

## Buccaneers honor Ricky Bell

Football fans at Tampa's Raymond James stadium attending the Panthers-Buccaneers game on October 18 learned about myositis and TMA, thanks to an effort by TMA, the Tampa Bay Buccaneers, and Southwest Florida KIT volunteers. Bell, a star running back at USC before entering the NFL, came to Tampa in 1977 as its top draft pick. In 1979, he led the Buccaneers to their first playoff win ever, against the Philadelphia Eagles. His career was cut short when he grew weak from dermatomyositis. His promising career and life ended when he died in 1984, at 29 years old.

Volunteers collected contributions for TMA in Bell's honor. To find out more about Ricky Bell, visit TMA's website at [www.myositis.org](http://www.myositis.org).



## Humor, frustration and hope: stories from real life

### Graham Rogers

*Charlotte, North Carolina*

Graham Rogers was an ordinary young man, he said, maybe even more interested in sports and competition than most of his peers. Although he was active in all sports, he especially loved tennis, lettered in it all three years at the Naval Academy, set records and won honors: "I was even what you might call semi-professional for a while," he said, laughing. His monetary gain was about \$25.

When he met Rosie, who was to become his wife, he knew he'd found someone who shared his love for the active life.

"Our first date was on the golf course," he said. Physical activity was a bond they continued to have after marriage, and one that seemed likely to be a huge part of their life together as a family.

Problems with his shoulders surfaced after several years of marriage, especially when he was playing golf and tennis. An orthopedist looked at Rogers' wrist, elbows and fingers, which seemed strange to the athlete who was complaining about a bad shoulder. "The good news was that I didn't have a sports injury," Rogers said. The bad news kept on coming. A rheumatologist diagnosed Rogers

with rheumatoid arthritis and treated him with Enbrel. Quickly, he lost almost complete use of his upper body. "I was lucky enough to have a new baby, and I was afraid to take care of it," he said. Time passed, the medicine did its work, and Rogers slowly regained what he'd lost.

Years later, he noticed himself becoming winded on the golf course. It was serious enough for him to consult a cardiologist right away. More good news and bad: "My heart was okay, but my lungs were a mess."

More tests showed he actually had polymyositis, accompanied by interstitial lung disease.

Medication treated the disease, but

Rogers knew he'd never be the same. He gained 35 pounds, found exercise a challenge, and felt drained emotionally. He was slipping at work and also struggled to find a way to forge a new relationship with his wife that didn't involve athletics. The family moved from Chicago to Charlotte for a new job opportunity.

"At one point, I kind of hit bottom," he said. Things began to turn around when he sought counseling; then improved again when he attended TMA's 2007 Annual Conference in Seattle. "For the first time, I saw people like me," he said.



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## Stories from real life,

*Continued from cover*

“Most important, we realized I wasn’t crazy.”

Rogers returned to Charlotte full of resolve to support other people feeling as alone and anxious as he had, and became the leader of the North Carolina KIT group. “We were too far-flung to have regular meetings,” he said. “We used email, conference calls, all kinds of ways to connect.”

Looking back, Rogers has some ideas for those recently diagnosed, tips that would have helped him at the beginning:

- Take one day at a time;
- Set reachable goals and re-evaluate them;
- Forgive yourself if you don’t reach your goals;
- Communicate with those you care about and ask for help.

### Renee Lantner

*Western Springs, Illinois*

Renee Lantner is a physician, but she wasn’t prepared for her own diagnosis of myositis. “It’s especially ironic, because I worked for a while in a pediatric rheumatology setting with Lauren Pachman (a juvenile myositis specialist),” she said. Lantner first suspected something was terribly wrong when she was playing with her baby. “I was tossing her up in the air and realized I couldn’t do it anymore,” she said.

Because of her profession, she got a “hallway diagnosis” from a friend at work rather than seeking a formal consultation. She also didn’t seek treatment, and became dramatically weaker very fast. “I lost 10 pounds and lost my rear end,” she said. “It hurt to sit down, and I didn’t look so good in pants.” Eventually, she regained strength without treatment, and Lantner believed it was a transitory episode.

When the skin rash appeared, her experience with dermatologists wasn’t any more productive than her attempt to find out the cause of her muscle weakness. “One diagnosed me with dry hands, another offered to zap my rash – a classic ‘shawl sign’ -- with a laser,” she said. Still another believed she was a victim of horrible sun damage.

Lantner never missed work, and she found she didn’t like talking about her own symptoms: “As an allergist and immunologist, I was used to talking to patients all day about their problems,” she said. “I didn’t like the idea of talking about my own illness.”

Other stresses in her life didn’t help. Her daughter struggled with mental illness and her father died. Now, years later, with a correct diagnosis and a good life, she has some advice: “We all need to find ways to support ourselves,” she said. “And always remember that knowledge is power.”

### Steve Morris

*Riverside, California*

Myositis put Steve Morris in a wheelchair at a time when disasters seemed to be piling up. Returning from a professional trip, he found his wife had moved 80 percent of their joint belongings out of their home. “What does this mean?” he asked the crowd. “It means she didn’t have a big enough truck.”

What it really meant was that he was divorced and alone. Even the SPCA found him unappealing, denying his request to adopt a homeless cat. Eventually, he looked for companionship through Internet dating, an effort that landed him a date with a woman whose home was overrun with ferrets.

Morris decided to leave the dating scene to work for other myositis patients and, as soon as his disease was in remission, he got back on his Harley again for a fund-raiser. One

year, he rolled into the black hills of South Dakota for the huge annual biker rally; the next, he traveled up into British Columbia, where he met with myositis patients along the way.

Remarried now and feeling stronger, Morris said he'd never forget what it was like in the early days. A middle school teacher, he gave the speech for the eighth-grade promotion from his wheel chair. "I spoke about inner strength," he said. "The most important thing I've learned is that, while I have myositis, myositis doesn't have me."

*Myositis patients shared their stories, above, at the 2009 TMA Annual Conference.*



## Panel reviews past, current and future myositis research

Ever wonder why there's always a limit to how big muscles can get? It's because of myostatin, a protein found in high concentrations in muscles, where it limits muscle growth. Scientists have been fascinated by this protein, reasoning that if it could be controlled, then muscles weakened by disease could experience growth and possibly gain strength.

In 1997, scientists at Johns Hopkins showed that myostatin production is controlled by a gene and "knocking out" this gene limits myostatin and doubles muscle production in normal mice.

Cattle breeders found a real-life example of what happens when they discovered a mutation that suppressed myostatin in certain kinds of cattle. They've selectively bred cattle with this gene for herds with an abnormally large muscle mass.

This is the path, says Brian Kaspar PhD, showing promise for restoration of quadriceps strength to patients with IBM. The myostatin-muscle connec-

tion has prompted the study by the team he leads, with Dr. Jerry Mendell, at The Research Institute at Nationwide Children's Hospital.

There are several ways to suppress myostatin, but careful studies with mice show that follistatin, also a protein, seems to be the most effective. Scientists have identified the gene controlling follistatin production, allowing research on the potential control of myostatin production to move forward. A 2008 trial showed that the systematic suppression of myostatin did not appear to pose any danger to a group of muscle disease patients.

Although other muscles are affected by inclusion-body myositis, the quadriceps is the most important, Dr. Kaspar said. Weakening of this main leg muscle causes falls and greatly affects independence, so researchers are focusing on the potential increase of strength in quadriceps muscles of mice and monkeys, although increased size in other muscles has also occurred and is expected.

Significant increases in strength and individual muscle weight were seen in mice that the Mendell-Kaspar team treated with follistatin. This was true even when the mice were old, Kaspar said, an important consideration since IBM occurs in aging bodies. Researchers also needed to prove that suppression of myostatin did not affect reproduction in the treated mice, and that the increased muscle mass translated into realistic everyday function.

Once the Mendell-Kaspar team made these important findings, it was time to move to working with non-human primates, monkeys. It was clear from casual observation and also meticulous measuring that monkeys treated with follistatin had significant gains in quadriceps size over the non-treated monkeys, and that their gain in strength was functional. No changes were found that could potentially affect reproduction.

Of special concern was the heart, since it is also a muscle. Careful study showed there were no cardiac implications in the monkeys, nor did autopsies reveal any changes in other organs.

The results have been so impressive that regulatory authorities have speeded up the approval process as the team moves forward. Toxicology studies are just beginning; they'll be finished in about a year (June 2010), Dr. Kaspar said. Human trials will begin shortly afterwards, if all looks good.

The initial study will be of patients with proven IBM who have weakness of knee extensor muscles. Nine patients (three cohorts with three patients per cohort) will receive 3 doses of follistatin, and return for evaluation on days 7, 14, 20, 60, 90, 120, and 180. They'll be assessed as follows:

- Quantitative strength measures of quadriceps muscles and functional tests (stair climbing, walking 30 feet, getting up from chair);
- MRI of quadriceps muscles after 180 days of treatment will be compared with pre-treatment;
- Patients will receive a muscle biopsy on both quadriceps on day 180.

TMA will notify all its members when recruitment for this trial begins.



## Studies examine new myositis treatments

Dr. Andrew Mammen, co-director of the Johns Hopkins Myositis Center, reviewed recent and current myositis research. Recent studies no longer enrolling, but yet to report results are:

- **Rituximab in Myositis.** In this largest multi-center trial to date, 200 patients with DM, PM and JDM were treated; half with placebo and half with rituxan. All patients were eventu-

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## Myositis studies,

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ally treated. Preliminary results are expected in fall, 2010.

### ■ **Etanercept in Dermatomyositis.**

Sixteen patients enrolled in this study, 12 of whom received the drug. Results are expected in May 2010.

■ **MEDI-545 in Dermatomyositis and Polymyositis.** This multi-center study enrolled 32 patients. The date of completion is unknown.

Studies currently enrolling myositis patients:

■ **Lithium in IBM.** Twenty IBM patients are needed for this observational study. Enroll by calling Nicole C. Hank, 602-258-2432 or emailing [nhank@pnal.net](mailto:nhank@pnal.net).

■ **Arimmocloimal in IBM.** This trial is enrolling 12 patients. To enroll, call 913-588-6094, or email [rbarohn@kumc.edu](mailto:rbarohn@kumc.edu).

■ **Etanercept in IBM.** This study, based at Washington University, is seeking 30 patients. To enroll, call 314-362-6981 or email Dr. Glenn Lopate at [lopateg@neuro.wustle.edu](mailto:lopateg@neuro.wustle.edu).

■ **Stem Cell Transplant in Myositis.** This study, at Northwestern University, will enroll 10 patients. To enroll, Contact: Dr. Dzemila Spahovic at 312-908-0059, [d-pahovic@northwestern.edu](mailto:d-pahovic@northwestern.edu).

■ **Stem-cell transplant in children with refractory autoimmune disorders.** This study, at the Fred Hutchinson Cancer Research Center, will enroll 20 children. To enroll, Contact: Dr. Carol A. Wallace, 206-987-4448, [cwallace@u.washington.edu](mailto:cwallace@u.washington.edu).

For detailed information on these trials, find Dr. Mammen's complete presentation at [www.myositis.org](http://www.myositis.org). A complete list of patient trials is available at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

With the generous help of its current and former members and friends, and the volunteer assistance of myositis experts all over the world, TMA has funded more than \$3 million in myositis research.

For details on TMA-funded research, go to [www.myositis.org](http://www.myositis.org).

## Myositis experts discuss disease management with patients

The 2009 TMA Annual Conference offered disease-specific sessions where patients learned conventional medication routines, new therapies, and common-sense ideas for living with their diseases. Physicians who see myositis patients every day gave formal presentations and answered dozens of very specific questions from patients. The full presentations are available online at [www.myositis.org](http://www.myositis.org).

### Inclusion-body myositis

*Dr. Lawrence Phillips*

IBM patients have a collection of signs and symptoms very different from other inflammatory diseases. Falling may be one of the first manifestations, due to the distinctive quadriceps weakness. Other features that often distinguish IBM from other forms of myositis are weakness in the finger and wrist flexors, and in the hand muscles that form a grip. Core muscles – the muscles in the center of the body – are spared, as are the deltoid and triceps, but the limb and hand weaknesses pose problems for general mobility and performing day-to-day tasks.

There's not much doubt about an IBM diagnosis when the pathologist takes a look at the biopsy, Phillips said. The muscles show a pattern of rimmed vacuoles (or holes) and deposits of amyloid proteins, the same misplaced deposits seen in another age-related condition, Alzheimer's disease. It's thought that the proteins cause inflammation but, unlike treatment for other forms of inflammatory myopathies like DM and PM, treating

the inflammation seldom relieves the weakness.

Some possible treatments:

■ IVIG is helpful to a small number of patients, but the improvement is temporary.

■ Immune system suppression rarely helps and causes its own problems.

■ Etanercept (Enbrel), an expensive and potentially toxic treatment, showed some promise in a small trial, disappointing results in another, and is under study in a larger trial.

■ A vaccine that works in mice shows promise and may have possibilities for stimulating an immune response to amyloid precursor protein. Mice strength improved substantially and tissue differences were found. This research, targeting the proteins involved in Alzheimer's disease, is being studied.

■ Other research avenues, such as testosterone and growth hormones, haven't proved effective in IBM.

■ The Lithium trial underway for IBM is not completed as yet.

■ Gene therapy is being studied. See page 3.

With no effective drugs on the immediate horizon, what can IBM patients do to maintain strength and quality of life? Dr. Phillips recommends vitamins that may be depleted in this group:

■ The B vitamins, B2, B6, B12. Take care with vitamin B-6, as amounts over 100 mg. can be toxic

■ Vitamin E (also check with your physician about appropriate amounts)

■ Other supplements that many find helpful are creatine, Co-Q10, and L-carnitine, all over-the-counter supplements.

Exercise has been recognized as an important part of treating IBM. Dr. Phillips recommends doing exercises that maintain flexibility and range of motion – yoga is good – and that work muscle groups without getting to the point of exhaustion. For those who are able to walk safely, this is a

good choice; another option is water exercise. Weight control is extremely important for IBM patients and may make a significant difference in maintaining independence.

Whether exercising or just getting through a normal day, fatigue is common in IBM, and sleep is sometimes interrupted by breathing and other problems caused by weakened muscles. Dr. Phillips recommends rest periods for those who find themselves exhausted during the day.

Many IBM patients have swallowing problems and there are strategies for controlling this. Some patients work with a speech therapist or other specialist to maintain normal swallowing. Changing the angle of your head as you eat (tucking your chin), or altering the consistency of your food helps people swallow more easily. Botox injections have worked for some people, but are not always reliable.

Feeding tubes often are tremendously helpful in getting adequate nutrition, and can be used temporarily or only as needed while also maintaining normal eating. When swallowing improves, they can be discontinued.

Some people have reported good results with Vita Stim, a device that uses small electrical currents to contract the muscles of the face and throat, targeting the muscle fibers that control some swallowing functions. Dr. Phillips notes that this therapy hasn't been studied in myositis.

Devices like braces for arms and legs, and also walkers and canes that provide stability can prevent falls when used appropriately. IBM patients should also monitor their homes for hazards like rugs, raised sills and other obstacles.

### **IBM patient finds relief from frequent falls**

TMA member Herb Schley, an IBM patient, read an article in the January

2008 OutLook in which another IBM patient, Jay Levitan, described his experience with frequent falls. Levitan tried acupuncture to improve his balance, and found this therapy effective in preventing falls.

Schley was diagnosed with IBM in November 2007 and was told there was nothing to help. He had been taking Crestor, a statin drug. He was told to exercise, take creatine and have a good life. "This was not acceptable," Schley said. Plagued by frequent falls, he decided to give acupuncture a trial. This is his story:

I stopped taking Crestor and refused to take any other type of statins or medicine to assist in maintaining lipid profile recommendations. It was interesting to note that after I got off the medicine and began to exercise, the lipid profile became normal.

Colleagues recommended a Chinese doctor who performed acupuncture and practiced Chinese medicine. The doctor, who grew up in China, was a medical doctor and surgeon in China and had learned acupuncture from his father and grandfather. He is 70 years old and has been practicing in the USA about 20 years. He is certified and licensed in the State of Florida.

The first visit was special. Not only was there a language barrier but the doctor had never heard of IBM. This did not surprise me since very few doctors have heard of this disease. He did notice the muscle loss in the legs and knew what needed to be done. Luckily, he had a computer program that could convert English to Chinese, so I was able to pull up the internet for him to read about IBM in Chinese.

The regimen that he established was to place the needles - ten in each leg - from the thighs to the ankles. He then places an electrical stimulator to certain needles and sends small amounts of current through 4 needles in each leg for 30 minutes. After this

treatment, the needles are removed and he performs a massage for about 10 minutes on each leg. Please note that this is not a deep massage.

The theory of this procedure is very simple. Place the needles into the nerve and then stimulate the nerve with an electrical current, which in turn helps strengthen the muscle where the nerve goes through the muscle.

Treatment varies from visit to visit. Sometimes the doctor applies a steady electrical current and other times he uses a pulsation current through the needles. At times he has also used four needles to the head, to the back, and to the back of the legs. Each treatment is the same length of time.

How do I know it works? Very simple. We took detailed measurements of the thigh and calf areas at the start of the treatment and every three months thereafter. It is important to measure in the same place each time.

I make two visits per week, and during the past two years, I have not fallen and have not lost any muscle. I have not gained any muscle, only maintained what I have.

In addition to the acupuncture, I started an exercise program with weights and bicycle riding. This did not work well, so I started a new exercise program of stretching, use of bands, some leg presses and riding a bike for endurance. I do not try to lift weights to build muscle. I still use creatine after each workout and on the days I do not work out. I work out three days each week. I don't use the treadmill or take very long walks since I do not want to tire the muscles. I have not gained or lost any weight during the past two years. I do use the handicap ramps and do not climb stairs since I do not want to stress the muscles.

When I talk with my doctors, I find they have no knowledge of

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## Myositis experts,

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Chinese medicine since they were not trained on this subject in school. They are very skeptical of the treatment, and many of them think acupuncture is only for pain. They do not understand that there are a variety of treatments with acupuncture and the use of Chinese medicine to replace other types of prescriptions.

Will it work for you? I do not know, but as long as I do not fall and do not lose any more muscle mass, it is working for me. Should you elect to try this form of treatment, I suggest that you locate an acupuncture doctor who has been trained in China. Discuss your problem with the doctor in advance.

As you probably know, acupuncture is not paid by Medicare at this time but some secondary insurance plans do pay a portion of this cost.

Should you wish any additional information, you may contact me at [hscley@aol.com](mailto:hscley@aol.com) or 352-242-5179.

--Herb Schley, IBM patient

## Dermatomyositis

*Dr. Joseph Jorizzo*

Hundreds of old-style rheumatologists over many decades can't be discounted, said Dr. Joseph Jorizzo. Aggressive treatment of dermatomyositis with corticosteroids right at the start, tapering as soon as it's appropriate – little by little – and conscientious sun protection are still the keys to treating dermatomyositis. Meanwhile physicians should make sure the potential side effects of prednisone are monitored and the possibility of overlap with cancer and other systemic diseases considered, Jorizzo said.

While not dismissing the possibility that other, newer treatments may

emerge and be effective, they're still unproven over the long term and expensive, he said.

Dr. Jorizzo said the traditional treatment he described, which takes an average of a couple of years including the tapering, has drastically lowered the death and permanent damage rate inherent in DM. "I've been treating DM for 24 years," he said. "In the 300 or so patients I've seen, most of these go into remission after 5-6 years. Less than one quarter seem to smolder on."

Dr. Jorizzo said his experience has told him that, when DM symptoms are controlled for a couple of years, "the disease just sort of gives up." He criticized the "misaligned incentives" of our present



health care system. "There's a financial disincentive for dermatologists to follow chronically-ill patients month after month, even though this relationship is the best in the long run for managing disease," he said. "Instead, surgical interventions are rewarded." This situation, he said, has prompted many dermatologists to go into cosmetic practice.

Dr. Jorizzo said it's important to note that the DM skin rash normally precedes (and often outlasts) the muscle weakness. He firmly believes in the strong association of the rash with the hours and intensity of sunlight. "In Winston-Salem, I've pin-pointed

the date of exposure (when the sun is bright enough to affect the skin) as January 29," he said. "By February 15, my patients will have a flare – some just with the skin, others with both skin and muscles."

The culprit, he said, is not sunbathing. "Let's face it, people with DM do not sunbathe. It's those trips, unprotected, to the car, from the car to the school or office. It only takes a few minutes."

For those whose diagnosis has wavered between lupus and DM, he suggests paying attention to the color of the rash: "In lupus, it's red," he said. "In dermatomyositis, it's clearly purple." Another clue is when the rash is on the scalp: common in DM, uncommon in lupus.

The scalp rash, he said, is extremely uncomfortable. His message is to break the cycle of scratching and itching as quickly as possible. The scratching aggravates the rash tremendously. Here, again, sun protection is key.

"My patients who do the best with clearing up their skin irritation have one thing in common," he said.

"They are fanatic about sun protection."

Dr. Jorizzo, based on his long-time practice, also has some ideas about the connection between DM and cancer. "It's not as strong as is sometimes believed," he said. "Remember that a Danish study found that the increased cancer rate only applies for two years from the start of the skin rash. Then, it goes back to normal." Also, the rate varies tremendously with the age of the patient. He recommends common-sense cancer screening every six months for two years, with an ultrasound for women.



Also overblown, he says, is the potential for lung disease. “We get our statistics from the institutions that treat the sickest myositis patients,” he said. Consult with a pulmonologist and treat the underlying disease aggressively to prevent complications. With this strategy, he said, the dermatology department he oversees has not seen a DM death in 24 years.

He has some advice for DM patients:

- Don’t get stuck between the dueling egos of two specialists. Try to educate yourself, and stay with a common-sense treatment program.

- Likewise, don’t be dragged into the dueling financial interests of drug companies. “Most likely, the horrifying information about long-established drugs is not originating with the FDA,” he said. “Often, it’s the competing drug company who would like you to use their drug. Remember, whenever there’s a ‘winner’ drug, there’s a ‘loser’ drug.

## Polymyositis

*Dr. Andrew Mammen*

Polymyositis has a major player: lymphocytes. Lymphocytes play a dual role in the body of a PM patient, something similar to Dr. Jekyll and Mr. Hyde. Ordinarily, lymphocytes help our bodies ward off foreign agents that make us ill. However, in the body of a PM patient, lymphocytes attack healthy muscle and tissue, thus causing extreme weakness.

Dr. Andrew Mammen, Assistant Professor of Neurology and Medicine and Co-Director of the Johns Hopkins Myositis Center, provided some insight into managing polymyositis.

The first step is to reduce muscle destruction with an immunosuppressant. The first line of medication is a steroid, usually prednisone. Prednisone is highly effective in the treatment of inflammation and bringing CK levels down, and it’s the only drug FDA approved for polymyositis. Upon initial treatment with pred-

nisone, patients should expect to take 60-100mg a day, depending on their weight.

Sometimes, prednisone is administered in large intravenous doses over a short period. Once the PM begins to show signs of progress, Dr. Mammen recommends the drug be tapered, usually, by less than 10mg a day. Patients should consult their doctors on the best method of tapering for them. Prednisone has unpleasant and potentially serious long-term side effects, so doctors prefer to treat PM aggressively at first, then taper, to avoid repeating the treatment over a long time.

Another medication known as the first-line-of-defense in steroid-sparing treatment is methotrexate. Methotrexate works to interfere with DNA synthesis, DNA repair and replication of immune cells. It is also effective in treating arthritis. Methotrexate has side effects, and should not be taken if a pre-existing lung or liver disease exists. Dosing is started low (10 mg. each week) and may increase (25 mg. each week). Blood monitoring is required for patients taking methotrexate, and patients are usually prescribed folate to help with associated side effects.

PM patients may take varying medications after or instead of prednisone or methotrexate. Other medications include: azathioprine (Imuran), mycophenolate mofetil (Cellcept), rituximab (Rituxan), and etanercept (Enbrel). These medications all have pros and cons associated with their use, and patients’ experiences and success with each will vary.

Another form of medication is given intravenously instead of orally. Intravenous Immuno Globulin, or IVIG, a blood product, is a pool of antibodies from more than 1,000 donors, and is sometimes effective in treating PM, although doctors do not know how it works. It’s possible that IVIG aides the patient by forming an

immune complex that is anti-inflammatory, stimulating the removal of the patient’s own antibodies, or it may bind to and inhibit macrophages (a type of inflammatory cell).

IVIG is usually a very expensive treatment course.

Another “treatment” not to be overlooked is exercise. Exercise that includes muscle strengthening is beneficial to patients, but it should be regulated by a physical therapist familiar with myositis who is aware of the patient’s strength level.

Some patients experience benefits from a creatine supplement, taken at 20 grams each day for one week, then 3 grams each day thereafter.

Dr. Mammen summarized his approach to treatment:

- It’s important to remember that everyone is different and will respond differently to the medications listed, the dosages, and will experience the side effects either mildly or full-blown.

- Start with prednisone. If myositis is severe or rapidly progressive, add a second medication immediately. Myositis is such a variable disease, it’s difficult to say how a patient will respond to treatment, however, an appropriate initial dose of prednisone will usually work.

- A second medication may also be given if disease flares during a prednisone taper.

- Don’t panic if you are given a secondary medication, as the majority of patients require additional medication.

- If your PM steadily gets worse, even with treatment, question if your PM diagnosis is correct. Some patients who do not respond to medication may actually have IBM.



# TOOLS FOR EMOTIONAL SUPPORT

## Myositis caregivers share ideas for stressful lives

Diagnosed with polymyositis himself, Andrew White has a special place in his heart for caregivers. “Your loved one would be different if it weren’t for you,” he says. “Because you are in their lives, you join them in this journey. It affects you, too.” Andrew White is a professor and counselor who spoke to caregivers at the TMA Conference in Charlotte. One participant said, “When they have a flare up, so do you.”

There’s no question that when the patient is stressed, caregivers stress out, too. Myositis truly is a family disease. However, the caregiver’s needs are often neglected since they tend to develop a habit of giving, and forget about themselves. Members of the audience shared what was stressful for them:

- It’s so frustrating when loved ones won’t take care of themselves and do what they have to do.
- My stress is when others (family or close friends) don’t understand because while someone looks okay to them, they’re really “in bad shape.” They don’t see it every single day so they have no idea of what’s going on and they can’t be supportive when they’re not in touch with the reality.
- There’s nothing I can do about the disease progression.
- When it comes down to it, it’s a constant 24/7, 365 days a year. When I try to get away, I’m always thinking about him and how he’s getting along. And when I get back, he might say that the person taking care of him doesn’t do the massage like I do it. It’s wearing.
- She is forgetful and that bothers me.
- It is hard for me to ask for help.
- When I don’t do things soon enough, he gets annoyed.
- I feel like I need a caregiver for the caregiver.

- The helplessness is hard; for example, when someone falls.
- It’s difficult when the patient feels strong then a few minutes later, she or he is weak.

There no question about it, White said. When you feel a lack of control, there’s stress. While each person copes in his or her own way, some people turn to unhealthy strategies that take a toll on them physically: They might neglect friends, drink or eat too much, argue, internalize (stuff the stress inside), or deny reality. When coping is unhealthy, caregivers get burned out early. And, unfortunately, the bottom line is that you’ll get sick if you don’t take care of yourself.

If you’re a caregiver and have formed unhealthy coping mechanisms, what can you do to change them? White suggests some healthy ways to deal with chronic illness:

- Give yourself a break without guilt. But train yourself not to talk about or think about your loved one at the time so it is truly a break.
- Be around people you cherish.
- Keep a journal and write your thoughts, feelings, struggles, and your joys down regularly. (Daily is best but every other day is fine too.)
- Spend some time alone.
- Listen to music.
- Be assertive and stand up for yourself if you need to.

Members of the audience gave examples of healthy coping from their lives:

- Do what I used to enjoy doing.
- Exercise makes me feel better.
- Volunteer in something that gives me joy.
- Watch movies
- Let the patients do for themselves where and when they can.
- Play ball, take a walk, or do something physical.
- Write poems.
- Meditate and go into deep relaxation.
- Get stuff done around the house that gives me satisfaction.
- Watch sports.

Passing out index cards, White asked everyone to set goals. “Write down three things that you will do to cope with the stress, things that make you happy. How long has it been since you’ve done these?”

Once you decide what you want, he said, tell someone so you are

accountable. Post the index cards where you look every day so you see them often. Make yourself engage in healthy ways to deal with stress.

Other ideas discussed by the group for healthy coping: A KIT

group, spiritual enrichment, a place of worship, or professional help. If there is a good hospice organization near you, you may find counselors who are very familiar with dealing with loss and grief.

During his presentation, White told a story about a holy man trying to save a scorpion’s life even though he was getting stung over and over. He compared that to our role as caregivers “acting in a graceful way, saving our loved ones from turmoil.” It may be in the patient’s nature to sting





but you're still there for them. For that, Andrew White is grateful.

--Adele Greenfield, *myositis caregiver*



## Myositis patients find emotional support

"I lost my muscles, not my brain," said a woman in the audience. "Sometimes we just have to remind people."

Another woman said her brother couldn't stand to look at her in a wheelchair because he remembered her as strong. This takes a huge emotional toll. Diagnosed with polymyositis in January 2006, Andrew White understands what myositis patients are going through and says that relating to others in conferences like TMA's is important.

In his own life, he feels the emotional effects with his own loss of strength. He's often ready to go back to bed after he brushes his teeth and takes a shower in the morning. "The strength is unbelievably different now. It affects not just you, but your whole family as they join you in your journey," he said.

Working from a "feeling sheet" listing many emotions, he asked, "How does chronic illness impact your life emotionally? What feeling do you experience when you think of the past when it comes to your daily living? What are the feelings that grip you now?"

People agreed that they feel weak, inadequate, detached, and aggravated. In the past, they felt powerful and had more self-esteem. There is a tremendous shift from how they used to feel to how they feel now. Living with the symptoms creates this shift in their lives and it spreads to their relationships.

The group shared their feelings about tolerance, hospital familiarity,

embarrassment, asking people to help (it takes a lot to ask), exhaustion, sadness, and depression. They said that when you're emotionally drained by your illness, things tend to bother you faster and easier. Families can be stressed, overprotective, worried, and constantly second-guessing you as they take a more active role. This, too, plays on their emotions and adds to their stress.

When we get stressed, physical symptoms flare up. And, because of the losses, we experience grief. Andrew said grief comes at the time of diagnosis whether we recognize it or not. Then he asked, "Have you really grieved or have you just rolled with the punches? Have you allowed yourself to experience these emotional impacts?" Then he added, "A good way to move forward is to experience them. It is OKAY to grieve. That's how to move forward."

He used Dr. Elizabeth Kubler-Ross' model of the five stages of grief to help identify these feelings:

■ **Denial.** If you don't go through denial, it may come up later. Some of us deny our illness so much, we can't talk about it. During this phase, we can be busy with activities for escape. We might not want to be around people.

■ **Anger.** Why me, what did I do? We can direct our anger outwardly towards others because of the emotional stress that piles up. Helplessness can cause frustration and anger. And we might feel confused.

■ **Bargaining.** Most bargains are made with God. Promises are often associated with guilt, especially when you can't follow through on a commitment because you just don't have the energy. These are attempts to postpone the reality of the loss.

■ **Depression.** This usually manifests itself when the denial, anger, and guilt no longer hide the full impact of our loss – the loss of tal-

ents, potential, companionship, dreams, hopes, and plans for the future. You have to change your goals and it shapes what you do.

■ **Acceptance.** This is not always a "happy" stage but there is a beauty and freedom when you come to accept. You realize that not all things in life are understandable or fair. And you find a new sense of strength when you face this reality and come to terms with it. You can then let go of anger, fear, and guilt.

Since we have no control over various events (and this lack of control causes stress) we might go through these stages multiple times. It recycles. We face more loss. We may also go into one or two of the stages for a time. They can overlap and we might feel two or three simultaneously. It's part of the process.

Family members grieve too. Different people can be in different places. We're not all on the same page since each one moves through the stages in their own time. And, with those outside your home, it can be hard to tell them how you feel, especially when they say, "Well, you look good." It's common to think: "If only they really knew."

Andrew talked about Dr. William Worden's work involving the four tasks of grief as a way to understand the mourning process, experience the pain, and move forward. Dr. Worden's work on death and acceptance is geared to both mourners who have lost a loved one and clinicians who help people through grief. But his work can be applied to myositis, as we experience many losses that we need to mourn. Andrew touched on Worden's tasks and adapted them to myositis patients:

■ Accept the reality of the loss. Acknowledge it.

■ Emotionally relocate and work through the pain of grief. This could mean moving from feelings of loss

## Emotional support,

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and longing to reinvesting in life in the present.

■ Adjust to the new environment, living without the things we had in the past. We may have to adjust to a new physical environment, like using devices to help us.

■ Move on with life. Andrew asked, “What are the positives that help you enjoy life?” This can be your springboard to help you see what can work for you.

He suggested that we grieve with someone. Select a person to help you but don’t let this be the only topic of your conversations. Other suggestions were:

■ Allow crying, mourning or shouting.

■ Do what helps, such as journaling or talking to a professional.

■ Let go of what you can’t control and grasp onto what you CAN control.

■ Choose joy!

Regarding joy, White said, “I have quality time with my kids now that I never had. I used to work early in the morning up until they were in bed.”

He asked everyone to write down how they are going to move forward from grief. “What resources will you use, how are you going to get there, and what action steps will you take? Will you start journaling, listening to music, talking to a friend?”

He told the “window story” about Lloyd and Allen, both sharing a room in a nursing home. Lloyd’s bed is near the window and he looks out to tell Allen what’s going on at the park. He describes the trees, children playing. When Lloyd died, Allen took his bed and

looked out. But all he saw was a brick wall.

A new patient, Fred, took over Allen’s old bed, the one away from the window. Allen, inspired by Lloyd, described the joys of the park to Fred.

When we are experiencing our symptoms, we can feel like we are at that brick wall. See past this and go for joy. Happiness is a journey, not a destination. Train yourself to choose joy and you will see the park.

--Adele Greenfield, myositis caregiver



## Save bones, prevent falls

Not only are people with myositis at risk for falls because of weak muscles, they may also be more likely to have brittle bones that are threatened by falls.

There are several factors contributing to bone loss in those with myositis. The inflammatory process contributes to the problem, as do the drugs commonly used to treat it. Steroids, such as prednisone, decrease bone building activity and calcium absorption, while increasing the breakdown of bone and secretion of calcium.

Methotrexate is thought to contribute to possible bone loss, and protein pump inhibitors (prilosec, prevacid, nexium) sometimes used in combination with over-the-counter and pre-

scription medications may increase osteoporosis or decrease calcium absorption. And, because of increased muscle weakness, patients with myositis may do fewer weight-bearing activities, which also puts them at greater risk for falls. Falls are respon-

sible for over 40 percent of nursing home admissions and 70 percent of accidental deaths in people more than 75 years of age.

To reduce the risk of fractures, your doctor will monitor your medications to make sure you’re using the lowest possible dose of steroids. You may also be screened to make sure your vitamin D is sufficient.

At TMA’s 2009 Annual Conference, occupational therapists from East Carolina University talked about everyday strategies you can use in your home to prevent falls. Lesley Evans, Melissa Colcord and Jaclyn Wilkerson said that falling can be a significant factor in the health of people with chronic disease, leading to injury, brain trauma, and ultimately to the inability to live independently. In the aftermath of a fall, patients are often unable to exercise, so their situation deteriorates still further. The threat to life and health of a broken bone in an already frail person is so great that physicians measure the success of treatment not in bone strength, but in the percentage of fractures experienced by a treatment group.

The good news, said the OTs, is that many falls can be prevented through modification of the home and other environments, use of adaptive equipment, and appropriate exercise. They started with the obvious measures that anyone with physical challenges – whether from age, disease or disability – should use routinely.

## Take steps to make your home safer

Go through all your rooms. Invite a friend or relative to accompany you if needed. Look at the paths you take daily in your home from one activity to another. Create a clear path from one home activity station to another. Rugs can be a problem, and cause a great many home accidents and injuries. Remove rugs that slip along the floor, tape them down if they are



unstable, or anchor them with a non-slip mat. Many OTs advise simply removing small rugs from your home altogether.



Next, look around with an eye towards removing clutter, especially clutter that accumulates at floor level, like electrical cords, books and bags dropped at doorways, and small stools. Tuck cords out of sight and tape them or secure them along channels away from walkways. Get in the habit of never setting anything on a stairway or in front of a door. Also remove clutter from counters and tables so you have clear surfaces to steady you as you move about your home.

Even if you have no vision problems, make sure there is plenty of light in your home – natural light in the daytime and nightlights and lamps after dark. Make sure you can easily reach a lamp with an easy motion at night and turn on the light before you make your first step. Glow-in-the-dark switches help, as do stair lights. Get in the habit of keeping a flashlight within easy reach, so you never have to walk in the dark.

Check stairs and steps. Make sure they are all in good condition, with sturdy handrails, and that there are no obstacles on any landing at the top or bottom. Brightly colored tape can signal the last step, or an uneven sill. Many myositis patients use a “half-step,” a device that allows you to lift your foot to only half the height of the step. Usually, a half-step has a handle that can be lifted onto each

step as you progress up the steps. Myositis patients generally use the half step going up the stairs and go downstairs backwards, keeping a firm hold on the rail. Often, a partner walks just below them to assist in case of a fall.

There are dozens of common-sense steps you can take to make your kitchens, bedrooms and bathrooms safer and more convenient. Find a complete checklist at National Center for Injury Prevention and Control. Home safety checklists, <http://www.cdc.gov/ncipc/falls/fall-prev4.pdf%20>.

### Find a way to move

Physical activity is an extremely important part of your fall-prevention plan. Choose gentle, systematic exercises like walking, water workouts or tai chi (a repetitive, graceful dance-like movement). Exercise reduces your risk of falls by improving strength, balance, coordination and flexibility. Ask your doctor to refer you to physical therapy for specific exercises and advice on how to find a regular exercise regimen, especially if you are avoiding exercise because you're afraid it will make a fall more likely. To improve your flexibility, the physical therapist may use techniques such as electrical stimulation, massage or ultrasound.

### Consider your shoes

Your days of stiletto heels or towering cowboy boots may be over as you change footwear as part of your fall-prevention plan. High heels, floppy slippers and shoes with slippery soles can cause stumbles and falls. It's also unsafe to do all your indoor walking in your socks. Buy properly fitting, sturdy shoes with nonskid soles. Don't go for extra-thick soles, which prevent your feet from feeling the ground. Choose lace-up shoes instead of slip-ons, and keep the laces tied. Buy shoes with fabric fasteners if you have trouble

tying laces. Don't pinch your feet: shop in the men's department if you're a woman who can't find wide enough shoes. Invest in a long shoehorn if bending over is a problem.

### If you fall

The OTs showed a number of strategies to help people with weakened muscles arise from a fall, and there were suggestions from the audience:

- If you fall a lot and have trouble getting up, even with your caregiver, introduce yourself to the neighborhood fire department, explain your situation, and thank them in advance for their help.

- If you feel like you are hurt, call for help if there's someone close by. Don't try to get up until you feel better.

- If you are not hurt, try rolling onto your side, turning your head in the direction you are rolling.

- Crawl over to a chair, couch or other sturdy piece of furniture, and slowly pull yourself up.

- Bend your stronger knee and keep the other knee on the floor, and slowly stand up.

See a short video on how to get up after a fall at <http://www.learnnotto-fall.com/content/what-if-i-fall/learn-to-get-up.jsp>

See the fall prevention presentation on TMA's website at [www.myositis.org](http://www.myositis.org).



### For the caregiver

East Carolina University occupational therapists Lindsie Webster and Sharon Faircloth showed myositis patients and caregivers how to work together when the patient has fallen. Using photos and also demonstrating themselves, they gave attendees at the 2009 TMA Annual Conference some practical tips for getting a fallen but unhelped patient back into a bed or a chair.

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## For caregivers,

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It's important to protect your own muscles and health while you take care of a spouse or family member at home, Webster said. Many motions that caregivers perform are potentially harmful to your back, including pulling a person who is reclining in bed into a sitting position; transferring a person from a bed to a chair, and leaning over and pulling up a patient who is on the floor.

There are general, everyday rules that caregivers should observe, Faircloth said:

- Maintain the proper alignment of your head and neck with your spine.
- Keep the natural curve of your spine. When you bend at the waist, you are at risk for injury.
- Do not twist your body when you support or carry a person.
- Keep the person who is being moved close to your body.

- Keep your feet shoulder-width apart to maintain your balance.
- Wear comfortable, non-slip shoes.
- Use the muscles in your legs to lift or pull.

If the person is too heavy, get help.

### Bed to chair

To move a person from bed to wheelchair, put the chair close to the bed and lock the wheels. If the person is not strong enough to push up with his or her hands to a sitting position, place one of your arms under the person's legs and your other arm under his or her back. Move the person's legs over the edge of the bed while pivoting his or her body so the person ends up sitting on the edge of the bed.

Keep your feet shoulder-width apart, your knees bent and your back in a natural straight position.

If the person needs assistance getting into the chair, face the patient, place your feet shoulder-width apart,

and bend your knees. Position the person's feet on the floor and slightly apart. The person's hands should be on the bed or on your shoulders. Place your arms around the person's back and clasp your hands together, nurses, physical therapists, and others in hospitals often use lifting belts, which are fastened around a person's waist. The caregiver grasps the belt when lifting the patient. Hold the person close to you, lean back and shift your weight. Pivot toward the chair, bend your knees, and lower the person into the chair. The person should have both hands on the arms of the chair before you lower him or her down.



## Meet Us in St. Louis

**TMA's 2010 Annual Conference will be September 23-25 at the Hilton at the Ballpark in St. Louis, Missouri. Mark your calendar now! Hope to see you in St. Louis next September.**