THE MYOSITIS ASSOCIATION

THE OUTLOOK

JUNE 2003

For the inflammatory myopathies

If you haven't visited TMA's web site recently, you should!

Myositis.org has undergone real changes over the past five months. Beginning with a "face-lift" in January, TMA rolled out a brand new look with a new logo, colors, and design. Keeping patients and members in mind, TMA restructured the web site to organize material more clearly and to add content and programs.

New patient materials include easy-to-understand definitions of myositis, explanations of diagnostic tests and research study announcements. We've included more about TMA: its history, programs and services, volunteer opportunities, and upcoming events. An area for health professionals provides diagnostic criteria, research articles, funding opportunities, and fact sheets.

More improvements are ahead. For TMA members, a members-only section will be available later this year offering access to electronic newsletters, research updates and other resources. *Keep In Touch* support group members will have access to KIT information online. Change your address, donate, register for events, or renew membership, with a few keystrokes.

An improved bulletin board program allows TMA to host online chats for the first time. In just one month, more than 550 people have registered to use the bulletin boards and there are already 2000 messages! This is a thriving online community and you are encouraged to participate!

The web site is updated frequently, so check back often, www.myositis.org.

Celiac disease and myositis:

Making the connection

After a diagnosis of an intestinal malignant tumor, life-threatening surgery and currently a diagnosis of dermatomyositis, TMA member Elaine Matthews is on a search. Elaine believes her chronic health problems are related and that the common thread is celiac disease, a condition that causes your body to react to common foods as if they were poison and to produce antibodies that destroy the digestive system. The disease is associated with both cancer and autoimmune disease. Elaine wasn't diagnosed with celiac until the disease had caused severe suffering and pain.

"When I went to my first Annual Conference, one of the first people I met with DM told me her sister had celiac disease and her mother suffered from lymphoma," Elaine said. "I knew it had to be more than a coincidence." Later Elaine met TMA Board Member Harriet Bollar who listened to Elaine's story and found that a number of her own family members, including granddaughter Amanda who has JDMS, have both celiac, digestive problems and other autoimmune-related diseases.

Doctors who treat DM and PM are increasingly aware that there might be a connection, although no study has yet confirmed this.

Celiac disease damages the small intestine and interferes with how your body absorbs nutrients from food. If you have celiac disease, you can't tolerate gluten, a protein in wheat, rye, barley, and possibly oats. When celiac patients eat foods containing gluten, their immune system responds by damaging the small intestine. Tiny fingerlike protrusions on the lining of the small intestine are destroyed. Since nutrients are absorbed into the bloodstream through these protrusions, the patient becomes malnourished no matter how good the diet. This is especially insidious, says Elaine, because often there are no symptoms except the quiet damage going on internally.

Celiac disease is genetic, so it runs in families. Like other autoimmune diseases, it is sometimes triggered—or becomes active for the first time—after surgery, childbirth, viral infection, or severe stress.

Elaine—as well as many scientists—questions whether this disease is more common in this country than formerly believed. It is extremely common in Europe, especially in Italy and Ireland. Children in these countries are routinely tested.

In our July electronic newsletter, *Myositis Update*, we will be compiling celiac information and resources. If you have myositis and celiac disease, please let us know, by emailing t@myositis.org or calling 540-433-7686, ext. 14.

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Dear Friends,

Enrichment: the act of making fuller or more meaningful or rewarding.

That is how the dictionary defines enrichment and that is the purpose of this issue of *The OutLook* and the other enrichment activities of The Myositis Association.

As you will discover when reading this issue, there are many ways to take control of life with myositis while we search for a cure. Coping with myositis is the first step toward taking control of the disease; the second step is restoring meaning to your life, which is the enrichment phase. Whether it be through physical exercise, counseling, meditation, diet, competition, or just relaxation, you can restore and add fulfillment to your life after being diagnosed with myositis.

As I meet TMA members and attend our KIT member support group meetings, I am constantly amazed by the strength and sheer will of our members living with this physically debilitating disease. Myositis patients aren't in denial but are finding ways to continue to pursue their interests while working within the physical limits imposed by the disease.

Enrichment is also the theme of this year's Annual Conference in Houston. Trained professionals will advise TMA members about exercise, nutrition and adaptation; and there will be many exhibits from TMA members who have accomplished much in the world of art, athletics, music, etc., despite having myositis. There will also be demonstrations of practical adaptations for homes, vans, and devices for everyday activities. You will be inspired by, and perhaps be in awe of, how much can be accomplished by those living with myositis. We have also included in this issue things to do and places to see in Houston to enrich your experience in this modern, cosmopolitan city.

And it is not just the person with myositis who is challenged. Family members and close friends also feel the effects of the disease as they help with caregiving or have the dynamics of their relationship impacted by the physical limitations of myositis. I think you will find the letters from caregivers in this issue of great interest.

There are many other stories in this *OutLook* about how TMA members overcome myositis - and it is but a small sampling of the many possibilities.

If you have a story to share or want to exhibit at the Annual Conference, there is still plenty of time to let us know. Just send an email to tma@myositis.org or send me a short note.

Continue to live life to the fullest!

MESSAGES FROM MEMBERS...

Caregivers find a new home on TMA Bulletin Board

Thanks for Forum

(A personal letter to TMA)

Thanks so much for providing a caregiver's forum on the TMA bulletin board. As the caregiver for an IBM patient, I feel a deep need to be able to speak frankly to other caregivers about some of the day-to-day emotional and physical problems of caregiving, including the feelings of isolation, misunderstanding and sometimes, mutual resentment, that come from a relationship as it changes from one of two equals to one of dependency and responsibility. This journey is not without great joy and accomplishment as well as sorrow and lost hope. The comments of patients on the board are also helpful. I suggest that we caregivers who also post on the other boards seek a more anonymous profile when posting on the caregiving board. I believe this will allow us to speak honestly about difficult topics without unintentionally hurting those we care for who might read the posts there.

Once again, thanks for the new Caregiver's Forum.

Sharlene Watson
San Francisco

Suggestions for Patients

(Posted to TMA's online bulletin board)

Some suggestions for patients to help their caregivers: make sure all who surround you know the facts about the disease. We have enrolled our children as associate members so they receive the *OutLook* and other materials directly to their home; encourage your caregiver to do some relief activities by letting some others occasionally help——this is sometimes hard for me to allow this as I feel I can "do it better" and don't need the time off; remember to say thank you and try not to be impatient——when you've been irritable, apologize, and use a sense of humor—- it "ain't easy" coping with the daily strife; try to thank God for the good moments and enjoy them together: accept assistive devices when needed, try to pace yourself and not get overtired on your "good days": know that we caregivers are so frustrated that we can't make you better. Communicate as best you can about your mood swings, not only that they occur, but why. Encourage your caregivers to include you in even a minor way, and urge them to take shortcuts. Sometimes we caregivers do some "busy work" that doesn't need to be done. Hope this gives you a perspective of one caregiver's thoughts.

JanIBMspouse
Indiana

A Caregiver Looks Back

(Posted to TMA's online bulletin board)

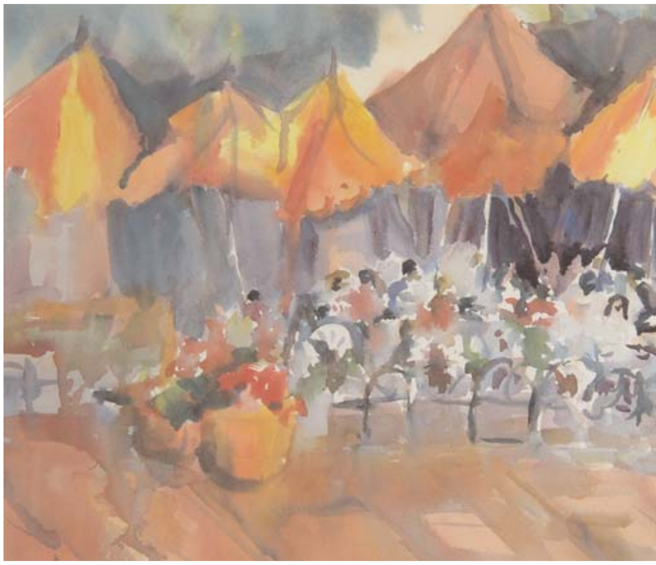
I was a caregiver for an IBM patient for more than 15 years. I look back on it, not with sadness – although there was plenty of that at the time – but with a feeling of enormous accomplishment. I hope all myositis patients will remember that when they feel guilty about the time and energy that myositis consumes from the family and extended family. There are some things I would have done differently and, in fact, did do differently after learning from experience. Sometimes, it just takes a long time to learn a lesson that should be very clear. My husband, George, was embarrassed by his weakness and wasn't open to anyone else caring for him. For years I wouldn't leave him, no matter what. Finally, my children intervened and set up a schedule of care that included me having three afternoons a week off and one weekend a month to get away. I resisted, George resisted; but my family insisted and after many tears and hugs I began a new life doing volunteer work and visiting my grandchildren. The result: I came home refreshed and with more energy. George was also refreshed by his conversations and visits with children and friends. We became closer than ever and I am forever grateful to my wonderful family for seeing what I could not. Please remember that everyone needs new interests and experiences, no matter how advanced their disease or pressing their responsibilities.

Elaine Browning
New Orleans

WAMO - Working Against Myositis for Others - is a new focus for family and friends of members who have myositis. We're reaching out to these valuable support people to include them in myositis education and events.

We'll keep you posted as this new program develops. If you have ideas or are interested in WAMO, email tma@myositis.org.

STAYING IN THE GAME: MEMBERS TELL US WHAT INSPIRES THEM AND WHY



"Old Town Diners," watercolor by Mike Shirk

In the March *OutLook*, we asked how you enriched your lives with creativity, adventure, and courage. In return, we received enough inspiration to fill a small book. Some of our favorites follow, and we thank everyone who contributed.

Lynda Oldham keeps going with determination and conviction: "My new word is anti-stagnation. I refuse to stay down," she said. Although Lynda appreciates a day of rest, she makes it a rule to walk the next day, even if it's just a little. Her passion is antiques, so she uses antique malls as her destinations. "I've been to three antique malls this week, walking and strolling around - keeping on the move," she said. Lynda, a schoolteacher, makes up for the days she's in pain and takes off by doing the best job possible when she's there. She closed her note with these words: "I guess what I'm saying is, I'm staying in the game and I'm going to be an advocate for my own health."

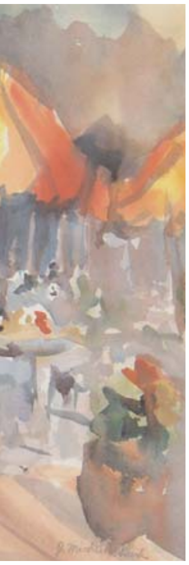
I would rather not be ill, but, since I had no choice, DM and I were going to be partners.

Mike Shirk had a creative profession, but his retirement pursuit calls for a different kind of creativity. When he was diagnosed with IBM, he had his own business working as an advertising copywriter. Soon the illness made it too difficult for Mike to call on clients, and weakness in his fingers made writing a slow and painful chore. Mike retired at the end of 1999 and was prepared to spend his time doing little more than coping with his IBM. It took about six months for Mike to abandon that idea – he became very bored. Mike took up watercolor painting, something he'd never dabbled in before. Since his wife is an artist, Mike had a general idea of how to go about it. "Since then I've taken classes and workshops, joined art organizations, entered local competitions and am having more fun than I did before I was diagnosed!" Mike says. He's on the board of the San Diego Watercolor Society, and the leader of the weekly "paintout" group.

"It turns out that having IBM makes painting outdoors a natural pursuit, " Mike explains, "because my scooter lets me take my equipment to all kinds of places people on foot might not attempt." Some of Mike's paintings are on his website at http://home.earthlink.net/~mikeshirk.

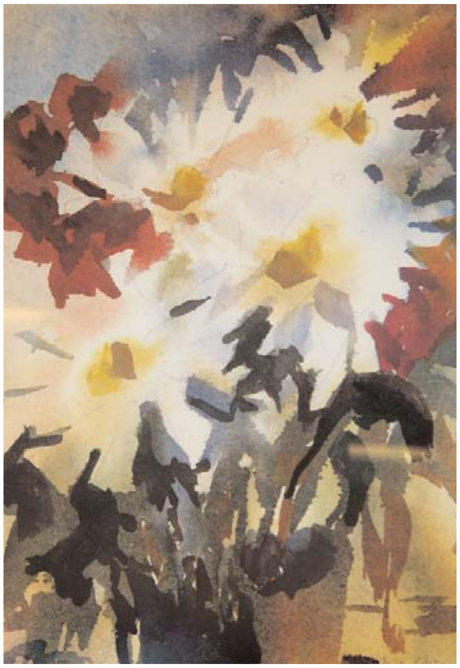
Lori Fisher, who has dermatomyositis and myasthenia gravis, recalled how often music and songwriting have helped her fight her way out of flareups. Since mid-February, Lori, who's now taking retuximab, has battled a DM flare, and her doctor gave her a "prescription" to keep up with her life-long passion. When her rheumatologist asked Lori, the creator of several songs about prayer and hope, about playing guitar and singing, Lori remembered she hadn't blown the dust off her guitar case in around a month. "Your article confirmed her prescription for healthy living with myositis," Lori said. "Although myositis flares may interfere to a substantial degree with our plans, it's so important to stay in touch with our own individual gifts and talents, and to pursue activities which give us joy. In my own case, I'm doubly blessed to know that my songs have — with the help of the TMA Store — touched others with myositis and also helped, one CD at a time, with fundraising."

Mark Roberts' inspiration is physical competition. Although Mark has never met another patient with DM in the seven years he's had the disease, he's been inspiring our bulletin board members from the sidelines. "I do better than most people with this illness," Mark says. He believes that attitude and nutrition are a huge part of the battle: "The rest is a combination of controlled rest, intelligent and appropriate exercise, and doctor's orders," Mark says. "I must have all these



elements to succeed." Mark, an athlete and airline pilot, was 31 years old when the classic symptoms appeared: weakness, rash, and sheer exhaustion. It hit him like a ton of bricks: "I went from rollerblading 10 miles at a fast pace to barely lifting my head off a pillow in about three weeks time," Mark said. With medication, he slowly improved and went back to work as an on-demand charter pilot after six months, later signing on with a major airline so he could better control his rest and diet on a more predictable schedule.

Mark began training in earnest for a goal he'd set while very ill. His adventurous 7th grade English teacher had swum the cold 4.1-mile Straits of Mackinaw some years earlier, and Mark set his sights on that. "If I could do that, then I was no longer a victim of a disease," he said. He went from a difficult first swim in the pool, barely able to swim a dozen or so laps. He progressed to a flexible schedule of swimming, biking, and light weights, taking days of rest when needed. On August 13th, 1999, shortly after dawn, Mark dove into the water at the southwest side of the Straits accompanied by a friend in a kayak, struggling exhausted out of the cold water an hour and 46 minutes later. Mark realized he'd stopped being a victim, not at that moment, but from the time he'd started training. "Had it not been for dermatomyositis I would never have known the feeling I had earned there on those rocks," Mark said. "I would rather not be ill, but, since I had no choice, DM and I were going to be partners." Later that fall, Mark completed the Ice Man, a 26-mile mountain bike race in northern Michigan in late November. With his signature slogan, "Never give up!" Mark shares his nutrition tips with bulletin board members and is planning new athletic goals for after the birth of his first child any day now.



"Pick These," watercolor by Mike Shirk

Dorris Norris boosts her physical energy daily by swimming and exercising in the pool at her local wellness center. Dorris has IBM and finds water supports her muscles and allows her to stretch them gently. For mental therapy, she putters in her greenhouse and enjoys the beauty of the outdoors. Most days, when weather permits, you'll find Dorris sitting on a stool weeding her flowerbeds. As most of us know, there is something very therapeutic about tending a flower garden.

Jeff Campbell, who battled juvenile myositis as a young man, also found satisfaction in setting physical challenges for himself. His story, "A Race to the Finish," is told in the December edition of the *JM Companion*. Jeff said that, although his illness took away many things, it couldn't stop him from getting up out of bed, putting on his running shoes and training for a race. He's been in countless foot races since he first found inspiration there, and continues to make athletic training a big part of his life.

Cecilia Thompson writes that listening to Mozart reminds her of the beauty and power of the human spirit. Diagnosed with PM 10 years ago, Cecilia was determined to enjoy her life-long love of classical music. Her grandchildren send her new recordings of Mozart favorites and her daughters and sons take turns escorting her to the symphony so she can appreciate the soaring strings and intricate woodwinds in person. Cecilia has 12 great-grandchildren who laugh about "granny's boom box." "I always have earphones on," she says. "I tell the kids I'm listening to rap, but I'm really listening to Mozart." Cecilia believes that the beauty of the music helps control her pain as well.

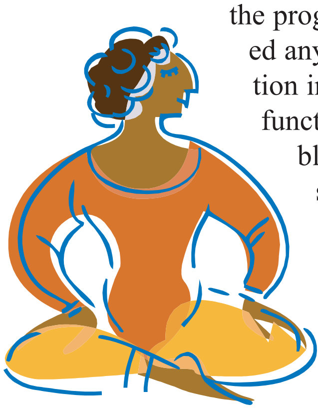
Jim Kilpatrick believes music saved his life several times when he lay in a coma, not expected to live. **Ann Navan** expresses her feelings through poetry; **Harris Teller** goes to the opera: others throw pots, climb mountains, stitch quilts, keep journals, weld jewelry, design clothing and tap dance. Many of them will talk about their experiences with creativity and adventure at the Annual Conference. If you have a similar story, or a personal creation you'd like to display, call Theresa Curry at 540-433-7686 ext 14; or email t@myositis.org.

STUDIES SHOW EXERCISE SAFE AND EFFECTIVE FOR MYOSITIS PATIENTS

More and more of our members are telling us that exercise helps them remain flexible and increases their energy, whatever the state of their disease. Whether stretching in a yoga class, swimming in a pool, or working out with light weights, patients confirm what physical therapy and rehabilitation experts are finding in studies with myositis patients: appropriate exercise is helpful and safe.

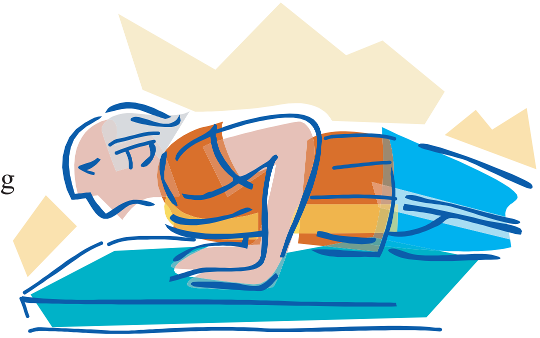
The first question myositis patients usually ask is "Is it safe for me to exercise?" Studies say that the answer is definitely "yes." Swedish researchers followed the progress of seven IBM patients in a study published early this year in the *Journal of Rehabilitation Medicine*. In "Sporadic inclusion body myositis: pilot study on the effects of a home exercise program on muscle function, histopathology and inflammatory reaction," scientists in the Division of Neurology at Karlolinska Hospital in Stockholm, studied selected patients over a 12-week period. The patients performed prescribed exercises in their homes five days a week. The safety of this program was closely monitored: researchers used clinical exams, repeated muscle biopsies and blood tests to determine levels of creatine kinase. They evaluated muscle strength by clinical exam, mechanical instrument and a functional index.

Their results, published in the January issue of the *Journal*, found that none of the patients completing the program reported any deterioration in muscle function. The blood tests showed there were no signs of increased muscle inflammation or other signs of worsening disease in the muscle biopsies. Creatine kinase levels were unchanged. They concluded that exercise may prevent loss of muscle strength due to the disease as well as to the inactivity that often accompanies it. This study is one in a series, showing that prudent exercise will not harm the myositis patient. These studies are important because previously, some health professionals believed that exercise would lead to more inflammation and, consequently, greater weakness.



Michael Harris-Love, staff physical therapist for the National Institutes of Health, helped the Myositis Assessment Group develop measurable standards for assessing improvement in neuromuscular disease. He's also worked for many years designing exercise programs for myositis patients and has been a TMA Annual Conference presenter.

Harris-Love recommends that your program reflect the limitations and needs imposed by your disease. If you have joint problems or neuropathies in addition to myositis, he suggests asking your physical therapist for exercises that account for these limitations. He's found that even patients highly reliant on a caregiver can exercise – often with the help of the caregiver – to keep muscles flexible. He recommends daily exercise if you spend a lot of time in bed, or on a scooter.



Conversely, he maintains, if you're fairly active, you may need to structure breaks or rest days in your week, to rest the muscles as they tire. Like the Swedish researchers, Harris-Love maintains that weakness caused by myositis is compounded by the weakness that results from forced inactivity the disease can cause. For those who have trouble exercising because of weakened muscles, Harris-Love suggests approaching the subject with creativity. For instance, if you can't raise your arms above your head, try resting them on a shelf or a desk and then sitting down so the surface supports them in a raised position. He also recommends thera-bands and assisted exercise to make sure each muscle group gets some stretching and strengthening.

Finding a physical therapist

Patients benefit by starting their exercise program with the help of a physical therapist. Your doctor can prescribe physical therapy for you and may know a therapist or center that has worked with myositis patients. The therapist can also demonstrate how to do the exercises correctly, and give you alternative exercises if you're unable to effectively work a particular muscle group. Don't worry if your physical therapist has never heard of myositis. Since it's so rare, this is quite possible; but he or she should be able to design a program for someone with inflamed muscles. Sherry Backus, senior research physical therapist at New York's Hospital for Special Surgery, suggests you ask the therapist if he or she has ever treated someone with a similar condition and listen carefully to the response. "If someone pretends to know exactly what will 'cure' you, be skeptical," Backus said. Be just as concerned about a person who doesn't take myositis seriously, is unwilling to research your disease, or who's not interested in consulting with your doctor for further information.

Heading for Houston: Make your trip to the Annual Conference a real adventure

At press time, more of you have registered for the Annual Conference thus far than any Annual Conference in TMA's history. We encourage everyone to make the Conference a memorable experience by getting to know this sophisticated, western city while you're there. Included in these pages is information to help you plan your trip. In each case, the mileage listed is the distance from the Conference headquarters at the Inter-Continental Hotel.

Galleria Shopping Center
(1 block) (713) 622-0663

Even if you're not as rich as a Texas oil baron, you'll love the Galleria, where you can do much more than shop. Besides the hundreds of shops, this building is an architectural and commercial landmark with restaurants, entertainment and art galleries.

Museum District (6.5 miles)

The Museum District is becoming more and more popular as a Houston destination and cultural experience. Find the Lawndale Art Center, Children's Museum, Holocaust Museum, Museum of Fine Arts, Contemporary Arts Museum, Menil Collection, Museum of Natural Science, and Rice University Gallery.

Space Center Houston
(33.5 miles) (281) 244-2100

The huge crowds interested in NASA's Johnson Space Center inspired this building. Finished in 1992, the Space Center has a full-size mock-up of a spacecraft crew compartment and a Lunar Excursion Module trainer used by Apollo astronauts. Children and adults can jump on the Lunar Rover, direct the space shuttle and build rockets. There's a selection of space suits, and a collection of moon rocks and soil samples that's the largest anywhere. The most popular attraction is the tram tour of NASA, which stops at the vacuum chamber and the neutral buoyancy lab, where astronauts train.

Reliant Astrodome & Reliant Park
(7.7 miles) (832) 667-1400

When the Astrodome opened in 1965, it made news as the first fully-enclosed, air-conditioned, domed stadium in the country. For many years, it was home to the Astros baseball team and the Oilers football team. Now, it's a showplace for the Houston Rodeo, major-league soccer, championship boxing, concerts and political meetings. Reliant Park is Houston's top trade show, convention, sports and entertainment campus, and includes the Astrodome, Reliant Stadium, Center and Arena.

Williams Tower & Water Wall
(2 miles)

This landmark dominates the Galleria skyline and its glistening Water Wall fascinates visitors. Architect Philip Johnson's creation penetrates the urban sprawl with a 64-story upward thrust. It's one of the tallest suburban office buildings in the world. The main attraction is an observation deck on the 51st floor, presenting an aerial panorama of the city. The nearby Water Wall sends thousands of gallons of water cascading down a slick rock surface into the pool below.

Children's Museum
(7 miles) (713) 522-1138

Visitors to the museum quickly discover that this is a thinking child's playground, thanks to the friendly architecture that includes giant children "holding up" the structure with outstretched arms. There are 14 galleries of interactive exhibits that educate and fascinate. Visit a Mexican mountain village, test water quality, make giant bubbles, or produce your own television show. You'll be just as entertained as your children, and you'll also find a parents' resource gallery.

Houston Zoo (6.5 miles)

What began with one bison named Earl in 1920 has now grown into a collection of more than 5,000 animals. The park covers 55 acres. There's a tropical bird exhibit, large and small cat houses, a huge collection of reptiles including an albino alligator, the Wortham World of Primates, a two-acre rain forest and natural habitat, and the Children's Zoo, which allows children to pet various farm animals.

San Jacinto Monument & Battleground Historical Park
(30 miles) (281) 479-2431

The San Jacinto Monument marks the spot where an unruly army of Texans led by Sam Houston overwhelmed a superior Mexican force on April 21, 1836. It rivals the Alamo as the most celebrated site in Texas history. It's listed in the Guinness Book of Records as the tallest monument column in the world – 12 feet taller than the Washington Monument. Visitors ride to the observation floor for breath-taking views of the city and the Houston Ship Channel.

For breaking conference news, visit our web site at www.myositis.org.

We're heading for Houston!

Join us at our Annual Conference - October 10-13

Here's what you will learn about:

★ Research Reports from our Expert Medical Panel ★
★ ExerciseTherapy ★ New Medications ★ Swallowing ★
★ Nutrition ★ Alternative Medicine ★ Insurance ★ Yoga ★
★ Tai Chi ★ Skin Care ★ Support ★ Caregiving ★
★ Creative Solutions ★ Family Dynamics ★

Register Now! Online at www.myositis.org, or by calling 540-433-7686 ext 19
Discounted conference registration rates available through July 31.

THE MYOSITIS ASSOCIATION

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