

Speak out for publicity, recognition

TMA has added an advocacy section to the web site, with everything you need to find media contacts in your area, work with the local media, and become an advocate for research and education.

Why raise awareness of myositis? Introducing others to myositis leads to quicker, more accurate diagnoses; better collaboration among treating physicians and researchers; increased funding for research into all forms of autoimmune disease; and more.

What can you do? Start small: teach your friends, neighbors or child's classmates about myositis and how it affects people daily. Or work on a broader scale: contact your local or state representatives to encourage them to support legislation important to myositis research funding.

TMA members have created awareness in different ways - organizing local golf tournaments and walkathons, designing myositis magnetic ribbons, and reaching out to local media to share their stories with their communities. Contact TMA with your ideas for bringing attention to myositis. Or visit the web site at [www.myositis.org](http://www.myositis.org) and click on "Advocacy."



## Dr. Robert Buckman talks about being a patient, becoming a healer

It's a story too familiar to many myositis patients and their families. When Robert Buckman battled dermatomyositis, it bludgeoned him with just about every symptom and syndrome imaginable. Buckman, an Englishman diagnosed in London, suffered pain; weakness; rashes; bouts of cold, fever and itching; lung problems; swallowing problems; confusion; and extreme fatigue. Raynaud's Syndrome added the characteristic freezing hands and feet; prednisone added sleeplessness, manic periods, depression and weight gain. One day, the previously healthy 39-year-old looked in the mirror and saw a stranger. The man looking back seemed to be wrapped in gauze with slits for eyes. He had sticks for arms and legs, a swollen belly and face, and purple blotches where his skin used to be. A final indignity (in his words): "my bum had disappeared." The doctor warned his wife that he might very well die. For weeks he hovered at a place where, he realized one long, horrible night, if it got any worse, death would be a blessing.

And it seemed certain to get worse. Prednisone wasn't helping. Plasmapheresis gave him one day of blessed clarity but then once again made him worse. In desperation, his physicians tried a combination of plasmapheresis and cyclophosphamide, which eventually stabilized him and set him on a long, difficult journey back to better health. The experience forever changed the way Buckman, at that time a physician seeking a PhD in

Oncology, as well as a successful comedian and comic writer, would look at health, his patients, and the communication between doctor and patient.

From doctor to patient and back again

He writes about his life and his bout with DM in his popular book, *Not Dead Yet: A Long Strange Trip from Doctor to Patient and Back Again*, and has written several books for doctors and families of those who are seriously ill. Buckman teaches communications skills to doctors, wrote an online column for cancer patients and collaborates with his long-time friend and comic partner John Cleese on videos designed to help patients understand their conditions. Buckman had a second chance to observe the practice of medicine as a patient more recently, when an inflammation of his spinal cord left him with numbness on one side of his body. That episode, along with the chance to work with Cleese on the videos, convinced him to devote more time to writing and performance and continue his medical practice part-time.

Looking back on his ordeal with DM, Buckman believes that his medical background helped keep him optimistic. "After all, I was a man of science and I believed in it," he said in a recent interview. Still, he had moments of despair. One problem - common, he believes, in physicians, but also in

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Dear Friends,

This issue of *The Outlook* focuses largely on research and leading full, enriching lives despite having myositis. These are areas of focus for TMA and will remain so throughout the year.

In this issue, you will learn about a physician who has discovered firsthand what it is like to live with myositis and how physicians need to approach patients who have a chronic disease. You will also read about additions to our Medical Advisory Board, reports on past research funded by The Myositis Association, and six new grants and fellowships funded by TMA at the beginning of the year.

TMA held a conference specific to s-IBM in January, with some of the best researchers in the world meeting to discuss myositis and suggest possible avenues for future research, and we include a short summary of that conference in this issue of *The Outlook*. A Juvenile Myositis Conference for families and children will take place at the end of April, and smaller regional JM events will be occurring in Ohio, Pennsylvania, North Carolina, Connecticut and Georgia.

We are currently planning for the 2005 Annual Conference in Cleveland. Research into all forms of myositis will be prominently on the agenda as well as a continuation from last year's Conference of looking at ways exercise, nutrition, spiritualism, and humor can help one cope with myositis.

This year promises to be a year of specific achievement and accomplishment for TMA, and I hope that it is a productive year for you as well.

TMA staff is here to serve the members of The Myositis Association and the scientists and researchers studying myositis. Please call on us at any time if you have questions or think we can be of assistance to you.

A handwritten signature in black ink, appearing to read 'Bob Goldberg'.

Bob Goldberg  
Executive Director

# INTERNATIONAL SCIENTIFIC CONFERENCE ON SPORADIC INCLUSION-BODY MYOSITIS

*TMA Medical Advisory Board members Valerie Askanas, MD, PhD, Professor of Neurology and Pathology at the University of Southern California Keck School of Medicine in Los Angeles, and Marinos C. Dalakas, MD, Chief, Neuromuscular Diseases Section at the National Institute of Neurological Disorders and Stroke, NIH, in Bethesda MD, organized the first international scientific conference on sporadic inclusion-body myositis January 26-28, 2005, in Los Angeles. W. King Engel, MD, Professor of Neurology and Pathology at the University of Southern California Keck School of Medicine in Los Angeles, assisted in leading and developing the program agenda.*

TMA sponsored this very successful first international scientific Conference on sporadic inclusion-body myositis. The full title of the Conference was *Frontiers of Research Potentially Relevant to Treatment of Inclusion-Body Myositis*. Sporadic IBM is so named because, although it may have genetic components, it is not an inherited illness like hereditary IBM.

The purpose of this highly focused Conference was for the prominent scientists - all of whom were specifically invited - to identify priorities for further research and treatment. Those invited were leaders in research fields related to the disease process of s-IBM. Conference organizers invited the world's leading experts on s-IBM, and also experts in the fields they identified as related: cellular disturbances in Alzheimer's Disease, protein degradation, oxidative stress, and immunology. Among the presenters was 2004 Nobel Laureate in

Chemistry, Dr. Aaron Ciechanover from Israel. One of the major goals, said Dr. Askanas, was to involve Conference participants who are world-class basic scientists but who have not yet worked on s-IBM. She reported that the Conference was successful in this regard, as the attendees expressed their interest in participating in s-IBM research and developing various collaborations.

## Conference summary

Dr. Askanas provided the following report. The proceedings will be published in *Neurology*, the journal of the American Academy of Neurologists.

Sporadic inclusion-body myositis is the most common progressive muscle disease in people older than 50. It causes progressively severe weakness of all four limbs but no impairment of mental function. No successful treatment is currently available. Neither the cause of s-IBM nor the exact disease process is known. Two theories predominate: an amyloid-beta-related degenerative process, and an autoimmune dysregulation. An intriguing feature is the accumulation within s-IBM muscle fibers of amyloid- $\beta$  (A $\beta$ ), phosphorylated tau and several other Alzheimer-characteristic proteins. There is also prominent evidence of misfolding of proteins. The pronounced T-cell inflammation is also striking, characterized by activated, antigen-driven, cytotoxic CD8<sup>+</sup> T cells.

The Conference opened with a lecture by Caleb E. Finch, PhD, a world expert on aging from the University of Southern California in Los Angeles. The scientific program opened with a lecture by Dr. W. King Engel. Dr. Engel devoted his presentation to clinical features, pathologic

diagnostic criteria and the clinical course of s-IBM. In order to demonstrate to the basic scientists the clinical issues and the degree of disability caused by s-IBM, Dr. Engel presented two volunteer patients as part of his lecture. Two intense days of lectures followed.

Dr. Ciechanover gave a very stimulating, one-hour, after-dinner lecture, presenting the work that led to identifying the important role of ubiquitin in the degradation of proteins, the research that led to his Nobel Prize.

During the meeting and during the breaks, there were lively and intense discussions among the participants. Presentations and discussions at the Conference identified the following areas as worthy of further pursuit in the treatment for s-IBM:

- identify better compounds to treat an inflammatory component;
- develop new approaches to combat intra-cellular amyloidosis;
- seek new compounds to prevent oligomerization of amyloid-b4;
- seek new compounds to increase the function of the 26S proteasome system selectively in muscle.

*Publication and distribution of the supplement is being funded by the Muscular Dystrophy Association. Additional financial support for the Conference was provided by Crescent Healthcare, Inc.*



Patient to healer, from cover

anyone of a helping nature or in a helping profession - is reluctance to

admit that anything is really wrong. "My coping strategy at first was denial," he said. "That's always my first choice. I just kept bashing on."

Buckman was actually appearing in a television series during his early regimen of prednisone. "I got notes from fans who noticed I

had gained weight and wrote me: 'shouldn't I eat less?'" he said. As he got weaker and more frightened, he recalled one visit with a medical mentor, a man with whom he shared a relationship of mutual respect but no particular warmth. "He said something like, 'Robert, you've got purple blotches all over, you're weak and in pain. This must be terrible for you.'" That simple acknowledgement of his personal suffering made a huge impact on Buckman, and somehow made him feel enormously better.

The arrogance of the healthy

What didn't help? "Well, what really didn't help is when people sent me magnets, or herbal preparations, or astrology books. It was appalling. Other demoralizing contributions were recommendations to do this or that or theories on what I should have done before to prevent my disease," Buckman said. He calls this the "arrogance of the healthy," the unspoken belief by those who have never suffered from a chronic disease that the disease is somehow the patient's fault. "This is natural," he said, "because people don't want to believe that ill-

ness can randomly come to them, that somehow they can prevent it. But it's damaging to the patient." Buckman writes about ways in which families



Robert Buckman, DM patient

and friends can help patients in *I Don't Know What to Say*, an important book for anyone wondering how to support a seriously ill friend or family member. "Take your cue from them," he said in the interview. "If they use humor as a coping strategy, it's fine for you to do that, too." Although Buckman is certainly an expert in humor, he also waits for cues from his patients before he injects humor into his conversations with them.

"I tell families and friends wondering what to do to offer practical, 'bite-size' help," he said. "Ask what food they like to eat and bring a meal at a time previously arranged. Take the children to a movie or for an outing of some kind. Arrange a time to come by and relieve the caregiver. Take shirts to the laundry. Don't ever underestimate the simple act of sitting and listening to the patient. These are practical, helpful things and they make the patient and family feel less alone." He advises friends to avoid questioning the patient's medical care or relating their own tragic interfaces with illness.

Buckman has some coping strategies for patients, too. "Try to really understand your limits and do the best you can within those limits," he said. He finds many patients spend all their energy wishing their limits were not there, energy better spent finding meaning within the life that's possible for them. Also important: myositis patients should follow whatever exercise program is appropriate for them, he says - obviously, they shouldn't exercise when they're in severe pain, but some exercise is appropriate for almost every stage of illness, both for

its physical and psychological benefits.

As a doctor, a performer, an author, a patient and someone fascinated by the complexities of human communication, Buckman is in a unique position to help doctors with healing skills that benefit their patients. He gives seminars to medical professionals and has written a book for doctors on how best to talk to their terminally ill patients. His interest in the full spectrum of healing skills led him to co-author *Magic or Medicine?*, which traces the history of healing arts through the ages. Buckman believes the "art" of medicine somehow got separated from the "science," and that it was a separation that works to the disadvantage of patients and their doctors. He believes that the narrowing down of medical practice to diagnosis and prescription is part of the reason why people who are sick often seek out alternative treatments without much evidence of effectiveness. In the book, he talks about the healer as someone who helps the patient, providing insight and guidance even for diseases that have no treatment, or diseases that naturally get better over time. A television series based on the book and produced by the authors won a Gemini award, Canada's highest honor for excellence.

Buckman says he believes that doctors are becoming more open to this expansion of their role which, after all, has only been so drastically narrowed in modern times. In his practice, he encourages patients to write down their questions before meeting with him to make sure he's answered everything; and asks them to bring a family member or friend to help them remember the answers. He makes sure that he spends time with his patients when they are fully dressed and seated in a position that gives them comfort and dignity. "In the final analysis," he writes in *Magic*, "diseases need treatment, but human beings need a healer."



ROBERT BUCKMAN: DOCTOR,  
PERFORMER, AUTHOR,  
PATIENT, HUMANIST

Dr. Buckman lives in Toronto, is an oncologist at the Princess Margaret Hospital and a Professor in the Department of Medicine at the University of Toronto. He qualified as a physician from Cambridge University in 1972, completed his training in medical oncology at the Royal Marsden Hospital in London, and emigrated to Toronto in 1985. Buckman has a second career in communication and broadcasting, presenting television science-and-medicine programs first in Britain and then Canada. Besides *Magic or Medicine?*, which won him a Gemini award, he had a series of six one-hour programs called *Human Wildlife - The Life That Lives On Us*, broadcast on Discovery Channel and earning a Gemini nomination.

Buckman appears as a guest on Canadian TV's medical program *Balance* and on *More To Life*. He became Canadian Humanist of the Year in 1994 and has been president of the Humanist Association of Canada since 1999. He also wrote *I Don't Know What To Say - How To Help And Support Someone Who Is Dying*, a guide for friends and family, and *What You Really Need to Know About Cancer - A Comprehensive Guide for Patients and Family*. His autobiography *Not Dead Yet - The Unauthorized Autobiography* was published in Canada in April 1999. His latest book is *Can We Be Good Without God?* Currently he writes and presents a series of medical information videos, called *What You Really Need To Know About...*, with the English actor and writer John Cleese.

*Not Dead Yet: A Long Strange Trip from Doctor to Patient and Back Again* and Buckman's other books are available from Amazon's Canadian web site, [www.amazon.ca](http://www.amazon.ca).



## FOCUS ON RESEARCH: FOREIGN CELLS INVOLVED IN JM INFLAMMATION

Carol Artlett's project, *Characterization of Maternal Microchimeric Cells in Males with Juvenile Dermatomyositis*, was funded in The Myositis Association's first round of research grants. Artlett, BSc, PhD, of Thomas Jefferson University, set out to identify foreign (or microchimeric) cells in the muscle lesions of JM children. Usually, the foreign cells found in JM children come from their mothers. Artlett's research confirmed that children with idiopathic inflammatory myopathies have microchimeric cells circulating at a higher incidence than children who do not have the disease.

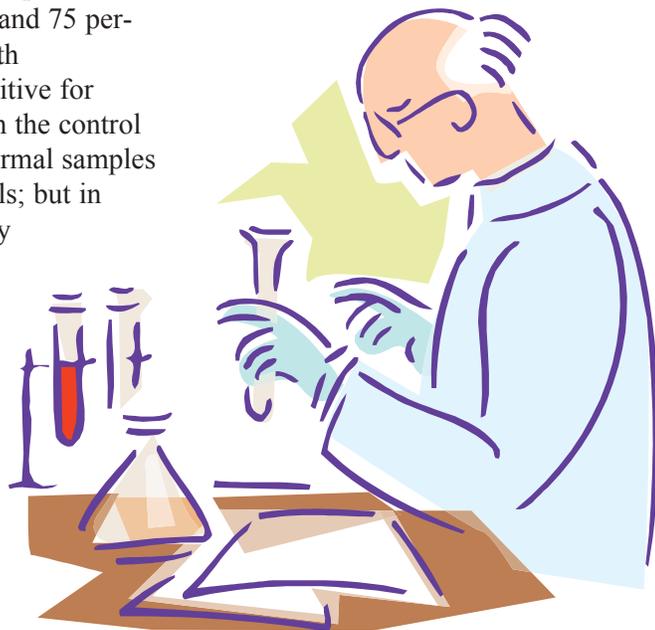
Artlett studied 23 biopsies - 9 juvenile dermatomyositis, 4 juvenile polymyositis, 6 Duchenne's muscular dystrophy, and 4 normal - for the presence of maternal cells. Using a panel of antibodies, Artlett found inflammatory T cells and T cell activation markers. She also inspected the cell nuclei for X and Y chromosomes to determine which cells came from the mother and which were from the patient.

Artlett found that all patients with dermatomyositis and 75 percent of the patients with polymyositis were positive for microchimeric cells. In the control groups, none of the normal samples had microchimeric cells; but in the muscular dystrophy group, all were found to have microchimeric cells.

Artlett also investigated the percentage of the microchimeric cells in different disease groups, and the percentage of T cells that were

microchimeric. Finally, she looked at the concentration of microchimeric cells in the tissue sections and found that all myositis patients investigated had a similar concentration of microchimeric cells as the muscular dystrophy patients had. In the normal muscle, she did not observe any microchimeric cells to be present.

Artlett said the data suggest that microchimeric cells are involved in the inflammatory response in the muscle tissues since they were also found in the inflammatory control (Duchenne's muscular dystrophy), and not in the non-inflammatory control (normal muscle). However, she said, we do not know if these cells are present in the child first and somehow cause the inflammatory response or if they are recruited because other inflammatory cells are present. Artlett and others are continuing research to determine the exact role of these cells in idiopathic inflammatory myopathies.



## New faces for Medical Advisory Board

TMA's medical advisors met recently to elect new officers and members for the upcoming term:

Chair: **Richard Barohn, MD**, Professor and Chair, Neurology, University of Kansas Medical Center

Vice Chair: **Lisa G. Rider, MD**, Deputy Chief, NIEHS, National Institutes of Health

Association Board Member: **Chester V. Oddis, MD**, Professor, Rheumatology and Immunology, University of Pittsburgh School of Medicine

New members elected to the Medical Advisory Board are **Anthony A. Amato, MD**, Vice Chairman, Department of Neurology, Brigham and Women's Hospital; **Michael Harris-Love, PhD, MPT, CSCS**, Physical Therapist, National Institutes of Health Clinical Center; **Joseph Jorizzo, MD**, Professor, Dermatology, Wake Forest University Baptist Medical Center; and **Ingrid F. Lundberg, MD**, Associate Professor, Department of Dermatology, Karolinska Hospital, Sweden.



## Research grants and fellowships awarded by The Myositis Association

The Myositis Association supports research into rare autoimmune diseases polymyositis, dermatomyositis, inclusion-body myositis and juvenile forms of myositis.

To date, TMA has awarded 16 grants and fellowships totaling nearly \$1.8 million. In 2004, three grants and three fellowships were awarded. One of the grants, designated as the Dr. Martha Bishop Challenge Grant, totals \$200,000 over the course of two years and was awarded to **Valerie Askanas, MD, PhD**, a professor of Neurology and Pathology at the

University of Southern California Keck School of Medicine, for her study of the role of myostatin in the pathogenesis and potential treatment of sporadic inclusion-body myositis.

Other grants awarded in this cycle are to:

**Consuelo Lopez, MD**, of Mayo Clinic, Rochester, a fellowship of \$50,000 a year for two years to study the role of chimeric dendritic cells in the inflammatory process of juvenile dermatomyositis.

**Satoshi Okada, MD**, of Stanford University, \$54,472 for a two-year study of the role of granulysin in muscle fiber injury in idiopathic inflammatory myopathies.

**Angelo Ravelli, MD**, of Istituto G. Gaslini, Genova, Italy, \$25,000 a year for two years for a multicenter study of the long-term outcome of juvenile idiopathic inflammatory myopathies.

**Stina Salomonsson, MD**, of the Center for Molecular Medicine, Karolinska Hospital, Stockholm, a fellowship of \$50,000 a year for two years to study the possible connection between IL-1a and muscle function in muscle weakness experienced by patients with idiopathic inflammatory myopathies.

**Conrad Wehl, MD**, of Washington University in St. Louis, a fellowship of \$50,000 a year for two years to study the role of p97/VCP in the pathogenesis of inclusion-body myositis/myopathy.



## Messages from members

*TMA's online bulletin boards provide a sense of community, with messages sharing encouragement, support, reassurance, and information. Here is a sampling of what you'll find in the Community Forum of [www.myositis.org](http://www.myositis.org):*

## Going to the Annual Conference?

I hope to be able to go (depending on health). I have been to the past three and have found them very worthwhile. I have learned so much from the medical panels, breakaway meetings by disease and just by talking with others at the breakfast/lunch or dinner table. - Annette/DM

Really enjoyed the conference in Houston, Vegas as a location just isn't our cup of tea but good conference, and have made lasting friendships from these conferences. - 2cats

## Support for spouses

Does anyone know of a good support group for spouses of patients with myositis? My wife gets discouraged as she goes through this with me and she knows that I have some BBs that I use to ask questions and "bond" with other sufferers. I think that she needs to have some type of support from other wives going through what she is as far as a supporting role and maybe a couple of email pals. I think that it would do her good to be able to vent a little with someone else who knows exactly where she is coming from. - Troy

We went through it last year with complications, so I can sympathize with how scary it can be. When I was pulling apart an old pony shed last year by myself, I would just stop and cry my heart out. I was afraid my husband would never be able to do things like that with me again. This year is starting out totally different, and we have been out snowshoeing together. But there are times I feel I want to hold my breath for fear it will change again. I find myself constantly looking to see if signs of a DM flare up are there and worry that he may not improve further. Knowing we are not alone in this has been very helpful. Best wishes - Michelle

*Editor's note: If your spouse or caregiver is interested in communicating with others, please email [tma@myosi-](mailto:tma@myosi-)*

*tis.org, and we'll help connect him or her with other caregivers who can relate to their feelings and concerns.*



### Camperships for summer fun

TMA offers scholarships for children with JM to join others with the same challenges at summer camps. This is often the first time young patients meet children with JM or with other chronic illnesses. It's a place where they can be understood without having to explain why their skin is red or itchy, why they have to rest frequently, or why they're taking so many medicines.

How can you help? TMA wants every child to have the opportunity to enjoy the thrills of a carefree summer at the camp of their choice. Help us help every child go to camp by donating to the JM campership fund. Contribute to TMA by mail to TMA, 1233 20th Street NW, Suite 402, Washington DC 20036; by phone at 1-800-821-7356; or online at [www.myositis.org](http://www.myositis.org); and let us know your donation is for JM camperships.

Thank you for your support of this invaluable program for JM families!



### Researchers find etanercept helpful in small IBM study

TMA Medical Advisory Board Member Richard J. Barohn, MD, and others studied nine IBM patients who were treated with etanercept (Enbrel) to assess whether the drug - sometimes used with good effect in other forms of myositis - could slow the progression of weakness in inclusion-body myositis (IBM). They treated the group of IBM patients with etanercept, a tumor necrosis factor inhibitor, and monitored disease progression in the patients.

In a retrospective pilot study the patients, meeting accepted diagnostic criteria, received 25 mgs of etanercept

two times over a time period of 11 to 23 months for an average duration of 17 months. The strength of the elbow flexors and handgrip was assessed at the beginning of the trial and again at six and 12 months. The data from the patients in the etanercept group were compared to a control group of six IBM patients who had undergone similar testing but who had not received the drug. The etanercept was well tolerated by the group of IBM patients who received it.

Researchers noted that grip strength improved in IBM patients treated with etanercept. In untreated patients, grip strength worsened. This difference was significant at 12 months. This preliminary data suggest that etanercept may affect disease progression in IBM. The researchers concluded that longer, prospective, controlled studies are warranted.



### New test may replace biopsy

Use of diffusion-weighted imaging, a method of magnetic resonance imaging based on the movement of water within cells and tissues, noninvasively assessed 14 patients with dermatomyositis or polymyositis, Jane H. Park, PhD, said at the annual meeting of the International Society for Magnetic Resonance in Medicine. This is one of the first applications of diffusion-weighted imaging for the assessment of muscle diseases, reports the Society. This test has previously been used successfully in tests of the brain, said Dr. Park, a professor of molecular physiology and biophysics at Vanderbilt University in Nashville, Tenn. A news release by the Society said this test might also be used for the assessment of joints in patients with rheumatoid arthritis.

The test uses water diffusion patterns to show a change in inflammation, and results from the preliminary study showed that DM patients with

clinical improvement during treatment over a certain time period also had improvements in the water diffusion patterns on the special MRI.

The PM patients who were not being treated also showed changes on the serial imaging indicating fat replacement of muscle tissue consistent with the muscle atrophy of their disease progress. Park hopes this type of MRI will allow physicians to quantify changes in muscles or joints, she said at the meeting. It would also help diagnose and evaluate patients who are in the early stages of these diseases and would allow for noninvasive serial assessment of patients, eliminating the need for repeat biopsies, an invasive procedure.



### Itchy skin? Wash with care

At a meeting sponsored by the Sjogren's Foundation, Dr. Darren L. Casey said that skin problems in Sjogren's and other autoimmune disease like dermatomyositis can be worsened by the type of skin care patients choose. Dr. Casey, a dermatologist in private practice in Atlanta, told the group that washing too aggressively gets rid of the protective barrier that occurs naturally on skin, resulting in chronically dry, itchy, and scaly skin.

Dr. Casey suggests that patients limit washing to 20 minutes and recommends using Cetaphil, Dove, or Oil of Olay gentle skin cleansers. Use of emollients such as Aquaphor immediately after a bath or shower can help retain moisture if lotions and creams do not provide relief. For patients who don't respond to over-the-counter products, prescription humectants such as Carmol 20 and Carmol 40 may help, Dr. Casey said. He also encourages patients to use humidifiers and fragrance-free laundry detergents to reduce irritation of dry skin.



# Plan ahead for TMA's 2005 Annual Conference

October 6-9 in Cleveland

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## MEET DR. BUCKMAN IN CLEVELAND

Dr. Robert Buckman, DM patient, author, physician and actor, will be the keynote speaker for TMA's Annual Conference. Buckman is featured in this issue of *The Outlook* (see page one), and is currently working with Monty Python's John Cleese on a series of patient information videos. He also sees patients at his oncology clinic in Toronto and speaks extensively on doctor-patient communication.



THE MYOSITIS ASSOCIATION

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