



SUMMER 2009

For the inflammatory myopathies

TMA has moved

The Myositis Association has a new address and phone number. Reach TMA at:

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2009 Annual Conference

This is a conference you're not going to want to miss. There's still time to register for TMA's Annual Conference in Charlotte, NC. Find out more, page 8. Register at www.myositis.org.

Myositis Awareness Day

Myositis Awareness Day is coming -- September 21! Create awareness of myositis in your community. Visit TMA's website, www.myositis.org for ideas. Or contact Quineesa Smith at quineesa@myositis.org.

In this issue

Sick humor.....	1
Fundraising 101	2
Respiratory devices	3
Myositis studies	4
Transferring	6
IVIG.....	7
Annual Conference	8

Sick humor: Carla's story

Singer, songwriter and comedienne Carla Ulbrich will be the opening speaker at TMA's Annual Conference, September 10-12, in Charlotte, North Carolina. Carla uses the universal challenges of chronic disease to create parodies of popular songs.

When Carla Ulbrich was a child playing guitar, piano, flute, tuba, clarinet and piccolo, she had no idea that her instruments would show her a path through the pain and despair that would threaten to derail her life.

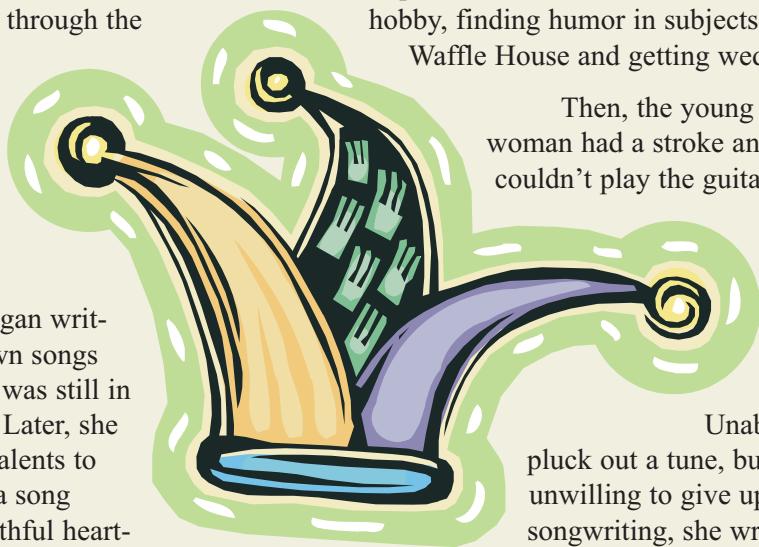
She began writing her own songs while she was still in her teens. Later, she used her talents to compose a song about youthful heartbreak: "Writing has always been my safe haven when I'm going through something that no one around me can really understand," she said. "For example, my first song was about a relationship that was tanking. I had just graduated college and my folks had moved, so I had no friends to talk to, and my folks were scrambling around with the move."

It wasn't long before things went from bad to worse: "When I was first diagnosed with an autoimmune disease at age 25, I felt like a complete failure," Ulbrich said. "Just as I was

supposed to be getting out on my own, I fell on my face. And my family was so devastated I couldn't talk to them about it. My job fired me for being sick."

Her church "fired" her, too, because she didn't respond to spiritual healing efforts. "I felt entirely alone," Ulbrich said, "So I started writing songs about my illness." As her health improved, she continued with her new hobby, finding humor in subjects like Waffle House and getting wedgies.

Then, the young woman had a stroke and couldn't play the guitar.



Unable to pluck out a tune, but unwilling to give up her songwriting, she wrote parodies of existing songs.

"I had a lot to be frustrated about," she said. "Being able to continue writing lyrics was a gigantic relief for me." She found comfort in this strange paradox: "I forgot all my troubles when I was writing, even though I was writing about my troubles."

Her life that summer was pretty bleak: "My kidneys were barely working, so my legs and feet were so swollen I couldn't wear shoes. I wore 'Snoopy' slippers that whole summer, to the doctor's office, to the drugstore." A cane for balance completed

Continued on page 2

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Sick Humor,

Continued from cover

her ensemble: "Well, I was quite the fashion plate," she said.

Eventually she gained just enough strength to play a few chords, but not on the guitar: "It was very painful to push down on the steel strings, so I got a cheap ukulele on eBay."

Ulrich was practicing the first song in the instruction book, "Little Brown Jug," except she had to keep putting the instrument down to go to the bathroom. "I was on diuretics for the swelling in my legs, so I was always in the bathroom. On that particular day, I was doing this kidney test where you collect all your pee in a jug for 24 hours, then bring it in to the lab for testing. The jug was brown. A song was born." During that time Ulrich wrote another song on the same topic, "On the Commode Again."

Another song had a kind of irony: "I wrote one called 'Sitting in the Waiting Room' about being bounced from specialist to specialist and sitting there waiting for hours after my appointment time. I actually worked on this one in the waiting rooms. It helped keep me from getting mad," she said. "Sitting in the Waiting Room" uses the music of the popular 60s song by the Dave Clark Five, with the refrain "over and over and over again." This song really touches a nerve: "Pretty much every audience I play for bursts into applause at the 'Sitting in the Waiting Room' song," she said. There's another song about her eight days in the hospital ("Patient 2946065"). "Unfortunately," she says, "my experience of being depersonalized is all too common, and so folks cheer when they hear me taking our health care system to task."

Ulrich says she's painfully aware that it's not all funny: "While we are suffering from a very real and frustrating illness, it does not have to rule your life. There is life after diagnosis.

We are not victims. There are things we can do to improve our situation and to make the most of it."

She said that being forced to slow down can have its benefits. "By remaining hopeful and solution-oriented, we can regain quite a bit of our quality of life. We can get back our laugh, our smile, our hope, joy and meaning in our lives."

Ulrich adapts her selection to the crowd: "When I have the opportunity to play for patients and caregivers, that is truly the best audience for my 'sick humor' material." When she plays for a mainstream crowd, she also tries to relate to a common experience, like dating when you're older. As for health professionals: "Nurses and caregivers love what I do. They are on the front lines and they are just as frustrated as we are about how hard it is to give and receive good care." She says doctors are a mixed bag: "They're not as likely to laugh at themselves."



Fundraising 101: Getting back to the basics

We all remember the famous phrase, "Elementary, my dear Watson." Sherlock Holmes said this to his faithful sidekick, usually when Watson discovered that something was much easier than he had initially assumed.

This is true for fundraising. Of course, we all think of it as painstaking work involving face-to-face solicitation of family, friends, and even strangers, to support our cause. However, this isn't true for all types of fundraising campaigns. TMA's online campaign system makes it easy for anyone interested in raising funds to do so.

Take JDM patient, Peyton Hutchins, a student. Peyton wanted to do "something" to help, and she didn't let her age stand in her way.

She began her campaign aiming to raise \$3,000. "All I had to do was send a few emails out with the link, and before I knew it donations were coming in left and right. It is such a great tool to raise money for TMA and get the word out about myositis," she said. Peyton was also able to get her school interested in helping raise awareness about myositis.

"As I was sending e-mails to friends and family, the editor of my college newspaper e-mailed me and asked if she could interview me for the school paper. She did a very nice interview and my story was on the front page! That got the word out to the local community and before I knew it I was receiving donations from people I didn't even know, who had read my story and wanted to help. And it all started with the online campaign!"

KIT support groups have also taken advantage of the online fundraising system, with great success. The southwest Florida support group wanted to raise funds easily and quickly. They contemplated a few options and chose the online method.

"The SW Florida KIT wanted to help TMA raise money for myositis research. We wanted easy and we wanted major impact. Easy was sending an e-mail to friends and relatives, asking them to support us. Easy for them was to go to TMA's website and make a donation. The major impact resulted from people giving over \$10,000," said Marianne Moyer, the support group's leader.

What Marianne means by "easy" is this: you set up your campaign page through My TMA; you write a short message to your donors telling them why you'd like them to support you. Maybe you put your picture up as well; you indicate your goal amount, whatever you are comfortable with raising; you send an email to your friends and family members that contains a link to your donation page;

donors make secure donations to your campaign, online, quickly and easily. That's it.

Online campaigns also extend beyond the borders of the United States, allowing those in other countries to use this system to raise funds as well. Mike Coates, myositis patient in Kelowna, British Columbia, is currently sponsoring a campaign to help TMA and myositis patients. "I have used the online campaign to raise several hundred dollars for myositis research, but I am still working towards the goal I set. I found the website easy to use. The good part about it is that you can copy and paste your donation website address into an email and send to friends, relatives or acquaintances to help raise funds. That makes it easy for them to donate to your campaign. It is important that we all try to raise funds to help find a cure and beat this disease," Mike commented.

The face of fundraising has changed. There are simpler, quicker, ways to request support from friends and relatives that require less interpersonal interaction and are extremely secure. If you want to do more to help myositis patients, let TMA staff know, and consider an online campaign. After all, "It's elementary, my dear Watson."



New labeling regulations for respiratory devices on planes

If you have respiratory problems and plan to fly, make sure you understand the new labeling requirements for ventilators, respirators, positive airway pressure devices like CPAP and BiPAP, and other personal oxygen devices.

The new Department of Transportation rule, effective May 13, changes existing Federal Aviation Administration (FAA) regulations.

Those not in compliance may be refused a seat. Here's the wording:

"U.S. carriers permit individuals to use electronic respiratory assistive devices in the passenger cabin so long as the devices have been tested and labeled by their manufacturer(s) as meeting the applicable FAA [Federal Aviation Administration] requirements for medical portable electronic devices..."

If there is no label on the passenger's respiratory equipment, the airline may deny a seat on the plane. But if the label is present, the airline must allow the passenger to board.

Airlines may require travelers to have enough battery power to operate their respiratory equipment for at least 150 percent of the estimated maximum flight time, and may refuse them if they don't.

Some airlines ask passengers flying with respiratory equipment to give notice to the airlines at least two days in advance, and ask them to show up at the gate one hour earlier than normal boarding time so airline staff can confirm that the equipment is properly labeled.

Passengers should check with their specific air carrier well in advance of their flights to learn the regulations.

Find the new regulations, as well as questions and answers, at

http://airconsumer.ost.dot.gov/rules/FAQ_5_13_09.pdf



Myositis studies examine myositis vaccine, osteoporosis, exercise, herbal tradition

Common root from Chinese medicine shows promise

A major challenge in treating autoimmune disorders is suppressing inflammatory attacks without shutting down all immune function. Now, a drug from Chinese medicine shows potential in mice for a more targeted approach. Researchers are cautiously predicting that the treatment may trigger a revolution in treating certain kinds of autoimmune disease.

In both mice and humans, a drug derived from the hydrangea root inhibited development of Th17 cells, newly-recognized immune cells recently implicated in multiple autoimmune disorders without altering other kinds of T cells involved in normal immune function.

The hydrangea root substance, halofuginone, used for centuries in traditional Chinese medicine, shows promise in treating a variety of autoimmune disorders, report researchers from the Program in Cellular and Molecular Medicine and the Immune Disease Institute at Children's Hospital Boston (PCMM/IDI), along with the Harvard School of Dental Medicine.

In the June 5 edition of "Science," researchers also demonstrate that halofuginone reduces disease pathology in a mouse model of autoimmunity by halting the disease process the TH17 cells trigger, and is selective in its effects. Another benefit of the substance is that it has the potential to be taken orally, a far less expensive treatment than injection or infusion. "This is really the first description of a small molecule that interferes with autoimmune pathology but is not a general immune suppressant," says Mark

Sundrud, PhD, the study's first author.

Identified in 2006, Th17 cells have been implicated in a variety of autoimmune disorders including inflammatory bowel disease, rheumatoid arthritis, multiple sclerosis, type 1 diabetes, myositis, eczema and psoriasis. After a series of studies, researchers found that halofuginone acts by activating a biochemical pathway known as the "amino acid starvation response," which typically protects cells when amino acids, essential building blocks of proteins, are in short supply. When

medicine, and has been used as an anti-malarial agent. Decades ago, the U.S. Army tried to improve upon the anti-malarial properties of halofuginine without success. It has been in clinical trials for scleroderma, but because it is now in the public domain, the pharmaceutical industry has not shown interest in further developing it therapeutically.

But halofuginone, or some yet-to-be developed derivative compound, could potentially be used to address any autoimmune or inflammatory disease related to Th17 cells by activating the AAR, the researchers say. "This recalls the actions of cyclosporin A and FK506, two other immunosuppressive drugs that block the activity of calcineurin," said Dr. Rao, a senior investigator.

"Calcineurin is present in all cells, but selectively prevents the rejection of heart, lung, liver and bone marrow transplants when given to patients. These drugs revolutionized transplant medicine when they were introduced over 20 years ago, and halofuginone may herald a revolution in the treatment of certain types of autoimmune/inflammatory diseases."



excess

amino acids were added to cultured T cells exposed to halofuginone, the AAR didn't switch on, and Th17 cells were able to develop. Conversely, the researchers were able to inhibit Th17 differentiation simply by depleting amino acids, thereby inducing the amino acid starvation response.

Halofuginine is one of the 50 fundamental herbs of traditional Chinese

Malcolm Whitman, PhD and Tracy Keller, PhD, of the Harvard School of Dental Medicine, and Anjana Rao, PhD, of the PCMM/IDI, were the study's senior investigators. The study was funded by grants from the National Institutes of Health, the Juvenile Diabetes Research Foundation, and the Cancer Research Institute.

Researchers recommend once-yearly therapy to prevent prednisone-related bone loss

In the 2009 "Lancet" article, "Zoledronic acid and risedronate in the prevention and treatment of glucocorticoid-induced osteoporosis," researchers found that a once-yearly infusion of zoledronate is safe and could be more effective than daily or weekly oral bisphosphonate therapy in the treatment of glucocorticoid-induced osteoporosis.

Bone loss and an increased risk of fracture are serious and common effects of long-term prednisone therapy, and are usually prevented by frequent treatment with an oral bisphosphonate such as risedronate.

Because those taking prednisone for chronic disease often are taking many other drugs, the treatment management becomes extremely complex, explained the study's lead investigator, David Reid. "Treatment with an additional drug required to be taken in a fasting state daily or even weekly can be problematic, potentially leading to poor adherence and compliance. To have an effective medication that could be administered very infrequently could be extremely valuable." A further potential benefit of zoledronate is its quick bone-protecting effect, beginning after only nine days. This is important because some patients report serious reactions in losing bone mineral density and sustaining fractures just a few months after beginning prednisone therapy.

In a multicenter, double-blind, controlled study, 833 patients (mean age 57.1 years) receiving daily oral prednisolone were randomly assigned to receive one intravenous infusion of the potent bisphosphonate zoledronate (5 mg) followed by daily oral placebo, or a placebo infusion followed by 5 mg daily risedronate, for 12 months. To compare the effects of zoledronate and risedronate on bone loss, the

researchers measured changes in bone mineral density at the lumbar spine, total hip, femoral neck, trochanter and distal radius at regular intervals from baseline to the end of the study period.

At 6 and 12 months, both drugs showed increases in bone mineral density at all measurement sites, suggesting that zoledronate is not inferior to risedronate in this respect. Interestingly, however, even after 6 months of therapy, improvements at the lumbar spine, total hip and femoral neck were significantly greater in most patients who had received the single intravenous infusion of zoledronate than in those assigned daily risedronate therapy, and these differences were maintained at 12 months.

The investigators found similar numbers of new vertebral fractures in both groups—just five in the zoledronate group and three in risedronate-treated patients. "Fractures are the ultimate adverse effect of glucocorticoid-induced osteoporosis," says Reid. "These were very rare in this study compared with previous work in the field, for example where placebo was compared with risedronate, suggesting that both therapies are effective in preventing this problem." Adverse events were significantly more frequent in patients receiving zoledronate than in those receiving risedronate, but only during the first 3 days of treatment, after which the rate was similar in both groups. Deaths were similar in the two groups, but none were related to the treatment.

These findings from a large, well-designed study show that an intravenous infusion of zoledronate is as good, if not better, than risedronate for inhibiting bone loss and preventing fractures in patients on prednisone. "As zoledronate has now been licensed in the US and Europe for the treatment of glucocorticoid-induced osteoporosis," says Reid, "it will hopefully start being used clinically to avoid osteoporosis associated with glucocorticoid use."

Japanese study finds intra-venous cyclophosphamide completely resolves dermatomyositis with refractory cutaneous vasculitis

Drs. Tsujimura, Saito and Tanaka of the First Department of Internal Medicine, University of Occupational and Environmental Health, School of Medicine in Kitakyushu report a case study in "Internal Medicine."

Cutaneous ulcers associated with vasculitis are rarely reported in adult dermatomyositis and are often resistant to treatment, resulting in a poor prognosis. There is no general treatment strategy and the effects of various treatments have never been confirmed by blood tests. A 43-year old man with dermatomyositis developed refractory multiple skin ulcers which were revealed as vasculitis by skin biopsy. Repeated intravenous cyclophosphamide pulse therapy without high-dose corticosteroid therapy resulted in complete resolution of the ulcers without adverse effects or severe complications. A repeat biopsy confirmed complete remission of vasculitis. The authors conclude that repeated intravenous cyclophosphamide is a useful treatment for induction of clinical remission of dermatomyositis with cutaneous vasculitis.

Exercise improves aerobic capacity in IBM

Writing in the June edition of the "Journal of Clinical Neuromuscular Disease," Australian researchers Johnson, Collier, Edwards, Philippe, Eastwood, Walters, Thickbroom and Mastaglia report on a 12-week exercise program in seven inclusion-body myositis patients. The study aimed to investigate the effects of a combined functional and aerobic exercise program on aerobic capacity, muscle strength, and functional mobility in a group of patients with sporadic inclusion body myositis.

Proper techniques protect caregiver and patient

It's no secret that caregivers live physically demanding, stressful lives. They have a 20 percent higher mortality rate than the general population of the same age, stick themselves with needles, neglect their diet and lose sleep. But by far the most common complaint of caregivers is back injury, affecting more than half of all caregivers at one time or another.

Protect your back, counsels Anne Williams of Mountainside Therapy, a Virginia clinic. You do this, not by keeping a totally rigid back, but by preserving the natural curve of your back at all times and by using strategic positioning and leverage to balance patients who have limited ability to move themselves.

One strategy Williams recommends is the dependent standing pivot, a transfer technique for patients who are unable to stand independently, but who can bear some weight on their legs.

To properly help someone transfer from a wheelchair to another surface (called a "destination surface"), follow these steps:

- Place the wheelchair at a 45 degree angle to the bed or chair or examining table. Make sure it's locked.
- Place the patient's feet on the floor, raise the footplates and swing them out of the way or remove them.
- Remove the armrest nearest the transfer destination.
- Move the patient forward in the wheelchair.
- Provide stability for the patient's legs and feet by blocking the patient's feet and knees. This is done by placing your feet and knees outside the patient's and holding the patient's knees between yours.
- Staying close to the patient, place your hands under the patient's

buttocks or around the patient's belt in back.

- Ask the patient to place his arms and hands around your upper back. Make sure that the arms are not around your neck. This step is to control the upper body of the patient, not for the patient to "hang" on your upper back.
 - Keeping the curve in your spine, establish a count, so you and the patient can synchronize your actions. As you count, begin a rocking motion in time to the counts to build momentum.
 - On the command "up" straighten your legs and lift the patient from the wheelchair. Lift only high enough to clear the wheelchair and the height distance between the wheelchair and the destination surface. Pivot towards the surface, rotating the patient to the proper sitting position.
 - Do not release the patient until he or she is in a position that can be maintained independently.
- To sit or stand from a wheelchair**
- Always lock the wheelchair wheels, positioning against a wall if possible.
 - Swing footplates and footrests out of the way.
 - Have the patient sit on the front edge of the seat and place the feet flat on the floor below the front edge of the seat.
 - Have the patient put his or her hands on the wheelchair for initial assistance in pushing up.
 - Once the patient is standing, hand any assistive devices to the patient.
 - If the assistive device (such as a walker) is used to help the patient push up, one of the patient's hands may be placed on it; the other on the armrest.
- The standing movement should be a controlled, continuous motion.
 - Stabilize the assistive device while the patient pulls himself up.
- Assisting someone from the floor**
- Make sure the patient is not injured before helping him or her to get up.
 - Have the patient crawl towards a surface that can be used to help raise him up.
 - Have the patient bring the stronger leg up to a half-kneel position and use that leg to push up, while also pushing up with the hands.
 - If the patient can't assume a half-kneel position, place a stool next to the patient and help the patient sit on the stool.
 - Assist the patient from the raised surface into a chair, using the techniques of the dependent pivot transfer.
- Tips for home caregivers**
- If you are taking care of a family member, you are at greatest risk for back pain when you are:
- Pulling a person who is reclining in bed into a sitting position.
 - Transferring a person from a bed to a chair.
 - Leaning over a person for long periods of time.
- When you lift or move a patient:**
- Maintain the proper alignment of your head and neck with your spine.
 - Maintain the natural curve of your spine; do not bend at the waist.
 - Avoid twisting your body when carrying a person.

- Always keep the person who is being moved close to your body.
- Keep your feet shoulder-width apart to maintain your balance.
- Use the muscles in your legs to lift or pull.
- If the person is obviously too heavy for you alone, get help.

Assistive devices that help in transferring:

- Transfer belts: a wide, webbed belt, up to five feet long, that is placed around a patient's waist. It is used to stabilize and direct the patient, not to lift.
- Hydraulic lifts: a mechanical device used for heavy patients and those who cannot bear weight on their legs. They are never used to wheel patients to another location. Caregivers must be specially trained to use lifts safely.
- Slide boards: a smooth plank of hard material that is placed between two surfaces of equal height such as a bed and a chair. The patient slides across the "bridge" with assistance from the caregiver.
- Transfer boards: a full-length board used to transfer patients, in a flat, lying-down position. Usually used for patients who must keep their spines straight because of spinal injury or suspected spinal injury.
- Draw sheets: a sheet placed beneath the patient's hips and shoulders used to turn or transfer a patient who must remain lying down. Never use a draw sheet for a patient who has or is at risk for a back injury.

TMA's Annual Conference in Charlotte, NC, will feature several hands-on sessions with trained occupational therapists who will demonstrate transferring and bathing.

Myositis studies,

Continued from page 5

Aerobic capacity, muscle strength, and functional capacity assessments were conducted on seven participants with sporadic IBM before and after a 12-week exercise program, which included resistance exercises and aerobic stationary cycling 3 times a week on alternate days. The authors found that the aerobic capacity of the group increased significantly (38%), and significant strength improvements were observed in four out of the five muscle groups tested. The exercise program was well tolerated, and there was no significant change in the serum creatine kinase level after the exercise period.

The study concluded that an aerobic exercise program can be safely tolerated by patients with sporadic IBM and can improve aerobic capacity and muscle strength when combined with resistance training. These findings indicate that aerobic and functional muscle strengthening exercise should be considered in the management of patients with IBM.

"Vaccine" helps in mouse model of inclusion-body myositis

Scientists at the University of California at Irvine found that immunization with amyloid-beta improves a mouse version of inclusion body myositis and motor impairment in transgenic mice.

Kitazawa, Vasilevko, Cribbs and LaFerla published their findings in the May edition of "Neuroscience."

The authors said the hallmark pathological features of inclusion-body myositis include T-cell mediated inflammatory infiltrates and aberrant accumulations of amyloid-beta and other proteins in skeletal muscle.

A large body of work indicates that aberrant amyloid-beta accumulation contributes to the degeneration of muscle in IBM. The researchers investigated whether active immunization to

promote clearance of amyloid beta from affected skeletal muscle fibers would improve the IBM-like muscle disease features as well as motor impairment in a genetically altered mouse.

They found that active immunization markedly reduces intracellular amyloid beta deposits and lessens the motor impairment compared with untreated mice. The antibodies to amyloid beta produced in the immunized mice blocked the toxicity caused by the protein *in vitro*, providing a possible key mechanism for the functional recovery. These findings provide support for the hypothesis that amyloid beta is one of the key pathogenic components in IBM pathology and subsequent skeletal muscle degeneration.



Concerned about Access to IVIG?

Have you found IVIG important to your treatment? Have you experienced problems finding places to receive your IVIG treatment? Do you want to make sure Congress knows that IVIG is a vital treatment for many living with myositis? Then do something now to make sure Washington knows!

Contact your Members of Congress and let them know that you want them to support HR 2002 and S 701 – the Medicare IVIG Patient Access Act of 2009.





SEEKING ANSWERS
The Myositis Association
2009 Annual Conference
September 10-12, Charlotte, NC



THE MYOSITIS ASSOCIATION

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Seeking Answers is the theme of TMA's 2009 Annual Conference. Finding answers to questions about treatment, adapting to the limitations imposed by myositis, and ultimately finding a cure for myositis are what those with the disease seek.

This year's Conference will address all of these interests. Whether you're looking for practical nuts-and-bolts information about myositis or you want to learn about new treatments and the potential for a cure, you will find the answers to your questions at TMA's Annual Conference in Charlotte, North Carolina.

Register online at www.myositis.org!

THE OUTLOOK