMARDs (disease-modifying anti-rheumatic drugs). This is a multi-center study with international as well as domestic centers participating. US centers now recruiting are in Miami, Boston and Arizona and more are expected to begin. To be seen at any center, call Novartis Pharmaceuticals, 1-888-669-6682.

Dr. Christopher-Stine also mentioned an upcoming study, as yet unnamed, that will investigate a drug interrupting the cycle of pro-inflammatory activation that causes ongoing muscle inflammation.

It is TMA's policy to let members know

as soon as a new study begins recruitment.

In addition to the studies mentioned by Dr. Christopher-Stine, there are a number of environmental and epidemiological studies for IBM, PM, DM and JDM. All are listed on the website, www.clinicaltrials.gov. To locate a trial, type the name of your particular disease into the search box.

There's also a study of BAF312 in dermatomyositis similar to the one for patients with polymyositis:

Safety and Efficacy of BAF312 in Dermatomyositis

This study investigates the dose-response relationship for the efficacy

See *Current trials*, page 17.

IBM Follistatin trial: one man's report

Shortly before TMA's Annual Patient Conference, TMA Board of Directors Chair Augie DeAugustinis let colleagues know they might be surprised at first when they saw him in Reno. "You'll notice I'm walking a lot better and have better balance," he said. This was wonderful news for Augie and for everyone with inclusion-body myositis.

Augie is participating in the Follistatin Gene Therapy Clinical Trial led by Dr. Jerry Mendell at Nationwide Children's Hospital in Columbus, Ohio. He had been selected to be one of the three to receive high-dose injections in both legs. Augie was injected in January, 2014.

Augie gives us an inside glimpse of the meticulous preparation for a trial of this magnitude and importance. In his case it included an initial biopsy so there would be a baseline for comparison, then a waiting period of eight weeks so the biopsy site could heal. Before his legs were injected, Augie also had an MRI (magnetic resource imaging) both for comparison purposes and to guide the researchers to the appropriate injection sites. Augie said he'd been told that it's crucial to choose good muscle for these injections.

The injection itself was not painful, he recalls. He checked into a hospital room in the morning, and was examined by Dr. Mendell. The doctor identified three areas on his leg with purple circles, based on the information from the MRI and ultrasounds. Augie received a mild sedative, then was injected with a small needle, about the size of a needle used for a flu shot.

Augie received 12 injections in each leg, in what doctors marked as the healthiest part of his muscle. Ideally, he said, the injections would be distributed throughout the leg, but some of his muscles, particularly in the middle of his leg, were so atrophied that his injections were more concentrated within the healthiest muscle. "It was completely painless," he said. The procedure took about 45 minutes. To make sure there was no immediate adverse reaction to the study drug, Augie spent the night in the hospital, where staff checked periodically for redness, pain or any other ill effects.

With that behind him, Augie was released to his daily life as a human guinea pig. Two other IBM patients were injected at about the same time with the same level of dosage in both quadriceps.

His first sense of improvement was vague and he wondered if it

was subjective: "It seemed like I could walk farther and faster," he said. Starting at about three months, he was comfortable believing this was an accurate observation, and it was confirmed by his timed walk at Nationwide Children's Hospital.

At about the same time, something even more startling happened. Augie had been instructed to carefully preserve the markers that identified the injection sites. This meant that each time they started to fade from wear or washing, he meticulously renewed them with a purple marker.

Augie watched the markers on each leg as they moved farther and farther away from the actual scar. "I was concerned, but also excited," he said. When he checked with the researchers they were excited, too, he remembers: "They said, 'of course! This is what we expect.'" Augie's skin was being stretched by the growth of new muscle. Augie could also see and feel firm new muscle, and — best of all — he could cover significantly more ground in six minutes than he'd been able to at the start of the trial. He also experienced better balance and less fatigue.

What's in Augie's future? The only response is from muscles that were actually injected, so Augie still has weakness in his hands, and he still finds it difficult to go upstairs. Augie was told that his muscles may continue to grow for a year. This doesn't mean that he doesn't have IBM anymore: he was told that the disease will continue to attack his muscle, although possibly at a slower rate. "The follistatin seems not only to build muscles at the injection site, but to dampen the inflammation," he said. And Augie's efforts — and those of the others in the trial — will pave the way for future treatment. "The evidence is overwhelming that this is safe," Augie said. "Future trials may use significantly higher doses and more muscle groups."

See Follistatin, page 17.

BYM338 trial advances

IBM patient Craig Patterson received his fifth infusion of the trial drug BYM338 (also called bimagrumab) at the end of September. Craig suspects that he is receiving the drug rather than the placebo because he has had some mild symptoms that are typical side effects of the drug.

Craig is receiving his infusions at Kansas University Clinical Trial Center. He is walking farther in the timed walk, but is not sure yet if it is a significant change.

Novartis updates information about its trials at the website www.clinicaltrials.gov, but patients have found some information to be contradictory. One trial, "Efficacy and Safety of Bimagrumab/BYM338 at 52 Weeks on Physical Function, Muscle Strength, Mobility in sIBM Patients (RESILIENT)" has 43 sites throughout the world but some of the US sites listed are no longer recruiting.

Another trial, "Study of Long-term Safety, Efficacy Tolerability of BYM338 in Patients With Sporadic Inclusion Body Myositis," is being conducted in Boston and Arizona but it is restricted to patients who were in an earlier BYM338 trial.

In both cases, Novartis asks interested patients to call Novartis Pharmaceuticals at 1-888-669-6682.

TMA also has a special forum where those enrolled in a clinical trial can describe their experiences and answer questions. To find the forum, "Clinical Trials," go to www.myositis.org; click on "Community," then "Community Forum."

Save the date!

TMA returns to Orlando for the 2015 Annual Patient Conference, Sept. 10-13, with a full Conference program focused on coping, the latest research, emotional support and all the information you need to live your best life with myositis. The Conference is at Caribe Royale, the fabulous resort that hosted the Conference in 2012. Watch your mailbox for the Conference flyer and plan now to be with us in Orlando!

Find an event

Wanting to join a support group in your area but not sure where to start? Find meetings near you at TMA's website: <http://www.myositis.org/event-calendar>, or go to the website at www.myositis.org, and click "events" in the top righthand corner.

Looking for a myositis specialist?

Most of TMA's medical advisors see patients. To find their names and contact information, go to TMA's website, www.myositis.org and click on "About TMA" in the lower righthand corner, then select "Medical Advisory Board" from the menu on the right.

You'll also find the full names of staff members, members of the TMA board of directors, and medical advisory board members on page 2 of this publication.



Conserving energy, fighting fear

IBM patient finds peace and poise with Alexander Technique

The following is an abbreviated version of an article originally written by IBM patient Dennis Chada and Alexander Technique teacher Lauren Hill for the Minnesota KIT Myositis Support Group. Find the full version at www.AlexanderTeachingStudio.com.

The Alexander Technique

The Alexander Technique is a practical method for helping people function with less effort and more ease. It is not something you "do" separately, like strengthening exercises or a yoga practice. Instead it is a set of skills learned and applied to any activity you already do, so you do it more easefully and efficiently and with less tension and strain.

Typically, students work with a teacher to learn effective ways to manage conditions like chronic back pain or muscle tension; to improve performance in activities like music, athletics

or dance; or to play a more active role in their well-being as they age.

There's another group of people who can benefit from the Alexander Technique: those living with chronic conditions such as inclusion-body myositis. People often fail to recognize how daily movement and postural habits contribute to their problems and, in the case of a chronic condition, make management of the condition and simple daily activities more difficult than necessary. It is these habits that the Alexander Technique addresses.

The Alexander Technique teaches students to be more aware of their patterns of unnecessary tension. More specifically, it teaches students to notice how they habitually react to certain situations, avoid reactions that aren't helpful, and choose more reasoned responses. For instance, those with fear of falling or fear of pain may react in ways

that make the situation worse, with the reactions becoming so ingrained that they don't notice what they're doing.

Learning to recognize unhelpful patterns and realizing you have a choice can be very helpful. Making even very small changes improves your ability to navigate daily activity and improve your outlook on life. It always feels better if you can do something to help yourself, even if it is something small.

The Alexander Technique considers the relationship between the head and the spine to be of primary importance, exerting a considerable influence on our balance, coordination and ability to move with ease. Alexander teachers place a lot of emphasis on noticing and "unlearning" habitual interference in this key area of the body.

Alexander teachers work with students one on one, allowing the teacher to focus on the student's unique habits,

limitations and learning style. The Alexander Technique skills are simple but it is often hard to see your own habits, especially at first, so a certified teacher can be quite helpful. In a typical lesson the teacher will use verbal instruction and gentle hands-on guidance to teach you to consciously reduce interference with the head-spine relationship and to approach everyday movements in a healthier way. You may also work on releasing habitual tension while lying on a bodywork table.

From the student:

After my diagnosis, I was searching for non-traditional treatment options when a friend of mine suggested the Alexander Technique. I found a teacher near my home, but before we met I went to Las Vegas for The Myositis Association Annual Patient Conference. While there, I met another man with IBM who encouraged me to pursue this option. He was in a wheelchair, but believed the Alexander Technique had prolonged his mobility.

Lauren showed good humor in dealing with the quirks of my condition. Since spontaneous falling without warning is one of the symptoms of the disease, it's easy to become very insecure and even fearful. Working with Lauren helped me overcome my fears: of falling; of being on the ground and unable to get up; and of being unable to rise from a chair.

A good bit of our time was spent changing my rigid posture, and after several lessons and some reading about the history and current practice of the Alexander Technique, I progressed to a more poised and balanced way of standing and moving. In our work together, I have become more mindful and able to find new ways to accomplish goals with my sometimes limited abilities. For instance, I learned that standing rigidly made me unstable and left me more prone to falling than standing in a poised manner. Lauren and I have

explored getting up off the floor unaided and rising from a chair without struggling.

Another symptom of IBM is constant fatigue: every activity is more strenuous than it would be for a "normal" person. I have learned to stand and move in a manner that allows me to conserve energy, retain mobility, and be less fearful of my disease. Learning to change the way I handle the challenge of everyday activities has been a slow process, but very worthwhile. I would recommend the Alexander Technique for people in a situation similar to mine.

Lauren has a quote pinned to the bulletin board in her studio that I think sums up her philosophy and my experience: "Habit is habit and not to be flung out of the window by any man, but coaxed downstairs a step at a time." (Mark Twain)

The Teacher's Perspective

I have had the sincere privilege of working with Dennis weekly since the fall of 2011. Dennis is still able to walk on his own with the occasional aid of a cane. However, he experiences spontaneous falling, and feels insecure when standing, walking or when needing to sit down or rise from a chair.

Dennis' habitual response to the fear of falling is to lock his knees and tense his entire body. Besides being fatiguing, locking the knees and that unnecessary tension throws his weight further back on his heels than normal. With his weight predominately on his heels, Dennis is off balance, leading to more instability and more fear, more tensing and fatigue, putting him further off balance, and on and on in an endless cycle.

Dennis has been learning to become more aware of his fear of falling (a potent stimulus for anyone) and his habitual reaction to that fear. He has learned how to consciously let go of the habits that are making such things as standing, walking or simply getting out

of a chair unnecessarily laborious acts.

Sometimes I work with Dennis lying down in a semi-supine position (lying on his back, head supported, with the knees bent and feet flat) on a comfortable padded table. This has proved important, especially at the beginning of our work together. It gives him a safe place, as he doesn't worry about balancing upright and the possibility of spontaneous falling as he experiments with letting go of the habitual patterns, which were so practiced that they were essentially a part of him. His practice outside of lessons has helped him advance.

Gradually we have taken these experiences into standing and moving. We work with simple everyday activities. Where once walking felt insecure and required a large expenditure of energy, Dennis now finds balance and is a bit more at ease. Where once rising from a chair was an act of sheer willpower and strength, he manages with much less effort. He has learned to calm himself when he does fall (which he will do) and has learned how to get up off the floor easily without the aid of furniture or the wall.

See Alexander Technique, page 10.



"Like a miracle" More than service from an extraordinary dog

Mary Anne Hunt-Valencia was skeptical when she discovered her service dog was going to be a poodle. "A poodle!" she said, remembering her shock. "All I could think of was Fifi. And, believe me, I am not a 'Fifi' type of person. I was not sure at all that this would work." But, as she saw it, she had few options at the time.

Frustrated by the progression of her IBM, Mary Anne had spent some time searching for ways to make her life better. A dog lover, she had thought of a service dog, but she was severely allergic and so did not really pursue it.

A couple of things happened that caused her to press further. At dinner downtown, she sat near a man and noticed that like her, he was in a wheelchair. She watched in fascination as his dog picked up items he had fumbled and dropped to the ground. Interested, she struck up a conversation. "You have no idea what this dog has meant in my life," he told her.

Next, a chance encounter with a woman on a plane convinced her further that a dog was a good idea for her. Flying back from the 2012 Annual Patient Conference in Orlando, she saw a woman on the plane with a very large black labrador. By then, "I had fallen many, many times and I had even fallen while at the Conference," Mary Anne said. "It just made sense to me to make some positive changes."

The woman was in a hurry and couldn't do much more than give her a card, Mary Anne said. "But as she rushed off, she told me that getting a service dog would be the best thing I ever did." At the time, Mary Anne found it hard to understand. "Now I'm a believer," she said. "Damon has been like a miracle in my life."

Shortly after her conversation with the woman on the plane, Mary Anne applied for a service dog. She expected a long wait and knew she would be a tough case. Mary Anne's previous dogs

had to be sheltered outside her own living quarters. "I found out there were laboradoodles used as service dogs," she said. This was good news because, after several generations, the labrador-poodle crossbred dogs do not affect people with dog allergies.

Mary Anne was on a waiting list for a laboradoodle, but someone else received the one she wanted and no more were available. That's how she found herself discussing a dog she thought of as little more than a cartoon copy of a "real" dog.

"You don't understand," said the service dog agency representative. "This dog is not a 'Fifi' dog. This dog is big, he's smart, he's beautiful, and he's at the head of his training class."



To qualify, Mary Anne had gone through several interviews and a complicated application process. She learned that service dogs are trained for obedience and to follow many commands, but that's just a start. They also go through a very extensive training process jointly with their owners. They go everywhere together, both outdoors and indoors, so the training supervisor can identify the problems, and tailor the training to each person's individual needs.

Mary Anne held her breath as she waited to meet Damon, the two-year-old who was to change her life. "I was astonished," she said. "He was not only large and beautiful, he was also mellow, which is not always the case with the young dogs in training." But he wasn't totally sedate. He came right to her and jumped up. "He still had a lot of that puppy energy," she said. Mary Anne trained Damon to open doors and let her go ahead of him. He also learned to move the footpads on her wheelchair as she stood up or sat down.

"It's hard to work all these things out," she said. "You have to be committed." When things got

rough, Mary Anne was inclined to blame herself. "I was the one who was behind. He'd been in training two years, while I had only been training for two weeks." What bothered her the most, she said, is when she inadvertently ran over his toes, which happened more than once. Together, they kept at it. She found out that poodles are not only non-allergenic, but also less likely to have hip problems than other service dog breeds.

Once Mary Anne and her new companion became accustomed to each other, there were still a few bumps in the road. "Dogs need to adapt to different ways that people speak," she said. For instance, even when she said Damon's name twice instead of once it was confusing to him.

Now that the two understand each other, Damon has become indispensable. "It starts in the morning when he helps me get up," she said. Damon helps her get dressed by picking up things she drops, also by pulling on sleeves of sweaters or shirts she is taking off. With weak fingers from IBM, Mary Anne appreciates him helping her pull her pants up. "He literally takes the waistband in his mouth." After Mary Anne feeds him, they both go outside. "We have a large property with several levels," she said. "But he will sit down and wait for me to say 'go' before he takes off."

Once Damon is exercised, Mary Anne lies down again for a while, Damon beside her. Whatever has to be done during the day, he accompanies her. "I really like the fact that when we're out in public, he becomes the focus of people's attention, rather than me," she said. People are not encouraged to pet service dogs, and that's an important part of ongoing training and discipline. "When dogs are working, they need to keep their focus." Mary Anne said her extended family respects this wish, and they also love what Damon has done for her.

Damon knows how to open the sliding glass doors and he could potentially get help if Mary Anne fell. "That's tricky," she said. "He's trained not to bark and not to leave me, but in order to get help he'd have to do one or the other."

There's a certain amount of anxiety involved in living with a chronic disease, Mary Anne said. "Damon calms me. When I know he's there, I feel more peaceful. I can actually feel my blood pressure go down."

Damon knows 65 basic commands, plus the extra commands Mary Anne and he have worked out. That doesn't even begin to describe what he does in her life, though, she said: "I could give you a list of the useful things he does, but what he does for my soul is worth a lot more."



Would a dog help you?

If you are a veteran

The Veterans Administration supports service dogs to veterans with mobility problems as long as they help in the management of the problems. The benefits include assistance with veterinary care, travel associated with obtaining and training a dog, and the hardware required for the dog in his work of assisting the veteran.

Will your dog have specific jobs?

Because of the high demand for service dogs, the expense of training, and the number of people waiting for dogs, it's important to prove that a dog will have a substantial role in your life. Discuss this with your health professionals. Do they agree that you are legally disabled (under the ADA guidelines) and that you need a service dog? You will need their support to get the medical documentation needed for a training program. The dog must actively do jobs you cannot do for yourself.

Is a dog realistic in your situation?

Do you have the facilities and financial resources for a service dog? Are you able to care for the dog yourself? These are important considerations.

Find financial help

The IRS considers service dogs to be durable medical equipment just like wheelchairs for people with physical disabilities. You can include in medical expenses the costs of buying, training, and maintaining a service dog. In general, this includes any costs, such as food, grooming, and veterinary care, that maintain the health and vitality of the service animal so that it may perform its duties.

A variety of charities and foundations offer help with the initial expenses involved in finding and training a service dog. Some are listed below:

- Assistance Dogs United Campaign: <http://www.assistedogunitedcampaign.org>
- Pet Partners: <http://www.petpartners.org>
- Planet Dog Foundation: <http://www.planetdogfoundation.org>
- Gaias Dogs: <http://gaiasdogs.bravesites.com>

These agencies have limited funds and some are for specific patient groups and geographical regions. They recommend also that you look in your area for help from civic organizations, charities and churches.

Alexander Technique, from page 7

Dennis has changed his habitual reaction to the fear of falling — holding on with more and more effort and tension — and learned to do less. This has been the key to finding balance, stability, energy, and more full and efficient breathing. What is more fundamental to life than efficient breathing?

Dennis' new ability to move with less effort and unnecessary tension has resulted in more energy, a precious commodity for him. One day he told me of a recent visit to the Mayo Clinic, a huge complex with a labyrinth of tunnels connecting all the buildings, miles of halls to traverse from one appointment to the next. Dennis had recounted in past lessons that these

marathon visits to the clinic were very taxing. This time, however, Dennis reported that as he walked the long passageways he was not constantly looking for the next chair because he had more energy—yet another reminder of the profound effect of doing less. This was such wonderful news! More energy and more confidence is just what Dennis needs to continue to live the full life he wants to lead.

Lauren Hill is an Alexander Technique teacher certified by AmSAT (American Society for the Alexander Technique). She has been teaching in St. Paul, Minnesota since 2003.

Dennis Chada is a retired 62-year old man of pleasant demeanor who

spent the last 30 years of his working life as a mechanical inspector for the City of St. Paul, Minnesota. Dennis enjoys photography, writing, travel, and visiting casinos to play blackjack. Dennis hopes his often rigid posture does not lead to rigidity in his thinking! For more information on the Alexander Technique visit: AmSATonline.org or AlexanderTeachingStudio.com.

Support groups share strategies, expand, educate

by Charlia Sanchez, TMA Member Services Coordinator

More than 400 people attended this year's Annual Patient Conference in Reno. Early the first day, 40 members attended the KIT session, the "Workshop on Building Support Groups." TMA hosts conference calls for KIT Leaders several times a year, but this unique meeting allows the leaders to put faces with familiar names, seek out advice and offer suggestions as they do in local meetings.

Representing 12 support groups, several leaders and interested members asked general questions about member retention and expansion, fundraising, and the logistics of actually meeting and keeping in touch outside the meetings. TMA KIT leaders also took this annual opportunity to discuss specific issues such as finding speakers, what to include in newsletters and how often to have a meeting.

Seasoned leaders told the group that the answer to many of the questions is to improve the meetings themselves. This is crucial to keeping members involved in the support group and eager to return. They offered some suggestions for making sure that selected speakers and presentations for support group meetings are interesting and informative:

- View the list of potential types of speakers provided by TMA and take suggestions from members about their interests
- Use speakers from TMA's medical advisory board
- Always have a speaker or presentation that people can relate to

- Plan ahead and stay in touch between meetings

- Offer other activities such as door prizes



- Have a special welcome package for first time meeting attendees

- Include multimedia presentations, visuals and handouts for members

- Send newsletters or minutes to TMA and to members so everyone knows what took place at previous meetings

- Have some social time before or after meetings

- Stick to a schedule

- Plan your space, keeping in mind location and accessibility

- Host occasional conference calls for members in the area who are not able to attend meetings

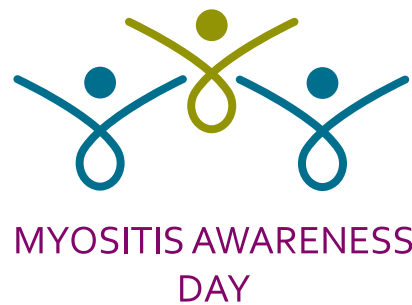
Most leaders agreed that hosting meetings on a quarterly schedule is sufficient for their group's needs. Some groups take a more ambitious approach and meet monthly. There is no single best way to run a meeting. Rather, it's important that leaders tune into the specific needs of their members and plan their support groups accordingly.

The conference session ended with a challenge to everyone present to take as much information as possible back to their groups, family, friends and peers to help TMA support those with myositis.

The KIT Leadership Manual

Leadership skills strengthen support groups. To help KIT leaders, TMA has assembled a Leadership Manual. This guide outlines the importance of the support group, the role of the leader, TMA's role and responsibilities, inspirational leadership stories, expectations and case studies. The guide includes tips for improving support groups, making sure that each one is able to meet the unique needs of its members.

Leadership Manuals are available upon request by contacting TMA by email or phone. They are for support group leaders or those who sincerely intend to start a support group in their community.



Myositis Awareness Day

Following the Annual Patient Conference, TMA promoted Myositis Awareness Day efforts across the nation. Efforts among the support groups included reaching out to local news stations and newspapers, getting Myositis Awareness Day proclamations from local government, and hosting special events and information tables in their neighborhoods to bring more attention to the disease. Some highlights:

- Tom Smith (Central FL KIT) was featured in the "Villages Daily Sun" newspaper.
- Cheryle Miller (GA KIT) was featured in "The Walton Tribune" newspaper.
- Stanley Prather (NM, TX Northwest) set up an information table in Albuquerque at the New Mexico State Fair and did an interview for his local morning news station.
- Sal Negron (Long Island, NY) organized a Jeans Day Benefit at Katten Muchin Rosenman LLP.
- The Bolgers (Colorado KIT) arranged for the 2nd Annual Picnic in the Park Myositis Awareness Event.
- Rose Mary Istre (Houston, TX KIT) organized a fundraiser with Kroger Grocery Stores.
- Marianne Moyer (SW Florida KIT) organized the "Text to Donate" Fundraiser during the month of September.
- Nancy Cannon (Carolinas) helped to get a proclamation recognizing

Myositis Awareness Day in South Carolina.

Several others hosted events and held fundraisers to spread awareness about myositis, or made plans to continue working for awareness throughout the year.

Shortly before the Annual Patient Conference, TMA sent informational materials to nearly 2,000 physicians nationwide and packages of awareness materials to all support groups so they in turn could share information with the general public.

The Virtual KIT

The virtual KIT provides a support group for members not living near a physical KIT, via conference calls set up on weekends. There will be a myositis patient helping to facilitate the calls, and topics for discussion will be decided in advance. There was a phone call for dermatomyositis patients on November 1. The polymyositis conference call will take place in December, and there will be a call in January for inclusion-body myositis patients.

New support groups forming

In the last year, KITs have formed in several places:

- Carolinas
- New England
- Pacific Northwest
- Eastern PA

In the upcoming year, the following KITs will also form:

- Southern New Jersey
- A subgroup in New York City
- A subgroup in Georgia, northwest of Atlanta

Our Canadian membership continues to expand and is gaining momentum. The Canadian support network is currently being led by Keith Tarrant. As he is working hard to establish a myositis community out of Ontario, another group of myositis patients led by Barb Romaniuk hosted a couple meetings in the western region of Canada in Alberta. To stay informed about the progress of Myositis-Canada, visit the discussion board on

the Community Forum in English or French and also check the Facebook page, "Myositis-Canada."

For more information about any of the items discussed here, contact TMA by email at tma@myositis.org or call 1-800-821-7356.



It's in the mail!

Myositis Awareness Day mailings designed to heighten awareness

As part of the observance of Myositis Awareness Day September 21, and with the support of Mallinckrodt Pharmaceuticals, TMA sent packages to physicians with materials for their own reference as well as for their myositis patients. Nearly 2,000 physicians received these materials:

- 1 copy "Myositis 101," a publication for patients
- 1 copy "A Physician's Guide to the Inflammatory Myopathies," a TMA publication for physicians
- 1 office myositis awareness poster with TMA referral pad attached
- 1 spare TMA referral pad
- 10 copies of each of the 5 myositis disease brochures

Leaders of TMA's 45 support groups also received materials designed to help them educate the public on Myositis Awareness Day and every day in their communities:

- 25 copies of "Myositis 101"
- 50 copies of "A Physician's Guide to the Inflammatory Myopathies"
- 100 copies of each of TMA's disease brochures
- 50 myositis awareness car magnets
- 300 myositis awareness wristbands
- 50 copies of "The Myositis Advocate"
- 20 win pins – a flashing pin designed to get people to ask about myositis
- 1 myositis awareness banner to be used at an event to draw the public's attention to myositis

TMA, with the help of Mallinckrodt Pharmaceuticals, has published a special newsletter, "The Advocate." If you want some ideas for advocacy and publicizing myositis on Myositis Awareness Day or any day, email TMA, tma@myositis.org.

TMA's medical advisory board

Two new members have joined TMA's medical advisory board and two former members have returned.

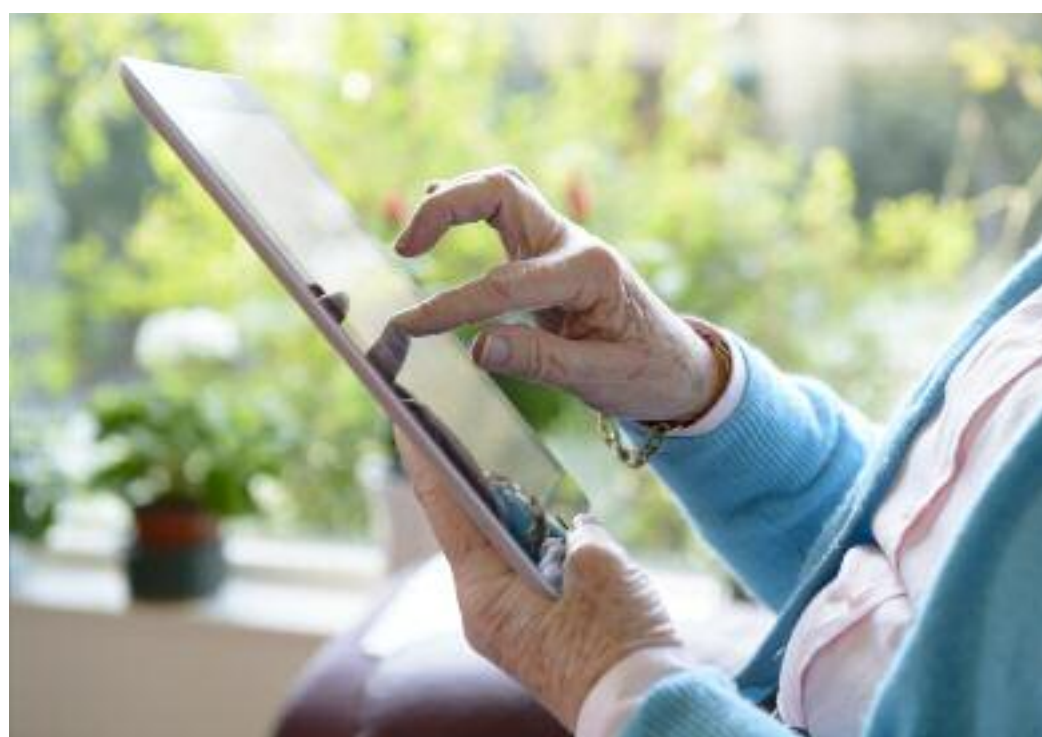
Neil McHugh, MD, is a rheumatologist and directs research and development for the Royal National Hospital for Rheumatic Diseases in Bath in the United Kingdom. Dr. McHugh is new to the board.

Margherita Milone, MD, PhD, a neurologist, is a consultant in the Department of Neurology, a professor of Neurology and the director of the Neuromuscular Medicine Fellowship, Department of Neurology, Mayo Clinic, Rochester, Minnesota. Dr. Milone is new to the board.

Steven Ytterberg, MD, a rheumatologist, is an associate professor of medicine, department of Rheumatology at the Mayo Clinic, Rochester, Minnesota. Dr. Ytterberg is returning to the board.

Kanneboyina Nagaraju, DVM, PhD, an immunologist, is tenured professor of Integrative Systems Biology and Pediatrics, The George Washington University and associate director, Research Center for Genetic Medicine, Children's National Medical Center, both in Washington, DC. Dr. Nagaraju is returning to the board.

Find names and contact information for TMA's medical advisors by going to www.myositis.org; scroll to the bottom of the page and click on "About Us" and then click on "Medical Advisory Board".



Conference captured in video, slides & live broadcasts

Below is a comprehensive record of the 2014 Annual Patient Conference. To find the sessions listed below, follow the link from the front page of TMA's website, www.myositis.org. For your convenience, the sessions are arranged according to a number of different categories.

What we can't capture here is the interaction that goes on at the Annual Conference outside the meeting rooms. Those who attend come together informally at meals and breaks to share stories, trade ideas, laugh and renew friendships. Plan to join TMA next year in Orlando for the 2015 Annual Patient Conference, September 10 to 13!

Especially for caregivers

- Caregivers panel - moderated by Dr. Amy Wood (live broadcast)
- Chronic illness and caregiving: ten lessons in ten years - Bruce & Kathy McIntyre (slides)
- Graceful transitions for caregivers - Bruce McIntyre (slides and video)
- Insights from an IBM caregiver and nurse - Nancy Harber (video)
- Finding balance - Dr. Teena Cahill (video)

Especially for those newly diagnosed

- Myositis 101 - Dr. Mark Gourley; Dr. Robert Wortmann (slides)
- Finding reliable information - PM patient Bill Simeral (slides and video)
- Finding strength through faith - TMA Board of Directors Chair Augie DeAugustinis (slides)

- Maintaining balance when your life is out of control - Dr. Amy Wood (slides)
- Questions and answers about prednisone - Dr. Mazen Dimachkie (video)
- Nutrition for inflammatory disease - Dr. Renee Lantner (video and slides)
- Reports from TMA's Medical Advisory Board (live broadcast)
- Meet the TMA Board of Directors (video)

Emotional issues

- Caregivers panel - moderated by Dr. Amy Wood (live broadcast)
- Chronic illness and caregiving: ten lessons in ten years - Bruce & Kathy McIntyre (slides)
- Graceful transitions for caregivers - Bruce McIntyre (slides and video)
- Insights from an IBM caregiver and nurse - Nancy Harber (video)
- Finding balance - Dr. Teena Cahill (video)
- Finding strength through faith - TMA Board of Directors Chair Augie DeAugustinis (slides)
- Maintaining balance when your life is out of control - Dr. Amy Wood (slides)
- Laughter yoga - Sheralee Beebe (video)
- Martial arts, focus and my healing path - Zachary Lewis (slides and video)

Myositis medications

- Questions and answers about prednisone - Dr. Mazen Dimachkie (video)
- Evolving uses of IVIG in myositis treatment - Dr. Rositza Chichkova (slides)
- Reports from TMA's Medical Advisory Board (live broadcast)

Complications

- Overlap syndrome - Dr. Christina Charles-Schoeman (slides and video)
- Lung disease - Dr. Dana Ascherman (slides and video)
- Dysphagia - Dr. Todd Levine (slides and video)
- Autoimmune diseases and infections - Dr. Marvin Lauwasser (video)
- What your autoantibodies tell us about your disease - Dr. Mark Gourley (slides)

Complementary approaches

- Martial arts, focus and my healing path - Zachary Lewis (slides and video)
- Nutrition for inflammatory disease - Dr. Renee Lantner (video and slides)
- Laughter yoga - Sheralee Beebe (video)
- Finding strength through faith - TMA Board of Directors Chair Augie DeAugustinis (slides)

Movement for all

- Classroom introduction to water therapy - Sheralee Beebe (slides)

- Laughter yoga - Sheralee Beebe (video)
- Martial arts, focus and my healing path - Zachary Lewis (slides and video)
- New approaches to exercise - Dr. Helene Alexanderson (slides and video)
- Lessons from the children - Dr. Sue Maillard (slides and video)

Especially for those with IBM

- Insights from an IBM caregiver and nurse - Nancy Harber (video)
- Dysphagia - Dr. Todd Levine (slides and video)
- Classroom introduction to water therapy - Sheralee Beebe (slides)
- Aging in place - Katherine Falcone - (slides and video)

Especially for those with PM and DM

- Evolving uses of IVIG in myositis treatment - Rositza Chichkova (slides)
- Lung disease - Dr. Dana Ascherman (slides and video)
- Overlap syndrome - Dr. Christina Charles-Schoeman (slides and video)
- Promising research - Dr. Lisa Christopher-Stine (slides and video)
- Questions and answers about prednisone - Dr. Mazen Dimachkie (video)
- Autoimmune diseases and infections - Dr. Marvin Lauwasser (video)
- What your autoantibodies tell us about your disease - Dr. Mark Gourley (slides)

Understanding the disease

- Myositis 101 - Dr. Mark Gourley; Dr. Robert Wortmann (slides)
- Finding reliable information - PM patient Bill Simeral (slides and video)

- Clues from the environment - Dr. Mark Gourley (slides and video)
- What your autoantibodies tell us about your disease - Dr. Mark Gourley (slides)

Resources for myositis patients

- Resources for veterans - Bob Greene (slides)
- Building strong support groups - Marianne Moyer and Charlia Sanchez (video)
- Aging in place - Katherine Falcone (slides and video)
- Finding reliable information - PM patient Bill Simeral (slides and video)
- Working with a service dog - IBM patient Mary Anne Hunt-Valencia (video)

Inside The Myositis Association

- Building strong support groups - Marianne Moyer and Charlia Sanchez (video)
- Reports from TMA's Medical Advisory Board (live broadcast)
- Welcome to the 2014 Conference - TMA Executive Director, Bob Goldberg and TMA Board of Directors Chair, Augie DeAugustinis (video)

- Meet the TMA Board of Directors (video)

All videos

- Aging in place - Katherine Falcone
- Autoimmune diseases and infections - Dr. Marvin Lauwasser
- Building strong support groups - Marianne Moyer and Charlia Sanchez
- Caregivers panel - moderated by Dr. Amy Wood (live broadcast)
- Clues from the environment - Dr. Mark Gourley
- Finding Balance - Dr. Teena Cahill
- Finding reliable information - PM patient Bill Simeral (slides and video)
- Graceful transitions for caregivers - Bruce McIntyre
- How to get the most out of TMA's Annual Patient Conference - TMA Executive Director Bob Goldberg
- Insights from an IBM caregiver and nurse - Nancy Harber
- Laughter yoga - Sheralee Beebe
- Lung disease - Dr. Dana Ascherman
- Martial arts, focus and my healing path - Zachary Lewis

See Conference, page 17.

About the videographer

The expanded video record of TMA's Annual Patient Conference is the work of Michael Peck, a TMA member from Ben Lomond, California. Mike has polymyositis with the antisynthetase syndrome and makes frequent trips to NIH as well as Stanford University Hospital. His myositis has ranged from serious disability to remission, with the troubling side effects and complications of his form of PM. He has also worked as a caregiver, first for his mother and later with older Parkinson's disease patients. As he gets stronger, he hopes to resume a project documenting Cuban musicians and dancers.

Mike was an early video pioneer who studied film and production at Santa Cruz and the College of San Mateo, and was one of the first to videotape weddings and other events in the 1970s. We are glad to have his help in bringing you a visual record of the Conference.

2014 Live Online Discussions

Several times a year, TMA offers live online discussions as a service for TMA members. The discussions are organized around subjects suggested by TMA members and feature members of TMA's medical advisory board and other experts. For those who have never participated, it's easy, and you don't have to be a computer whiz to ask your question. Simply go to www.myositis.org, and find "live discussions" under "My TMA."



feel free to suggest any topic of interest to you by emailing TMA@myositis.org.

As each discussion approaches, we'll let members know, via email, Facebook posts and home-page reminders. If you see you're unavailable at the time of the discussion, there's the option of leaving your question in advance. The medical professionals answering questions will pick the questions of most general interest and answer them during the discussion. If you can join TMA during the actual discussion, you can ask your question simply by typing it in the specified box. That's it! Shortly after the discussion a transcript will be found online with names removed for your privacy. TMA's experts try hard to answer every question that's not a duplicate.

Please take the time to look through the short summaries below for topics of interest to you, and read the whole transcripts of the six 2014 Live Discussions on TMA's website. Please

Understanding Autoimmunity - Dr. Tahseen Mozaffar, director of the Neuromuscular Center at UC Irvine Medical Center

Dr. Mozaffar answered questions about the connection of autoimmunity with risk factors, celiac disease, statins, fungal infections and hormones. He also responded to questions about treatment with stem cells, prednisone, plaquenil and physical therapy; and responded to the "cleanliness" theory of autoimmunity.

Autoantibodies - Dr. Mark Gourley, Washington, DC rheumatologist, researcher in myositis studies at the National Institutes of Health

Dr. Gourley answered questions about myositis syndromes, lung disease, amyopathic dermatomyositis, CPK levels, the body's response to toxins, and statins. He also explained why

autoantibodies can change and why scientists are unsure if they are a result or a cause of autoimmune disease.

Exercise - Dr. Helene Alexanderson, Division of Physical Therapy at Karolinska Institute in Sweden

Dr. Alexanderson fielded questions about exercising on a treadmill, using light and heavy weights and how often to exercise. She explained the impact of exercise on muscles both while in a flare and in remission, and suggested that exercise at appropriate levels can benefit people in almost every stage of muscle disease.

Rituximab - Dr. Rohit Aggarwal, Assistant Professor of Medicine and the Education Coordinator for the Rheumatology Division of the University of Pittsburgh Department of Medicine

Dr. Aggarwal answered questions about timing of rituximab treatment, its compatibility with other drugs, problems with infusion, its expense, and individual indications that rituximab might work. He also wrote about the large Rituximab in Myositis trial and its overall positive results.

Prednisone - Dr. Mazen Dimachkie, University of Kansas Medical Center, director of the Neuromuscular Section

Dr. Dimachkie explained the uses and side effects of prednisone and answered questions about tapering and drug interactions. He touched on the use of prednisone in IBM and answered your questions about a "safe" maintenance dose.

Current trials, from page 3

compared to placebo in active DM patients and to determine the minimum dose required for a maximal clinical effect. Domestic centers are now recruiting in California, Arizona, Miami, Massachusetts and Kansas, with more domestic and international centers to open. To be seen at any center, call Novartis Pharmaceuticals, 1-888-669-6682.

Look for updates at www.clinicaltrials.gov for all active studies. Remember to click on "Contacts and locations" to see the drop-down list. Several of these trials are opening new centers.

Follistatin, from page 5

At TMA's Annual Patient Conference, Dr. Zarife Sahenk, Director of the Clinical and Experimental Neuromuscular Pathology laboratory at Nationwide Childrens, confirmed that the other patients in the study also showed improvement in their timed walk, although not as dramatic as Augie, who walked 149 meters further at six months than at baseline. One patient walked 62 meters farther, she said, and the third walked 23 meters farther.

Conference, from page 15

- New approaches to exercise; Lessons from the children - Drs. Helene Alexanderson, Dr. Sue Maillard (slides and video)
- Overlap syndrome - Dr. Christina Charles Schoeman
- Questions and answers about prednisone - Dr. Mazen Dimachkie
- Reports from TMA's Medical Advisory Board (live broadcast)
- Welcome to the 2014 Conference - Bob Goldberg and Augie DeAugustinis

Myositis and infection

In a study published online in *Arthritis Care and Research*, infections were found to be the leading cause of in-hospital death among patients with dermatomyositis and polymyositis.

Among more than 15,000 hospitalizations between 2007 and 2011 for patients with these two conditions, infections were the main predictor of inpatient death, according to Sara G. Murray, MD, of the University of California, San Francisco, and colleagues. Mortality was strongly associated with bacterial infections, particularly pneumonia and bacteremia. Previous small studies have suggested that infections cause considerable morbidity in dermatomyositis/polymyositis, but population-based studies have not yet assessed the true burden or the contribution to mortality.

Murray and colleagues analyzed data from the Healthcare Cost and Utilization Project Nationwide Inpatient Sample, which represents about 20% of U.S. hospital discharges. The 15,407 hospitalizations for patients with dermatomyositis/polymyositis were compared with a random sample of hospitalizations among patients without these disorders, which included 27,990 patients.

Disease factors and comorbidities other than infection that were associated with mortality were interstitial lung disease, malignancy, and cardiovascular disease.

Dr. Marvin Lauwasser, an infectious disease specialist and a member of TMA's Board of Directors, made a presentation at TMA's 2014 Annual Patient Conference on autoimmune diseases and infection. Find the video and all the Conference videos linked from TMA's home page, www.myositis.org.



LIFT YOUR LIFE TOWARD INDEPENDENCE

FREEDOM Chair Battery-powered chair lift
 • From sitting to standing in home, office, etc.
 • Comfort and style for use anywhere

STAND AID
 YouTube Product Videos on Our Website
 Ask about our 30-Day Return Guarantee

POWER TOILET AID
 Battery-powered toilet seat lift
 • Perfect for those with muscle weakness
 • Standard or mobile models available
 • Lifts straight up; no forward push


Manual or battery-powered lift >
 • Rehab facility model with power height adjustment available
 • No transfer required! Stand while directly lifted from wheelchair
 Standing program provides many physical and psychological benefits

For information and a FREE demo video **800-831-8580**
www.stand-aid.com **sales@stand-aid.com**

MedPro Rx, Inc.
 Specialized Pharmacy Services
 Your IVIg and SCIg Specialists
www.medprorx.com
 phone (888) 571-3100 fax (800) 582-9315

- MedPro Rx,™ Inc. Provides:**
- Specialized care of patients with neuromuscular conditions, primary immunodeficiencies and rheumatologic disorders
 - Personalized delivery of all available IVIg products & ancillary supplies
 - Communication and coordination with your physician or clinic
 - Home infusion guidance with nursing support
 - Physician office and infusion suite IVIg support programs
 - Medicare D IVIg support initiatives
 - Coordination with insurance coverage, claims and reimbursement
 - Patient education and advocacy support programs
 - Access to clinical pharmacist 24/7

NO MATTER WHERE YOU ARE, WE ARE THERE FOR YOU!

ACCREDITATIONS


Together we can help ensure Lisa's story has a beautiful outcome

98% rate of incident-free infusion encounters™



Lisa—28 years old, IG infusion patient
 Photographer, favorite subject: her son

Walgreens Infusion Services

is Proud to Be a National Sponsor of The Myositis Association

Walgreens is a national leader, providing unmatched safety outcomes for home-based IG patients with autoimmune disorders, such as Myositis. Our patient-centered care, offering all brands of IG, focuses on education and communication.

Comprehensive support for IG therapy is provided by our expert staff of pharmacists, nurses and reimbursement specialists, who closely monitor patient's tolerance and response to therapy.

Walgreens is proud to be a partner in providing home IVIG therapy for Myositis patients.

For additional information on immunoglobulin therapy:
 Phone: (877) 974-4844 Fax: (877) 974-4845

Outlook topics

If you subscribe to the print copy of the "OutLook," remember that digital copies of current and past TMA newsletters are available to you online. Go to www.myositis.org, then "Community," then "My TMA." For your convenience, here are the topics covered in recent issues:

Alexander technique... Winter 2014

Aquatherapy..... Fall 2014

Betty Curry remembered..... Fall 2014

BYM338... Winter 2014, Spring 2014

Creativity eases pain, improves concentration... Fall 2014

Follistatin... Winter 2014

Gardens... Spring 2014

Heart risk... Spring 2014

Katherine Falcone... Spring 2014

KIT training at Conference... Winter 2014

New board members... Spring 2014

New beginnings for KIT... Spring 2014



New medical advisory board members... Spring 2014

New PM, DM drugs... Spring 2014

PM, DM research... Winter 2014

Prayer... Spring 2014

Privacy.... Spring 2014

Reports from Annual Patient Conference... Winter 2014

Rolling Back... Spring 2014

Service dogs... Winter 2014

Support for siblings... Fall 2014

Toilet troubles.... Fall 2014

Trials, treatments and discussions Fall 2014

Virtual support groups... Fall 2014