

## Join us in Houston for the 2003 Annual Conference!

The beautiful Inter-Continental Hotel is the setting for TMA's 2003 Annual Conference in Houston October 10-13. This recently opened contemporary hotel reflects the unique spirit of this progressive city. Free shuttles are provided to shopping and entertainment less than two blocks away, with more than 320 retail shops, restaurants and cafes. Our host is the enthusiastic Houston KIT group who will give you a true Texas welcome!

This hotel, famous for its international clientele, is fitting as TMA expands its reach around the world. TMA celebrates its 10<sup>th</sup> Anniversary this year and enters its 2<sup>nd</sup> decade of service to myositis patients and families. This year's theme is enrichment, and we're planning sessions and activities to enrich your life despite the challenges of myositis. You'll see how art, music, dance, competition, and adventure help heal as they lift your spirit. There will be treatment and research updates from experts; the chance to ask questions of leading researchers; time to socialize and share with others; the opportunity to meet the TMA Board; and practical advice on everything from modifying your home to looking your best.

You can save by registering early! See back cover for details. ■

## Life still has a dance for you...



## Members find energy and healing in creativity

Lori Fisher writes music, sings, and plays her flute, finding strength and inspiration in the music she's loved since she was a child. Alouise Ritter tap dances, the cheerful energy of this rhythmic dance form perfectly fitting her upbeat, humorous approach to life; Dale Sjogren paints in oils and acrylics; Alice Sogomonian does Bikram yoga exercises in a heated room; Harris Teller finds comfort in great literature and opera. Veteran tinkerers like John Moench and Bill Babyak apply their creative but logical minds to tackling the thorny logistical problems they face every day. Athletes Jeff Campbell and Mark Roberts push themselves to excel in physical competition.

These TMA members have IBM, DM, PM and JM, at varying stages and in various degrees of severity, but they all have something in common - they've discovered that with imagination and courage, they can keep doing the things they love;

and that new doors have opened to them. They've found that using the creativity and resourcefulness that's in all of us, they rise above some of the physical limitations of their disease and find joy, comfort, and even healing.

We know there are others of you like Lori, Alouise, Harris, Dale, Alice, John, Bill, Jeff and Mark, and we'd like to hear from you, for a couple of reasons. We're going to devote part of our June *OutLook* to the importance of finding ways to enrich your life in spite of chronic disease. And we're making enrichment a major focus of our Annual Conference in Houston, October 10-13. We invite you to participate in one of several member roundtables at the conference to discuss ways in which you manage to live life to the fullest. If you'd like to contribute to either the newsletter or conference, please call TMA at 540-433-7686 ext. 14; or email [t@myositis.org](mailto:t@myositis.org). ■

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## THE MYOSITIS ASSOCIATION

755-C Cantrell Avenue  
Harrisonburg, VA 22801

P: 540-433-7686

F: 540-432-0206

Email: [tma@myositis.org](mailto:tma@myositis.org)

Web: [www.myositis.org](http://www.myositis.org)

Executive Director: Bob Goldberg

Editor: Theresa Reynolds Curry

Art Editor: Jami Latham

Staff Writer: Kathryn Spooner

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## From the Executive Director

The Myositis Association is entering its second decade of service to its members, myositis patients, families and friends. This is a milestone accomplishment that we will be celebrating throughout 2003.

As you will see throughout this issue of the *OutLook*, we are reexamining how we “do business” and are intent on improving the quality of our publications and member benefits. Whether it is revamping print publications, adding e-newsletters and listservs, reducing member dues, redesigning our web site, expanding our KIT activities, or increasing the size of our Board of Directors, TMA is moving forward quickly. These changes have been carefully considered and are done with the full knowledge that change can sometimes be uncomfortable. But change we must if we are to take advantage of new technology and deliver information and services to you where, how, and when you want it.

Soon there will be announcements regarding the Annual Conference in Houston, a summer camps program for juvenile myositis patients, a book to be published by TMA for juvenile patients and their families, and additional conferences and publications to better serve patients, physicians, researchers, and caregivers. Throughout these activities you will notice our new emphasis is on enrichment. We are seeking to help you live better, more fulfilling lives despite your disease. We have heard your remarkable stories of courage, perseverance and determination not to let myositis restrict the joy and satisfaction of a full, stimulating, creative life. We will continue to help you learn how to live with myositis, but our emphasis is going to be on empowerment, not just coping. When you attend the 2003 Annual Conference, you will see a noticeable difference in its tone. Its theme will be enrichment.

We have increased our services for you, and we are also counting on you to help support TMA to the extent that you can. During these tough economic and uncertain international environment, it is critical for all of us to keep our “eye on the prize.” To do that, we will be calling on you to help.

The deadline for applications for TMA’s 2003 research grants is fast approaching, and after a thorough review of these applications, we will likely be issuing grants again this fall in the range of \$1 million. This is the future for all patients, and we will fund as much research as we can afford. We will strongly encourage Congress and the National Institutes of Health to adequately fund myositis research because, in the end, none of us can do as much as the federal government for myositis research. We will be joining other autoimmunity patient groups in holding a Congressional Briefing on March 14 and a rally on Capitol Hill later this year to demand enough money for NIH to adequately fund research into myositis and other autoimmune diseases.

We will call on you, when appropriate, to help us with your spirit, intellect, energy and resources. We will only succeed if each of us goes the extra mile and doesn’t let the disease or anything else stand in our way. There are no limits to what we can do together, and “Together We Will!” in 2003.

*The opinions expressed in this newsletter are not necessarily those of The Myositis Association. We do not endorse any product or treatment we report. It is our intent to keep you informed. We ask that you always check any treatment with your physician. Copyright 2003 by TMA, Inc.*

## TMA – A decade of making a difference

In Holland, Jan Scholten communicates with hundreds of IBM patients through a national patients' muscle disease group. Jan lets us know about European IBM trials and dispenses TMA materials to new patients. In Belgium, Esther Chantraine sends TMA materials to myositis patients in several languages. In England, Irene and Les Oakley keep their myositis group in touch via chatty newsletters; in Mexico, Dr. Ignacio de la Torres translates TMA materials for the growing number of Spanish-speaking patients in our association. Last summer, Laurel Colton called us from Mount Kilimanjaro at dawn, after successfully reaching the summit with six other climbers to raise money for research.

We've come a long way in 10 years! Last year's call for research inspired scientists from every continent to register on our web site; and we funded nearly \$1 million of research. We've changed our name to recognize our international partners, opened an office in Washington, DC, redesigned our web site, and steadily added to our member services and publications.

In the early days, no one could have known exactly how TMA would grow. Original board member Madeline Sabia remembers the first years. Like many inclusion-body myositis patients, Madeline was misdiagnosed with polymyositis for years before she drove down from her Connecticut home to the National Institutes of Health in September 1992 for a double-blind study. This trip not only brought her a correct diagnosis of IBM; it intro-

duced her to Betty Curry, an IBM patient and TMA's visionary founder.

Both women wanted to meet someone else with their perplexing disease, and an assistant to Dr. Marinos Dalakas made the connection. Soon, Madeline and Betty met for dinner and continued to meet each time Madeline traveled to Bethesda. Betty started the Inclusion-Body Myositis Association (IBMA) in her Harrisonburg home, using her own resources and talents. Working on a shoestring budget, this cottage enterprise reached out to everyone with IBM.

Madeline was a member of the first Board of Directors, meeting near Dulles Airport outside of Washington, DC. Madeline and Betty, along with family members and close friends, attended the next neurologist's meeting in Washington, educating physicians about the need for support and education of their patients back home.

Madeline sent an article from her local paper about the American Autoimmune Related Diseases Association (AARDA), which prompted Betty to get in touch with its director, Virginia Ladd. Soon IBMA incorporated the other forms of myositis and became the Myositis Association of America (MAA). Madeline instigated the first letter-writing campaign, and other board members joined in raising funds for operations.

"We did all the footwork," said Madeline. "We didn't get here overnight." MAA hired paid staff, planned annual conferences, outgrew Betty's Harrisonburg home, moved to its own offices, and joined the National Health Council.

Betty recently received an honor from the Giraffe Project for her boundless energy and enthusiasm. Madeline recently retired after a 10-year term on the board and is proud of her contribution and hopeful for the future. ■

There are many ways that TMA has touched the lives of those affected by myositis, and we appreciate hearing from you.

### **Thankful**

"You all do such a wonderful job in helping so many people and we are all so thankful to have you all."

BJ/PM

### **A glimmer of hope**

"Your new research grants and fellowships are exciting and are a glimmer of hope for our diseases."

Paulette/DM

### **Don't want to miss it**

"Your annual coverage of new treatments is saving my

mobility so I don't want to miss it!"

Judy/IBM

### **Loves the *OutLook***

"I joined MAA a month or two back but had been reading the site/boards since May.

The membership is definitely worth it, LOVE The "Outlook" newsletter and the HELPFUL caring MAA folks, and of course you all, my Myositis family!"

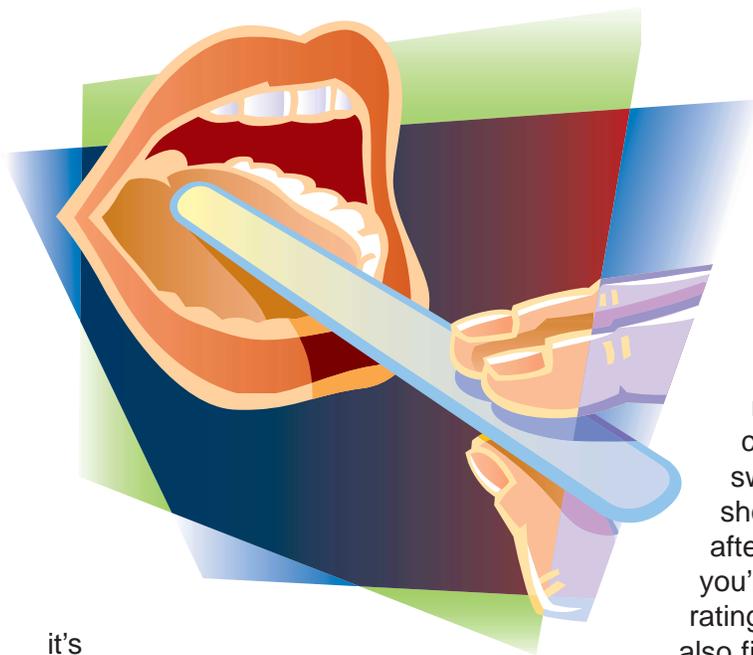
Jackie/DM

# DYSPHAGIA: SOLUTIONS FOR A COMMON PROBLEM

**S**peech professionals believe that as many as 80 percent of myositis patients may have either temporary or permanent problems with swallowing, ranging from very mild and treatable to severe. It's not surprising, says Dr. Don Barbarino, staff speech pathologist for Forbes Regional Hospital in Monroeville, PA: "More than 30 different muscles are involved in this process. Most of us don't give swallowing a thought – it's over in seconds, and works as naturally as breathing in and out."

For the myositis patient with weakened face, tongue and throat muscles, the process is much more complicated, and weak muscles can interfere in any of the steps of this deceptively complex process. Barbarino told myositis patients and families that weak muscles can change the process as you open your mouth and chew your food; as your tongue moves it to the back of your mouth; as you block off your windpipe (larynx) to allow the food to go down the right path (pharynx) to your stomach; and as the slight contractions of your esophagus move the food to your stomach.

Signs that muscle weakness may be interfering with your swallowing are many, and may be so subtle that you don't pay much attention. Early in the process you may find that you can't form the food into a mass (called a "bolus") on your tongue. You may find that



it's taking a long time to get the food to the back of your mouth, that it's slipping down your throat before you're ready, or that you're not able to close off your larynx, causing what we describe as "food going down the wrong way." The danger in this is that particles of food will lodge in your lungs, leading to aspiration pneumonia. Many patients tell us that

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You may find that other members of your family will get involved, too, as you learn what works for you in the management of this problem.

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they're bothered by reflux or heartburn. This may be an early sign that your swallowing has been affected.

Other signs, said Barbarino, are lip weakness and drooling, facial droop, a feeling of weakness in your tongue, aspirating food into your nose, coughing or

choking while you eat, or having to clear your throat a lot. Also watch out for the feeling of having a lump in your throat, tightness in your chest, pain when swallowing, or shortness of breath after you eat. If you're actually aspirating food, you may also find you're sneezing, burping, or hiccupping a great deal at mealtime. Tell your doctor right away if you have any of these symptoms.

There are a number of ways that you and your doctor can manage this troubling complication of myositis. Your physician may want to use a team approach, perhaps referring you to a speech pathologist, a gastroenterologist, an otolaryngologist, a dietician, or an occupational therapist. You may find that other members of your family will get involved, too, as you learn what works for you in the management of this problem. There are some diagnostic tools and tests that will allow your physician to observe your swallow, or he or she may make a diagnosis and treatment recommendation based solely on your symptoms.

Some techniques for improving your swallowing are quite simple. Dr. Barbarino recommends that even patients who don't have any dysphagia symptoms sit upright, chew thoroughly, avoid distractions and avoid eating after 8 p.m. You may work with a speech pathologist to change the way you hold your head, for example, positioning your chin at different angles, or you may discover that

you only have trouble with certain consistencies. Many of our members say it helps to only eat foods of the same consistency at one time. You may find that it helps to eat more slowly, or eat smaller portions.

The same medications that improve overall myositis symptoms may improve swallowing problems. In a recent paper, Medical Advisory Board Member Dr. Chester Oddis described a study in which three patients - two with dermatomyositis and one polymyositis patient with complications - had dramatic and rapid improvement with IVIg leading to improved swallowing within two weeks. However, Dr. Oddis observed, corticosteroids were also being used, making the contribution of IVIg difficult to judge. Dr. Oddis also found that patients with chronic contractions (more common in IBM), accompanied by a blocking sensation and cough with swallowing, often responded to myotomy, a simple surgical procedure that “stretches” part of the throat.

Some of our members have expressed satisfaction with feeding tubes, a step that isn't as drastic and final as you might believe. It can be a practical and very helpful way to avoid the danger of choking and aspiration pneumonia. Dr. Todd Levine, a Phoenix neurologist who has a number of myositis patients, recommends this for his patients BEFORE they experience pneumonia or a serious choking problem. The tube enters your stomach through a small button and can be used for supplemental feedings. Patients may continue to eat foods that they tolerate and to join their families and friends for part of dinner or a restaurant meal, and they may have the tube removed when symptoms disappear. ■

## GENERAL RECOMMENDATIONS FOR SWALLOWING:

- ❑ Sit upright while eating and 1-2 hours after eating. This position will help direct the food toward your stomach.
- ❑ Try to eat when you are not fatigued. Chewing and swallowing will be more efficient if you eat when you are rested.
- ❑ Take smaller bites of food and smaller sips of liquid. Smaller bites and sips are easier to manage in the mouth and throat.
- ❑ Take one bite or sip at a time. Be sure that your mouth is clear before taking another bite or sip.
- ❑ Increase sensory input you get from your food. By eating foods served either hot or cold, foods with texture, and foods that are flavorful, sensory information travels from your mouth to the brain and signals to your brain to begin the swallow.
- ❑ During mealtimes, focus your attention on eating. Try to avoid distractions such as television.
- ❑ Drink plenty of water and liquids. Your body functions best when properly hydrated. Cold liquids are recommended, as they tend to stimulate the swallow. One suggestion is to blend water or juice with ice in a blender to make a cold, slushy drink. Additionally, taking enough water will thin out your secretions and help to combat thick, stringy saliva.
- ❑ If mealtimes are taking too long, try eating six small meals per day rather than three large ones. Eating a smaller amount of food at each meal is less tiring.
- ❑ Avoid foods that are most difficult to chew and swallow and foods that are difficult to control in the mouth.
- ❑ Maintain good oral hygiene. Research shows that this prevents aspiration pneumonia in individuals with swallowing disorders.

*Courtesy of Pamela A. Mathy, Ph.D., CCC-SLP, Speech Language Pathologist, Arizona State University.*

## DYSPHAGIA GLOSSARY

- ❑ Deglutition (DEE gloo TISH un) – the act of swallowing
- ❑ Dysphagia (dis FAY jee yah) – difficulty swallowing; difficulty moving food or liquids from mouth to stomach
- ❑ Laryngeal (le RIN jee uhl) penetration – foreign material enters the larynx (vestibule, windpipe) but remains above the vocal chords
- ❑ Larynx (LARE inks) – muscle and cartilage that holds the vocal chords
- ❑ Pharynx (FARE inks) – area leading from the mouth and nose to the larynx and esophagus
- ❑ Esophagus (i SOF uh gus) – tube that passes food from the pharynx to the stomach
- ❑ Aspiration (AS puh RAY shen) – foreign material enters the larynx and below the vocal chords toward the lungs
- ❑ Stricture (STRIK cher) – narrowing of a tube
- ❑ Achalasia (A kuh LAY shuh) – failure to relax; persistent contraction

## TMA PUBLICATIONS: MORE LIFE, MORE KINDS, MORE OFTEN

Unless you've just joined us, you'll notice this issue of the *OutLook* is different from those published in the past. It's redesigned to be shorter and more concise, with full color and articles of interest to everyone. We hope you like it and, if you have suggestions or comments, that you'll email me at [t@myositis.org](mailto:t@myositis.org).

Why the changes? For our tenth year, we decided the *OutLook* – and all our publications – needed a facelift. Instead of trying to lump all the myositis news into one quarterly publication, we'll be mailing out several targeted publications, all with fresh design and color. *The OutLook* will have news that will interest people with any of the inflammatory myopathies and their families, and it will reach you in March, June, September and December, as before.

We're also adding a couple of supplements, slated for May and November. The May edition will be a round-up of exciting product news and a helpful, down-to-earth compilation of tried and true devices, processes and ingenious gimmickry rigged up by our clever members to help them solve common daily problems. The November issue will come to you fresh from the TMA Conference, with up-to-the-minute news about treatment and research.

The *JM Companion* will reach juvenile myositis families and friends quarterly, and now includes an insert designed

especially for children.

Your physician will receive an email newsletter every time we have news he or she can use to improve diagnosis, treatment and rehabilitation for myositis patients. Register your family doctor or specialist for the *Myositis Monitor* – a free service – by calling 540-433-7686 ext 12 or email [andy@myositis.org](mailto:andy@myositis.org).

Area Representatives for our *Keep In Touch* (KIT) support groups will now have a newsletter of their own to exchange ideas, and to highlight successful fundraising events, novel approaches to meetings, working with volunteers, and improving the exchange of support and information among KIT members.

Finally, if you are a full member of TMA, you'll be receiving email bulletins six times a year with the latest news about myositis research and treatments. Look for treatments and solutions especially geared for your disease type. If you are an associate member, why not take this chance to upgrade your membership so you won't miss any of our timely, focused publications?

We're excited about the chance to offer you these new services. If you have any questions or suggestions, please call me at 540-433-7686 ext 14 or email [t@myositis.org](mailto:t@myositis.org).

Theresa Reynolds Curry  
Communications Director  
TMA

## TMA: Advocating from the Courthouse to the Capitol

We realize the importance of promoting local and international awareness of myositis and support of research to the medical community, public, and officials who affect public policy. Everything you do, from county contacts to visits to Congress, helps in this important effort.

TMA's goal is to have September 21 proclaimed Myositis Awareness Day in every state, and many of you have started the process. Myositis Awareness Day has been officially declared in four states and one county already, with eight other states joining the effort in 2003. For more information on how you can be involved, visit our web site at [www.myositis.org/events/myositis\\_day.htm](http://www.myositis.org/events/myositis_day.htm) or contact Sandy Kinsey at 540-433-7686 ext 16, or [sandy@myositis.org](mailto:sandy@myositis.org). Thanks to those members who have worked diligently on this in the past, TMA has sample letters and petitions, along with easy-to-follow tips to help you get started. We can also put you in touch with members in your state whose efforts are already underway.

Working with other voluntary health organizations is an effective way for TMA to have more of an impact. As one of 80 identified autoimmune diseases, myositis is included in the recently released National Institutes of Health Autoimmune Diseases Research Plan, which offers specific recommendations for research into autoimmune diseases. NIH's Plan identifies clearly the overlap among autoimmune diseases and calls for a broader approach to funding for autoimmune diseases. It stresses the need for more education of physicians and the public; more accuracy in determining the number and severity of autoimmune diseases in the US; studying the genetic and environmental causes of these diseases; centralized research centers to examine diagnosis, treatment and prevention strategies; and

better access to information for new researchers and for the public. TMA will join other autoimmune disease organizations this spring in hosting a briefing and rally on Capitol Hill to call for funding from Congress to implement the Autoimmune Diseases Research Plan. ■

## New drug may be helpful, but just starting down the pipeline

Dr. Fred Miller, Chief, Environmental Autoimmunity Group NIEHS, National Institutes of Health, and TMA medical advisor, recently commented on the new drug Antegren. His comments are summarized here:

Much interest has been expressed in a new experimental drug called Antegren, an antibody which is one of the first in a new class of potential therapeutics designed to prevent migration of inflammatory cells from blood vessels to sites of inflammation.

Several recent Phase 1-2 clinical studies suggest that Antegren may be useful in the treatment of two autoimmune diseases, multiple sclerosis and Crohn's disease. Blocking cell receptors with Antegren prevents these cells from contributing to inflammation by stopping their movement to the site of the inflammation. This antibody may be useful in many immune-mediated diseases since most result from inflammation in tissues.

Several studies have shown that specific cell receptors (VLA-4) are present on the inflammatory cells in muscles of polymyositis and dermatomyositis patients, and are also likely to be present in juvenile and inclusion-body myositis, so there is a possibility that Antegren may be beneficial in treating myositis patients. At this time, to our knowledge, no myositis patient has been treated with Antegren and no studies are planned.

Like other immunotherapies, how-

ever, there will likely be side-effects from this treatment, including an increased likelihood of infections and delayed wound healing, so only carefully performed research studies in clinical trials will determine the safety and efficacy of such treatments in each disease.

Because other monoclonal antibodies (i.e. Enbrel, Remicade and Rituxan), which are already FDA-approved for other diseases, now show some evidence of effectively treating myositis and are being studied in myositis trials, it is likely that we will have useful information about the risks and benefits of these drugs in myositis long before such information is available about Antegren. ■

## Smallpox vaccinations and autoimmunity

Dr. Miller warns against smallpox vaccines for myositis patients:

“Because the current smallpox vaccine is a live viral vaccine and because myositis patients are immunosuppressed, the current recommendation is that they should not receive it. A related, and as important problem, however, is that those immunized may shed active virus for some time (possibly 3-6 weeks) after immunization which can be spread to others from the immunization site. So those living with myositis patients also should NOT receive the vaccine per the Centers for Disease Control (CDC) web site (<http://www.bt.cdc.gov/agent/smallpox/vaccination/contraindications-public.asp>).”

We realize that many of you may be worried about exposure to smallpox through others, especially health care workers, who have been vaccinated. If you have specific questions, Dr. Miller recommends that you call the CDC at 888-246-2675 (English), 888-246-2857 (Spanish) or 866-874-2646 (TTY). The hotlines are in operation from 8 a.m. to 11 p.m. EST, Monday through Friday and

from 10 a.m. to 8 p.m. Saturday and Sunday. ■

## TMA welcomes new board members

Five new members joined TMA's Board of Directors in January, increasing the size of the board to 11. They represent diverse regions and backgrounds. New this year are Lynn Chapman, Founder & President, NVS Consulting Firm, Hamilton, Virginia; John Ford, M.D., Retired, Surgeon, Health Care Consultant, Cardiff by the Sea, California; Jan Schuler, Retired, Economic Developer, Lawrenceburg, Indiana; Anne Marie Silver, Assistant Vice President, Deutsche Asset Management, Natick, Massachusetts; and Richard Stevenson, Retired, Engineer, Los Altos, California.

TMA gratefully thanks and acknowledges the contributions of retiring board members Nick Bradick, Madeline Sabia and Bob O'Leary. ■

## New to TMA? A bit about KIT

TMA's Member Support Network *Keep In Touch* (KIT) helps members become friends, feel less isolated, share coping strategies, and concentrate on abilities, not disabilities! Many newly diagnosed patients feel isolated and that no one really understands them. Friends, family and caregivers, although well-meaning, often just don't understand the medical and emotional complications.

TMA KITs cover more than fifty geographic areas. Volunteers coordinate these areas by encouraging communication among members by newsletter, telephone or email. Some groups meet regularly with speakers, meals and group discussions.

If you want to become a member of KIT, or would like to become a KIT Area Representative, please contact Sandy Kinsey at 540-433-7686 ext 16, or [sandy@myositis.org](mailto:sandy@myositis.org). ■

# Join us for The Myositis Association 2003 Annual Conference in Houston, TX.



## 1 Register with TMA...

Save by registering early!  
March 1 - April 15: \$109  
April 16 - July 31: \$139  
After July 31: \$159

As an added incentive, we are offering free registration and hotel stays for the 50<sup>th</sup> and 100<sup>th</sup> registrants! Register now.

## 2 Reserve your room...

Houston Inter-Continental  
Toll free: 866-342-0831

Call for reservations from 8am-8pm CST. Identify yourself with The Myositis Association Annual Conference group to receive the special rate of \$111/night. Reserve your rooms early to receive a handicapped-accessible room. When you call the hotel, make sure they have the services you need to be comfortable.

## 3 Still have questions?

Call Linda Stover, TMA Conference Coordinator, at 540-433-7686 ext. 19, or email [linda@myositis.org](mailto:linda@myositis.org).

Keep an eye on our web site at [www.myositis.org](http://www.myositis.org) and in future newsletters for more information as the Conference approaches.



THE MYOSITIS ASSOCIATION

755-C Cantrell Avenue  
Harrisonburg, VA 22801

# THE OUTLOOK