

The Outlook

SPRING 2014

Quarterly Newsletter



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Published by: TMA, Inc.

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Privacy a promise to TMA members

Your privacy and the protection of your personal health information has always been a high priority at The Myositis Association. With the increasing concern about protecting an individual's personal information, I thought it might be useful to reassure those who are members of TMA or use our online bulletin boards -- the Community Forum -- that TMA does not share your personal information with any entities outside of TMA.

For those who participate in TMA's support groups around the country, only those support group members who have agreed to allow their information to be shared with other myositis patients are listed as support group members and are able to access the contact information of other support group members.

TMA never shares the names or contact information of our members involuntarily with any corporate supporters of TMA so that you do not receive unwanted solicitations from our corporate partners.

Respect for your privacy is a high priority at TMA.

We also ask that you respect others who have myositis. Our online bulletin boards are an opportunity for those who have myositis to share their knowledge and experiences with others who face similar challenges in coping with the disease. While the Community Forum can be a source of useful information, it is important to remember that the information posted is not "vetted" by TMA or our Medical Advisory Board. The information should be viewed as one person's opinion and not necessarily sound medical advice.

We also ask that those using the Community Forum not engage in any personal attacks or abusive language. TMA provides the Community Forum as a place to freely exchange information and opinions. However, if someone abuses this opportunity by insulting others or using the Forum for personal financial gain, TMA will bar that person from the Forum.

We are here to help people connect with others who have myositis and to learn about their disease. We have added two new bulletin boards focused on Caregivers and Veterans. We will continue to grow the organization to better serve you, and we will remain vigilant to ensure that your privacy and dignity is always respected.



Bob Goldberg
Executive Director
The Myositis Association

Meet TMA medical advisors and board of directors at TMA's Annual Patient Conference, Sept. 4-7 in Reno!

New members join TMA Board of Directors in 2014

Dale Scott, a polymyositis patient, now works as a budget analyst for the Commonwealth of Pennsylvania after working as an administrator in private industry for 28 years. She is a long-time volunteer -- often at the board level -- for a variety of civic, arts and charitable organizations.

Christopher Dotur, who has a hereditary form of myositis, recently retired from active duty with Global Operations for the United States Air Force, where he served in increasingly strategic positions. He is also a published author, a project manager, and the CEO of a private corporation.

Carla Wood Stevenson, an IBM caregiver, is the owner of Bay Tree Designs, a business she established after many years as a successful businesswoman in both design and event production. She has worked as a volunteer leader in the arts, education and social justice.

Marvin Lauwasser, MD, is recently retired from private practice in Wisconsin. Dr. Lauwasser, an IBM patient, has a subspecialty in infectious disease and has written about the inflammatory response in connection with acute infection and also has an interest in its role in autoimmune disease.

The TMA Medical Advisory Board adds five members in 2014

Rohit Aggarwal, MD, MS, is Assistant Professor of Medicine in the Division of Rheumatology and Clinical Immunology, the Medical Director of the Arthritis and Autoimmunity Center; and the Co-director of the Myositis Center at the University of Pittsburgh Medical Center.

Helene Alexanderson, PhD, is a registered physical therapist at the physical therapy clinic at Karolinska University Hospital in Stockholm, Sweden. Dr. Alexanderson is also an author and co-author of many studies relating to myositis and exercise as well as a lecturer at Karolinska University.

Mazen M. Dimachkie, MD, FAAN, is professor of neurology, director of the neuromuscular disease program and director of the electromyography laboratory at the University of Kansas Medical Center. Dr. Dimachkie has authored and co-authored many myositis studies.

Ann M. Reed, MD, is a consultant with the division of rheumatology, department of internal medicine and the departments of pediatric rheumatology and pediatric and adolescent medicine, a professor of pediatrics, and co-director of the Mayo Clinic Children's Center at the Mayo Clinic in Rochester, Minnesota.

Ruth Ann Vleugels, MD, MPH, is the Associate Director for Education, Director of the Connective Tissue Disease Clinic; and Course Director of the DM-Rheumatology course for Brigham and Women's Hospital and directs the DM-Rheumatology course for Harvard Medical School.

Contact TMA boards

Reach medical advisors for consultation: www.myositis.org. Then go to the bottom of the page and click on About TMA, then, Medical Advisory Board.

Contact board of directors: www.myositis.org. Then go to the bottom of the page and click on About TMA and Board of directors.

Gardening for people with weakness, disability, pain, and loss of mobility has gotten a lot of attention from occupational therapists recently, and found to be very helpful both for strengthening muscles and fostering a positive outlook. In fact, there's a new phrase used to describe gardening when undertaken for these reasons: "horticultural therapy."

For most people, though, the motivation for gardening is the same as it was before their diagnosis: to beautify their

weight and comfort. Choose well-balanced lightweight tools to help prevent stresses and strains in your hands and arms. Find the best way for you to carry your tools, using a garden cart, wheelbarrow, tool carrier, bucket, or a tray or basket attachment if you use a wheelchair. A garden cart with an aluminum frame allows you to carry long tools and hand tools as well as a refuse sack. Carry hand tools in a tool belt, apron or bag, whatever you find easy.

How does your garden grow?

Gardening for exercise, fun, and a rewarding harvest

surroundings, connect with nature, enjoy the harvest and spend some time moving around in the fresh air. It's a plus that gardening also provides multiple benefits for muscles and state of mind. And occupational therapists say gardeners are more likely to stay physically active than those who go to a gym or work out at home. Why? Because they're doing what they like rather than "exercising."

There's another reason why gardening is more rewarding than individual exercises, says Lauren Catlett, whose job involves planning projects for aging and disabled adults: "Connecting with nature is important, and it's often a major loss as people become more disabled," she said. "Any exposure to the outside or to growing things is beneficial emotionally as well as physically."

Getting started

"Carry on Gardening," a service of "Thrive," an international non-profit devoted to the quality of life for people with disabilities, has some ideas you can use to get started. Actually, some of the ideas are worth considering BEFORE you start. Think about the job you're going to do and plan what will make it easier for you. It might be as simple as making sure you have a kneeler with you to save your knees, or a stool or seat to work from to take rests.

The right tools. Make sure you choose the right tools for the job. Try out tools before you buy them and check for

Pace yourself. Stop work before you get too tired, and be sure to take breaks. You might find it easier to move your equipment around the garden in relay fashion, taking your chair out first, then your tools. Hand rails and resting places can ease the strain of moving around the garden. Also, make sure that your paths are even and have a non-slip surface. If you find it difficult to carry things, you might want to carve out a garden near the house or the place you keep your gardening equipment. TMA members Nicole and Mo Bolger of Colorado engineered a slow but effective method for removing dirt from trenches or other building projects. Rather than filling a huge (and heavy) gardening bag, Mo simply doubles plastic grocery bags and fills them with dirt, easily carried and removed.

From a wheelchair. If you can transfer, choose a seat to work from that is comfortable to use, and stable. Some gar-



den kneelers can be used as a seat when turned upside down but make sure you place them on even ground. Rather than move a seat around everywhere, try to have permanent seating around the garden to work from as well. If you can't leave your wheelchair, re-think your garden layout to make it easier to work sitting down. Raised beds, containers, easy-reach trained fruit trees and replacing the lawn with hard surfacing are all ideas that can help.

Raised beds

As the world's population ages, raised beds are becoming popular as a universal solution to gardening for all ages. They're helpful as a way to improve soil, avoid erosion, outsmart small nibblers, cut down on weeding and allow people with impaired mobility to sit on the side while they perform gardening chores. Remember that straight-sided raised beds make it hard for people in a wheelchair, since they need to be able to lean over the bed; and that raised beds are likely to require more water.

The Bolgers have gotten very creative with raised beds, using four galvanized tubs—originally used for watering livestock—in their yard. They are 4' in diameter and 2.5' tall so they are easy to maintain from a seated position. The Bolgers attached these to their automatic watering system.

For smaller planters, Mo and Nicole also came up with the idea of using empty plastic bottles instead of rocks for drainage, eliminating many pounds from moveable pots and containers.

The Bolgers are fans of ergonomic tools to limit body strain. They like the Peta Easi Grip Arm Support Cuff that has a cuff which allows control of your work from your upper arm and shoulder.

Heidi Sibert suggested going with lightweight fiberglass or foam containers on your porch or patio for easy

access, picking a container half the height of expected growth, and adding lightweight potting mix.

Pick low-maintenance

For those who maintain a traditional yard despite disability, nurseryman Nick Murphy of Indiana has some suggestions for undemanding plants.

English ivy. It will spread on its own with no help from you. Make sure to trim it if it advances on your walk or up the walls of your house.

Hostas. Divide to get more once the plants get big. Otherwise, let them grow and spread.

Boxwood or yew. Simple and attractive, all they need is a yearly pruning, which you can even forget from time to time.

Hydrangea. Pick the blooms for renewed bloom each year, bringing the cut flower heads inside for long-lasting decoration. Be careful not to cut back varieties that produce blossoms on year-old wood.

"Knock Out" roses or lantana for drought-resistance. Both plants are disease-resistant, require little pruning and watering once they're established, and add a vibrant splash of color.

Get a grip

Sheila Minney suggests Bionic Garden Gloves for padding and grip. Find them at www.bionicgloves.com. Nicole Bolger likes Berkeley gloves, a brand she found at Walmart. The Bolgers also recommend grip tape, the tape most commonly used on hockey sticks. They add it to rakes, weeders and extension grabbers. It's cheap, removable, and you can find it in sporting goods stores.

Consider your hands

Occupational Therapist Patricia Stevens reminds us to pay attention to our hands, a major concern of myositis patients, especially those with inclu-



sion-body myositis. Stevens, a certified hand therapist, comments on the importance of pacing yourself in the garden.

To avoid damage from doing repetitive tasks, using the same muscles in the same way, Stevens recommends limiting this type of motion to 15 to 30 minutes at the most. "Then take a break," she says, "and stop for a few minutes or

See Garden, page 15.

DM Diagnosis changed direction of family business



Katherine promotes barrier-free living and uses her business to help people maintain their independence.

Dermatomyositis changed Katherine Falcone's life more than once. The first change, of course, was when she found out she had it. "I was lucky," she said, "I had the classic rash and it was quickly diagnosed." Katherine, a Philadelphia-area contractor, was referred to Thomas Jefferson Hospital, and said she received excellent care.

Prednisone was not for her: although effective, it caused a steroid myopathy; and Katherine's doctors recommended IVIG a couple of days a month, which remains the course she follows today.

However, it hasn't been all smooth sailing since then. A trial of rituximab was tremendously helpful but she had a bad reaction to this as well. A blood clot complicated her life, too. And running her family business did not allow her time off to rest. But all in all, Katherine forged ahead with her busy life, and "I considered myself lucky," she said.

The second change came when Katherine attended the 2012 Annual Patient Conference in Orlando. "I was sitting next to an older gentleman and his rash was very obvious. Also, I could tell he was very weak and just didn't feel well."

Katherine bought him a TMA t-shirt to cheer him up. "It made him smile, at least for a little while," she said. "That got me thinking. There must be something more I can do for people with myositis." Although Katherine's concern started from her empathy for individual patients like the man in Orlando, her larger goal was to do something more significant. She came up with a two-fold mission. "I wanted to offer something substantial and tangible to help people keep their independence," she said. "I also wanted to raise money for research into myositis."

Over the next year, she changed the major focus of her construction company, The SOS Group, to advise people about changes needed to keep them safe in their own homes, and trained her crews in this specialized renovation. To reach people outside the eastern seaboard, she added a product line for people with disabilities, available on the company's website. "We're all getting older," she said. "Even if you don't have a chronic disease, your abilities are going to change as you age." Katherine plans to donate a portion of each online sale to myositis research.

Along the way, she's become an expert and an advocate for barrier-free living. "Our motto is 'if it's predictable, it's preventable,'" she said. The SOS group has handled everything from completely gutting a house to simply adding some grab bars. She encourages people with myositis and other chronic diseases to take a careful look around them with regard to future as well as current abilities. "The



**Katherine Falcone, DM patient
and owner of The SOS Company**

percentage of emergency room visits due to falls is 60 percent in some hospitals," she warned.

Katherine noted a few sometimes-overlooked elements of barrier-free living:

- **Doorway width** - make sure the doors are wide enough for a wheelchair.
- **Kitchen cabinets** - there are ways to retrofit existing cabinets so the shelves can be pulled down easily. Check before replacing everything.
- **Lighting** - it's not worth it to skimp on lighting and cause a fall.
- **Visual aids** - it really helps to know where there's a step up or down. You can use different colors or strips to make sure you can always see when the level changes.
- **Stairlifts** - often overlooked, a lift for your stairway can make life a whole lot easier and is much less expensive than moving. "We can even install them in stairways that curve," she said.
- **Add a ground-floor room** - another option for people who would prefer to stay in their own home in a familiar neighborhood.

When The SOS Group calls on a potential client, they do a thorough assessment of what's needed, and guide their client through what may be future as well as immediate needs.

Employees are "certified aging in place specialists" (CAPS), a program monitored by the National Association of Homebuilders.

Katherine has some advice for those looking for a contractor in their region:

- **Look for CAPS credentials.** It's a national program. Have an overall plan before you start. Usually, an initial assessment is quite reasonable and avoids future problems.
- **Find out about subcontractors.** You'll want to know who will actually be installing the stairlift or shower.
- **Look for follow-up service for medical equipment.** You'll have more peace of mind if you know that the contractor or the manufacturer's representative will return to check on the installation.

Meanwhile, some advice from Katherine on what you may be able to accomplish yourself. Clutter is to blame, she says, for all kinds of accidents and falls. Keep corridors and stairways free, and allow for space in every room for devices. And don't forget suitable footwear, "Sometimes it can even be people wearing the wrong slippers that causes falls," she said. The SOS Group is developing a skid-free "shower shoe," treated with an anti-bacterial film, to promote shower safety.

Find out more about aging in place at www.sosgroup.info.

IBM drug BYM338

An article by Bloomberg News March 5 quotes Simon Moroney, chief executive officer of MorphoSys, the company that developed the drug BYM338 for Novartis. Moroney spoke at an investor event in Munich.

According to Bloomberg's report, Moroney said Novartis plans to ask regulators for permission to market the drug to treat sporadic inclusion body myositis as early as 2016.

The drug is currently being tested to also treat other illnesses, and the largest share of sales will probably be from ailments such as cachexia, the weight and muscle loss that's often found in patients with illnesses such as cancer and chronic obstructive pulmonary disease, Moroney said.

There are 36 study locations presently, including two locations that have begun recruitment in the United States. Those in the U.S. now recruiting are:

Neuromuscular Research Center
Phoenix, Arizona 85028
Contact: K. Sivakumar

Nerve & Muscle Center of Texas
Houston, Texas 77030

Contact: A. Shaibani

Other centers listed on www.clinicaltrials.gov as "not yet recruiting" are in Orange, CA; Sacramento, CA; Miami, FL; Kansas City, KS; Baltimore, MD; Boston, MA; Columbus, OH; Portland, OR, and Dallas, TX.

Those interested in being considered for recruitment at any domestic sites—whether presently recruiting or not—should call 888-669-6682. Although progress has been stalled for several months, some applicants in California have been sent the study protocol to consider whether they wish to be included.

Find sites in Europe, Asia and Australia at www.clinicaltrials.gov. To see the list in its entirety, click on the drop-down menu.

To help TMA track participation and provide accurate information on this historic study, we would appreciate knowing if you join the trial. TMA will continue to update its members on the trial status.



What does "improvement" mean to you?

In June, myositis investigators from all over the world will meet in Paris to develop improved myositis response criteria for use in future myositis clinical trials. In this session, the last of a number of such meetings, international myositis experts will hammer out a consensus. This is extremely important to researchers, who need some way to measure whether a particular drug or other treatment has indeed altered the disease course of those in the trial.

Researchers will reach an agreement on what constitutes clinically significant improvement, and, for the first time, set criteria for major clinical response for myositis. Researchers are also seeking comments from patients on what they would consider improvement and major clinical response. If you would like to make a comment, please email tma@myositis.org.

Heart risk examined in inflammatory disease

There's more evidence pointing to an inflammation-heart disease connection, say researchers at Brigham and Women's Hospital in Boston.

What's the connection? Inflammation makes the inner lining of arteries swell, researchers say, forcing the blood to flow through a smaller channel. The narrowed arteries in turn cause an increase in blood pressure and raise the risk of heart attack and stroke. Cholesterol, a major player in the sticky medium called plaque, further narrows arteries by clogging them with fat.

Arthritis Foundation-funded researcher Daniel Solomon, MD, and colleagues found that women with rheumatoid arthritis are twice as likely to have heart attacks as those who don't have the disease.

Another inflammation-blood pressure study indicates that a person's current level of C-reactive protein (CRP) – a key player in inflammation – can predict future high blood pressure development. In fact, the study's researchers suggest high blood pressure itself may be an inflammatory disorder.

Nor, says the report, can we go strictly by the accepted guidelines of 140/90 being the ideal blood pressure reading. Recently changed guidelines say that those people with prehypertension (a reading of 120 to 139 over 80 to 89) are at high risk of developing high blood pressure and should make some lifestyle changes, like quitting smoking, exercising more and losing excess weight.

Rheumatologists are also looking at their patients' total cholesterol with a more critical eye. More accurate than the total cholesterol test is one that measures its various components. Cholesterol is carried through the body by lipoproteins, and there are two basic types: high-density lipoproteins (HDLs) and low-density lipoproteins (LDLs). HDLs are the "good" type; they deposit excess cholesterol in the liver, where it is then metabolized out of the body. LDLs are the "bad" kind; they deposit cholesterol into the arteries.

Experts agree that the LDL level should be kept as low as possible. The standard target has been 100 mg/dL of LDL, but a recent study found significant benefit from driving LDL down into the 60s. HDL should be as high as possible. An HDL level below 40 mg/dL is considered a major risk factor for developing heart disease, so aim for an HDL level higher than 40 mg/dL for the best protection for your heart.

New drug in pipeline for DM, PM

In March, clinical stage biopharmaceutical company Idera Pharmaceuticals announced expansion of its pipeline into polymyositis and dermatomyositis.

The company plans to initiate clinical development of its major compound, called "IMO-8400," for the treatment of DM and PM patients, saying that these two "orphan autoimmune" diseases have high unmet clinical needs.

The company plans to submit a protocol to the US Food and Drug Administration in the first half of 2014 for a Phase I/II clinical trial to investigate the safety and potential utility of IMO-8400 for these two forms of myositis.

According to Idera's news release, this expansion represents the execution of a previously announced strategy to expand the clinical development of IMO-8400 in orphan autoimmune disease indications. Based on the results from this study, Idera anticipates that it will pursue separate later-stage clinical trials for each of these diseases.

Idera Pharmaceutical's senior vice president and chief medical officer Dr. Lou Brenner noted that the company's team of scientists, clinicians, and advisors has prioritized polymyositis and dermatomyositis among a wide range of orphan autoimmune diseases that may potentially benefit from the toll-like receptor (TLR) antagonist program.

"We are excited to explore the potential of IMO-8400 for the treatment of patients with these challenging conditions," Dr. Brenner said.

Idera's (TLR) antagonist platform is designed to inhibit over-activation of TLRs, which are implicated in diverse pathological conditions. IMO-8400, an antagonist of Toll-like receptors 7, 8, and 9, is currently being evaluated in a clinical proof-of-concept study in moderate-to-severe plaque psoriasis.

"Polymyositis and dermatomyositis are very challenging autoimmune diseases to manage, and currently there is a need for physicians to offer new treatments to patients suffering from these conditions," said TMA Medical Advisor Dr. Chester Oddis, Professor of Medicine, Division of Rheumatology and Clinical Immunology, University of Pittsburgh. "I am encouraged by the potential of this novel approach, which is targeted to a key disease driver and could represent a promising area of investigation for these life-impacting conditions."

TMA will notify members when trial recruitment begins.

Let us pray

by Andrea Taylor Langworthy

It doesn't seem right that someone should have to deal with more than one disease, one crisis or one life-altering situation at a time. A friend of mine had ovarian cancer. That's enough, right? It wasn't. She also had lupus. "Not fair," I say. The same thing I say when I hear someone has myositis and another illness, too.

At an appointment a few years ago, I told my doctor I had revised my opinion. It should be one "something" per family. I've got IBM so my husband should get a pass. After all, as my strength wanes, he will have to take over more and more. As it is, he does the shopping, runs the errands, fixes dinner and gets me to and from appointments.

It wasn't so many years ago that I did all that for myself. I was still working, still driving, still meeting friends for lunch. The only outward sign anything was amiss was my cane. Still, my need for it could have been misconstrued as a bum hip. Perhaps, a twisted ankle. Why should anyone suspect I had inherited a muscle-wasting disease from my father? Except for the walking stick in my right hand, I looked as healthy as the next person.

Even so, about seven years ago, as a friend and I stood in front of a counter at a Panera restaurant waiting for our orders, a woman rushed up to me and breathlessly proclaimed that she would carry my tray to the table. I thanked her and said it wasn't necessary. She persisted to the point of embarrassment. I gave in.

My friend and I had a lot to talk about. We had gone to grade school together and shared an apartment during college but hadn't seen each other

in a few years. As soon as we finished our soup and salad, we pushed aside our trays so we could finish chatting. Immediately, I felt a whoosh of air at my side.

It was the woman who had offered to carry my tray. She couldn't help but notice my cane, she said. Assuming she wanted to know where I purchased the coffee-colored walking stick with the curved tortoise-shell handle, I was about to say, "The Walking Company at the Mall of America," when she made her intention known. She wanted to pray for me.

I hoped she meant she would write down my name and get on her knees in the privacy of her home. Or put my name on a prayer list at her church. Even so, I squirmed in my chair. My mind filled with things to say. Not at the top of the list was, "Sure, go ahead. I'd like that."

I looked around, wondering who to foist her off on as she talked about a trip she and her husband had taken to another country where they had partic-

ipated in events that can only be described as healing extravaganzas.

She spoke of people throwing aside walking aids, one woman getting out of a wheelchair she no longer needed. As she went on, it became clear: she intended to pray for me right there—at the tall table next to the beverage dispenser in the crowded restaurant at lunch time. No doubt, she would want to place her hands firmly atop my head.

I began to resent her because sometimes, when I'm deep in conversation with a friend, it's like the good old days. I forget about the cane leaning against the chair next to me. Forget I might need to ask my friend to push open the heavy door to the ladies room for me. This woman brought me back to reality.

She mentioned her trip again. Spoke of bearing witness to hundreds of people being cured and throwing away their crutches. My lunch mate began chanting, "What have you got to lose? What have you got to lose?" My



brain began to do battle. One part said, "Exactly. What do you have to lose?" A second part answered, "Your dignity, that's what."

"Are you going to touch me?" I asked. When she said she didn't have to, my friend started up her litany of "What have you got to lose?"

The woman prayed quietly and when she asked that I be made well, I pictured myself casting the cane aside, kicking up my heels like Ginger Rogers and dancing my way to the parking lot.

Two-stepping, I'm not, but the experience made me think about the other people in the restaurant that day. How many of them have an invisible cross to bear? Heart disease, cancer, depression. Any one of them might be out of work or mourning the loss of a loved one.

If I were to come across that woman again, I would tell her I'm not opposed to prayer. In fact, quite often I have a silent conversation that begins with, "Please God." But I would advise her against picking and choosing the people she prays for based on outward appearances like canes or disfigurement.

"Everybody deserves a quiet prayer," I would say, "because everybody has something and some people have more 'somethings' than the rest of us."

Andrea Taylor Langworthy writes a periodic column for The OutLook about her experiences and observations as a patient. Andrea is a freelance writer who lives in Minnesota, where she and her husband lead the myositis "Keep-In-Touch" support group. Andrea has inclusion-body myositis.



A firsthand guide for IBM: Rolling Back

Do you ever wish you could go back in time and reach the younger you with advice that would have saved money, time and stress, had you only known it at the time? California inclusion-body myositis patient Mike Shirk does that in "Rolling Back," his thorough and thoughtful book for people with IBM. Those who are familiar with Mike's blog, "Life! Disabled," know that he meets situations with optimism and ingenuity, inventing solutions for problems as they come up and changing focus once one direction is no longer possible.

Of course, none of us, not even Mike, can go back and act on knowledge that we simply didn't have when we needed it. But those who are newly diagnosed will find clear-sighted guidance in this remarkable book, now available in digital form and paperback from Amazon.com.

Some of his advice is good for everyone: "If I could roll back time, my life would have turned out much differently," Mike writes. "I would have done a much better job of preparing for what lay ahead. I could have avoided being blindsided by changes I didn't see coming, traveled more and worried about money less, hugged my wife and children more, because I would have known there would come a day when I could not."

Other advice is more specific, with lots of concrete guidance for those with any disabling disease or injury. Mike's story is a little more complicated than most. He was diagnosed with inclusion body myositis in 1996, although he believes its onset was actually much earlier. Just as he was learning to adapt, his wife was diagnosed with myotonic muscular dystrophy, also rare and incurable, affecting her ability to walk and use other muscles. Within a short time of her diagnosis, both of them were in wheelchairs.

"Rolling Back" documents what Mike learned about independence and commitment; and what he continues to learn after the death of his wife last year. A word of caution: although Mike is upbeat, there's no denying that his experience has been particularly difficult. Although he never fails to make the best of it, he doesn't sugar-coat the reality that he, along with most IBM patients, is facing in the absence of better treatments and a cure.

Mike Shirk has been an athlete, a copywriter, a caregiver, an artist, a blogger and a videographer before becoming an author.





Keep In Touch

New Year, new beginnings

by Charlia Sanchez

The first few months of 2014 were extremely busy as TMA geared up to launch some new programs and services for our members.

Soon we plan to offer some of your favorite "Practical Solutions" (a popular quarterly feature in our newsletter) on our website. This will be a library of helpful tips, quick fixes, short articles and possibly some videos. We will need your help to put this together, so let us know what solutions interest you the most, as well as any handy fixes you may have.

We welcome any pictures, videos or articles from our members that are worth sharing so that other myositis patients can find something helpful that may work for them. Look for more information about this project in the "Practical Solutions" section of this newsletter, page 4.

Promoting Leadership

At the end of February, TMA hosted a conference call for our current and prospective support group leaders. They discussed many topics relating to effectively continuing to build successful support groups for our members. Awareness is a key initiative this year and it is our hope that through our growing support network, we can educate more physicians as well as the public about the disease.

Nearly two dozen support groups were represented on the recent conference call and we are thrilled that our groups have been so involved and enthusiastic about improving the myositis support community.

In a continued effort to promote leadership within our support groups, we have established a mentorship program for our support group leaders. Experienced and novice leaders have been paired up to work together to strengthen some of the newer or smaller groups to improve meetings, help

find informative speakers and provide equal resources to all support group members.

Also, we are working with Questcor Pharmaceuticals to produce a leadership manual for support group leaders. This will serve as a helpful training manual for current and prospective leaders on what is necessary to start and maintain a support group. Our volunteer leaders work hard to provide a chance for myositis patients to meet regularly and it is important that we equip them with the resources, guidance and support to take on such a huge responsibility.

New Areas of Support

TMA is looking into more ways to accommodate members who are isolated. In mid-March, we hosted the first virtual KIT conference call for dermatomyositis patients. TMA has thousands of members across the nation and many outside of the United States as well. We want to make sure that each and every member looking for support has access to a community of myositis peers even if there is no physical group located nearby.

These calls will continue throughout the year to give myositis patients the opportunity to vent, share experiences, ask questions and speak with others in similar circumstances. This virtual KIT is only initially available to members who do not have a support group within driving distance and each call will host up to 30 members, scheduled by disease type. Please contact Charlia Sanchez at Charlia@myositis.org or 1-800-821-7356 for more information about this virtual support community, and to participate in upcoming calls.

Suggestions for Social Media

In addition to offering a virtual KIT by phone, TMA plans to improve our connections with all of our members online. We currently provide an active Community Forum, as well as Facebook and Twitter pages for our members to engage and network with each other. TMA will increase our visibility on our existing social networking sites and also test out some new ones for members looking for additional online engagement.

Many of our members shared great ideas at last year's Annual Patient Conference in Louisville, KY and we are working to implement some of these. One idea was to record some of the support group meetings that feature doctors and guest speakers, so members who cannot attend meetings or who do not live close to support groups will have access to the same expert advice. This is just one of the many ways that we are looking to increase services and programs made possible using technology.

Share suggestions for social media and new ideas that you would like to see us implement by emailing tma@myositis.org.

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As muscle weakness and pain from conditions such as myositis limit mobility, simple tasks such as standing and sitting in the bathroom becomes more difficult. Research studies have shown we also become more susceptible to painful, debilitating bathroom falls.

According to the Centers for Disease Control and Prevention (CDC), the simple activity of getting on and off the toilet is a leading cause of non-fatal injuries. In a recent study¹, the CDC estimated that in 2008 alone, 234,094 nonfatal bathroom injuries were treated in emergency rooms across the United States. The study noted that injury rates increased with age and attributed most injuries (81.1%) to falls.

"All persons, but especially older adults, should be aware of bathroom activities that are associated with a high risk of injury and of environmental modifications that might reduce that risk," the study advised.

One such environmental modification now available is the LiftSeat powered toilet lift. Initially developed for use by healthcare professionals in hospitals, rehabilitation centers and nursing homes, LiftSeat's patented technology is now available for the home to safely and smoothly raise and lower a person for toileting.

LiftSeat has proven especially useful in protecting persons with myositis or neuromuscular disorders including amyotrophic lateral sclerosis, multiple sclerosis, muscular dystrophy and rheumatoid arthritis.

LiftSeat helps prevent painful, debilitating bathroom falls that could force someone you care for to move from their home to the next level of care such as an assisted living facility or nursing home. Beyond the emotional impact of leaving home, the costs are significant. Studies estimate the national average of even a single month in assisted living is \$3,500.²

LiftSeat costs a fraction of even one month in assisted living, installs in seconds and is easy to use. For more information on a LiftSeat powered toilet lift for your home or the home of someone you care for, visit www.liftseat4home.com/107 or call (877) 665-4381.

1. Centers For Disease Control And Prevention. "Nonfatal Bathroom Injuries Among Persons Aged ≥15 Years - United States 2008" MMWR 2011;60: pp 729-733

2. The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs October 2011

(877) 665-4381

www.liftseat4home.com/107

Services for veterans

Take a look at the pages TMA provides for veterans, including the real-life experiences of Ray Lesoine, pictured on cover. Please share your experiences on the TMA website page and Veterans forum, and on TMA's Facebook page. TMA also has a recently-added forum page for Caregivers.

Be prepared for an emergency

TMA has added a downloadable form that every member should fill out and keep handy to advise emergency workers on the special needs of myositis. Download this form, fill it out, and keep it nearby. Find it on TMA's website, www.myositis.org under "Find Support"; click on "patients living with myositis"; then click on "practical concerns"; and then scroll to the bottom of the page.

Become a fan of Myositis Dan

We're excited about Myositis Dan, the brave racehorse bringing attention to myositis diseases. Recently, Dan ran strongly against a very good bunch of horses in Florida, including a likely Kentucky Derby candidate. Dan came in second in the race and the announcer on the HRTV racing network described myositis to the many racing fans watching the race in the U.S. and around the world. TMA has created a Myositis Dan fan page on Facebook, where you can find out the latest developments and follow Dan's racing career. Become a Fan of Dan! Find Myositis Dan's Fans on Facebook and follow Myositis Dan on Twitter @myositisdan.

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Garden, from page 5

do something different using muscles in a different way. Gardeners tend to love to weed for hours! This is very stressful to the joints and can be fatiguing or feed into inflammation."

After their weeding time is up, she advises clients to stop and rest, or put something in the shed, or go in and get a glass of tea. "Just stop using the same muscles in the same way for hours. Gardeners can develop repetitive strain issues like nerve compression and tendinitis like people who are on computers all day, or factory workers on assembly lines doing the same repetitive task." Unlike the factory workers, she says, Gardeners don't HAVE to do that forceful repetitive task for eight hours and can pace themselves.

And it's important to watch your grip, Stevens says. "Try to avoid overhand gripping. It is so reflexive to reach out and pick things up with an overhand grip. We aren't efficient with our power when we do that and can exert force and strain the hand, wrist and forearm with this. Instead, use the palm of the hand to slide an object towards you with one hand and pick it up in the palm of the other hand---using your hand like a 'shelf' instead of a 'derrick'. Then you transfer the power of lifting to the big muscles in the forearm, upper arm and even the shoulder that can handle it more easily. I call this the 'powerful palm'. Also if you lift using two hands instead of one, only 50% of the force is on any one hand."

As for tools: "Fat handled instead of thin; lighter instead of heavy tools," she says. And, she notes, there's a whole world of ergonomically designed tools to be found simply by googling "ergonomic tools."



"Most importantly," she says, "people need to listen to pain. Do more gardening and heavier tasks on 'good days,' not 'bad days'. Using heat or ice after doing gardening tasks may help to relieve issues. Each person has to see what works best for them.

For more information on adaptable gardening, visit Thrive's website at <http://www.carryongardening.org.uk>.

Send us your practical solutions

Do you have an original "workaround" for accomplishing something that is difficult? Or an idea that makes your daily life a little easier? We welcome "selfies," links to videos and written articles for a new section of TMA's website. Send links, photos and written material to tma@myositis.org.



Consider the conference: TMA goes to Reno

September 4 - 7, 2014 — Each year, we've tried to make the Conference more focused on the needs of myositis patients and their caregivers. This year, there will be more topics, speakers, and sessions focused on practical solutions, as well as more opportunities to spend time talking with others who face the same challenges as you. We invite you to join us in Reno!

Thursday, September 4

10:00am Registration opens
1:30pm Get Acquainted
3:00pm General Session
4:00pm Practical Solutions

Friday, September 5

7:45am Early-bird sessions
8:30am Breakfast
9:30am Morning sessions
11:00am Mid-morning sessions
12:30pm Luncheon
2:00pm Afternoon sessions

Saturday, September 6

7:45am Early-bird sessions
8:30am Breakfast
9:30am Medical Panel
11:00am Mid-morning sessions
12:45pm Luncheon
2:00pm Afternoon sessions

Sunday, September 7

7:15am Breakfast
8:00am Meet the board
9:00am Keynote speaker
10:15am Conference ends



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**Annual Patient Conference
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THE OUTLOOK