

## “My TMA” online features

“My TMA” is your TMA. This new area of the web site was developed just for TMA members and is personalized for each individual. You can access “My TMA” by logging into TMA’s web site with a unique login and password of your choosing. (Login and password can only be changed after first logging in using your TMA-generated password.)

You will be prompted to log in when clicking “Community” and “My TMA,” or when renewing membership or placing orders online. You can also log in by clicking the “login” link at the top of the homepage, [www.myositis.org](http://www.myositis.org).

Once logged in, visit “My TMA” to access your individual record and TMA members-only materials. “My TMA” allows you to update your contact and patient information, choose mailing preferences, renew membership, view current KIT lists and read TMA publications. Also, once you’re logged into TMA’s web site, any orders or donations you submit are automatically credited to your account.

Currently “My TMA” and the Bulletin Boards are separate programs that require separate passwords. Soon you will be able to use the same password for both.

If you have problems logging in, comments or suggestions, please contact Jami Latham at 800-821-7356 x501 or [jami@myositis.org](mailto:jami@myositis.org).

## Long-term care or crisis?

We hear from many TMA members that facing the issue of long-term care insurance is bewildering and the cost is prohibitive once you’ve received a diagnosis. We will explore this issue in 2004 in a series of articles in *The Outlook*. Please write to *The Outlook* Editor Theresa Curry with your own experience with long-term care insurance — email [theresa@myositis.org](mailto:theresa@myositis.org) or call 202-887-0088 x600.

A recent AARP (American Association of Retired Persons) survey reported some astonishing misconceptions. Almost three-quarters of the people surveyed believed their insurance or Medicaid would pay for around-the-clock care for an extended time. The truth was very different: only one in five actually had long-term care insurance and often their policies were outdated and did not reflect their desires.

Long-term care insurance is often associated with nursing home care, an outcome that most people prefer to avoid. And in fact, most do avoid it: only one in five people requiring full-time care actually live in a nursing home. The rest are served by assisted living facilities, adult day-care centers and, most frequently, home care supported by services that most of today’s comprehensive private long-term care insurance policies do cover.

This isn’t always true of

Medicaid, the largest payer of nursing home bills, and Medicare, which pays only for limited nursing care following hospitalization. Not all Medicaid programs pay for assisted living, and although Medicare will pay for home care in certain situations, it’s for a limited number of visits. Although Medicaid programs are changing to cover alternative care, programs still vary widely in coverage and eligibility, and some states have long waiting lists for these services. To use Medicaid for long-term care coverage, you must be impoverished. Most often, long-term care insurance increases your choices and may allow you to live independently longer than if you choose to spend your assets and depend on government assistance.

For the kind of future care you want, choose the right policy by checking it thoroughly. If you already own a long-term care policy, examine it carefully.



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Dear Friends,

With the New Year underway, I want to share with you some of the plans for The Myositis Association this year and also some thoughts on how you can help TMA be more effective.

Year 2003 was a time of reorganization for TMA. We relocated the office to Washington, DC, redesigned all the publications and web site, added new publications, expanded our electronic communications, reconfigured TMA's staff structure, expanded the TMA Board of Directors and created new vehicles for communication between TMA and its members. It was a time of significant change and growth.

Year 2004 is expected to be equally productive, but with much of our activity focused externally to make the public, Congress and research community more aware of myositis and the challenges faced by TMA's members. We have identified advocacy in Washington, media outreach, development, expanded use of volunteers, and research as areas for increased emphasis this year. Of course, this doesn't mean that member services, support groups and public and physician education will receive any less attention. But we are going to make a concerted effort to do a better job of "telling the myositis story" to those not familiar with myositis who can help us grow and expand our research program.

To be effective, we will continue to need your support and advice. Let us know what you think. We recently sent an email to more than 1,000 TMA members asking for comments on going to Las Vegas in August for the Annual Conference. I was overwhelmed by the response we received – nearly 250 emails!! Not only did this exchange provide helpful advice to TMA in deciding what to do, but it was also a good reminder that we need to ask you for your thoughts and advice more often on issues important to you.

We are going to be aggressively pursuing the above agenda in 2004 and will be calling on you to help us – whether it is sending letters to Congress about drug coverage or asking you to contact your local paper to get Myositis Awareness Day publicized locally.

The membership remains the strength of TMA. We will need your help and know that you will do as much as you can to help us battle myositis. Because, Together We Will!



*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 2004 by TMA, Inc.*

## Long-term care, Cont'd from front cover

Older policies sometimes cover only nursing home care, or just a few kinds of alternative care. Ask for alternatives that cover home care and assisted living, but if you bought a policy before your diagnosis, be careful about replacing it, even if it's not exactly what you want. Be absolutely certain that you're insurable for a new policy first, and ask about adding the new coverage.

As you shop for insurance, read the fine print to see exactly what services a policy will cover and what conditions are necessary to qualify for them. For example, some policies don't pay for an

assisted living situation unless the state health department licenses it, and not all policies cover adult day care. Home care changes from policy to policy and may have requirements such as all aides must be hired through a licensed agency. Others may even include payments to traditional caregivers like neighbors, relatives and friends. Everyone in the health insurance business acknowledges that there is a shortage of home health care workers at any price.

Be sure to examine any group policy offered through your work. Group plans may not cover assisted living facilities, or may be restrictive in what they'll cover for in-home care.



## Messages from members... Asking for help

**I am finding it hard to explain to** family and friends my weakness and difficulties functioning. I have always been very independent and find it very hard to deal with having to ask anyone to do anything or to help me. I do not want to sound like I am asking for sympathy or pity. I would appreciate any tips, suggestions or stories of what has helped you.

- Injone

**It is hard to have to rely on others** to do things you have always done for yourself. I think we have to slowly learn to do that; just try to take one day at a time; and don't feel bad about saying, "I can't."

- Dorris/IBM

**I am another one that loves my** family dearly but sometimes gets frustrated with them. It took me being wheelchair bound for three months until they finally understood. Then my mother went the other direction and tried to do everything for me. Hopefully we will someday work out a balance.

- Tricia/DM

**The best thing my wife and I did** to educate my grown daughters was to take them to the last conference I was able to attend. We paid for the works so they couldn't refuse. They met many new friends, people with all types of myositis, IBMers like their father, and people in the various stages of this disease. They really came away with a new perspective not only about myositis, but also couldn't believe that we are such an upbeat group. Needless to say, I don't have to explain much to them about what is happening to me.

- Stu/IBM

**I can relate to your problems with** unfeeling friends but my family has fortunately rallied to help where possible. I

See Messages, page 7

## LONG-TERM CARE TERMS

### Assisted living

With assisted living you live in your own apartment and pay for costs depending on the level of care, which may include daily visits by staff, linen and maid service, and some meals. Usually, you can fix your own meals or eat at communal meals. Staff assistance can vary from simple housekeeping to bathing to medication. Costs are generally less than a nursing home – sometimes by as much as one-third to one-half.

### Adult day-care centers

These centers are popping up everywhere and generally are geared towards those with Alzheimer's Disease or some form of dementia. They typically provide meals, limited medical care, social activities, and sometimes transportation to and from home.

### Adult foster care

The person is cared for in a private home, often called a group home, with service ranging from meals to assistance for bathing or dressing, typically by the homeowner.

### Respite care

Some policies will provide temporary care for a person so a family caregiver can take a break or vacation.

### Home care

Home care may range from light homemaker services to round-the-clock skilled nursing care, so read carefully what the policy will cover. This is the alternative chosen by many since it can include a traditional family caregiver as well as outside help. Some policies even pay for a specialist to help find the appropriate people to provide the services.

# INTERSTITIAL LUNG DISEASE: WHAT MYOSITIS PATIENTS SHOULD KNOW

If you have polymyositis (PM) or dermatomyositis (DM), you may also be at risk for interstitial lung disease, and should report any breathing or coughing problems immediately. A recent study of patients treated for myositis at many different treatment centers found that as many as 32 percent of all PM or DM patients also have this lung disease, which has many different forms. This discussion of interstitial lung disease, also called ILD, is intended to encourage communication with your doctor, not to replace it.

## What is ILD?

The name “interstitial lung disease” comes from “interstitium,” the name for the tissue that lines and supports the tiny air sacs that make up your lungs. These sacs send oxygen into the blood and remove waste like carbon dioxide from the blood. When the interstitium becomes scarred, it’s much harder for oxygen to travel from the air into the bloodstream. Your doctor may ask if you cough or sometimes have trouble getting your breath.

Scientists don’t know yet why lung disease affects patients with myositis, but we do know that myositis patients are not alone in having this dubious distinction. Patients with other autoimmune diseases also have a higher number of interstitial lung disease cases. This is true of patients with rheumatoid arthritis, lupus, scleroderma and other less common autoimmune disorders. People who are exposed to asbestos fibers report most other cases, but people who have never worked with asbestos and don’t have autoimmune disorders can also get ILD.

Some of the symptoms you should report are shortness of breath when trying to exercise, or a dry, hacking cough that doesn’t go away. Some people have flu-like feelings, like being tired, slight fever, losing weight, or aches in muscles and joints.

If your doctor suspects that interstitial lung disease is causing these problems, he or she may suggest tests to find out for sure. You may be asked to have a chest x-ray, pulmonary function tests or a surgical procedure called an open lung biopsy. Blood tests, exercise testing, heart tests like EKGs and other diagnostic tests may be used to find out the exact nature and extent of your disease. Your doctor, whether it is your family doctor, a rheumatologist or a neurologist, will most likely involve a lung specialist, called a pulmonologist, in your treatment.

## What happens in the lungs in ILD?

Doctors suspect that the same kind of chain of events at work in PM and DM is at work here. Your body mistakenly thinks there’s a problem in your lungs and your immune system tries to fight it by “healing” the injury to the lung. It’s like the body forming a scar over an area that’s been cut to prevent further damage. In affected patients, this continues until the lung is scarred. Since the scarring is in the spaces around the air sacs (alveoli), the lining of these sacs (interstitium) slows the flow of oxygen from the air sacs into the bloodstream. Then your body doesn’t get quite enough oxygen for normal functioning, and you feel short of breath.

How can you reverse this process? There isn’t yet a surgical procedure or a drug to remove the scar tissue once it forms in your lungs, so it becomes a permanent part of the lung. But physicians are succeeding in slowing down or stopping the scarring. That’s why it’s important to mention your symptoms to your physician right away, even if you suspect you may just have a common cough. After your physician makes a diagnosis, he or she may decide to treat you with prednisone, methotrexate, cytoxan, or

other drugs that help stop the scar formation in the lungs of ILD patients.

Some patients will have their lung disease stopped by medication and remain on medication for life. Others will be able to slowly reduce and eliminate medication. There are also patients who do not respond well to therapy and develop more and more scarring in the lungs. New drugs – and new combinations of drugs – are offering more hope for these patients than ever before. Research is coming closer to identifying who will respond well to medication and who won’t, so that medication with potential side effects is not used needlessly.

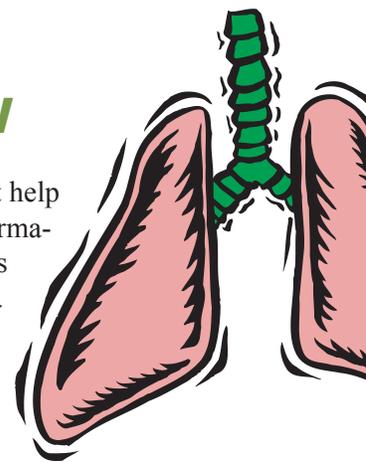
## Tests and Procedures

### Pulmonary Function Testing

Part of managing your illness is frequent pulmonary (lung) function testing. One of the tests measures how much air you can blow out normally and also after filling your lungs with air; another measures lung volume; others help doctors understand how well oxygen gets into your bloodstream. Pulmonary function tests are fast and safe and can easily be done to compare progress from one doctor’s visit to the next.

### Chest X-ray and CT Scans

Physicians can usually tell if you have interstitial lung disease by a routine x-ray of your chest. That’s because x-ray beams can’t pass through scarred tissue as easily as they pass through normal tissue. A small number of patients with the disease have normal chest x-rays, so they’re not as helpful in checking the progress of the disease.





CT scans give doctors a better look at the lung tissue damaged from interstitial lung disease to better understand the extent of your disease.

### Bronchoscopy

When your pulmonary function tests and x-rays indicate interstitial lung disease, your doctor might take a small sample of lung tissue to make sure you have ILD.

Usually, he or she will use a flexible fiber optic tool called a bronchoscope to perform the test, called a bronchoscopy. Typically, you will be awake but slightly sedated for this test. Your doctor will numb your mouth and throat enough to prevent coughing or gagging and pass this flexible scope through your mouth and into your lungs to take several small tissue samples. Bronchoscopy is safe and is often an outpatient procedure, but sometimes the small size of the samples the doctor gets this way is not enough to confirm the diagnosis.

### Open Lung Biopsy

In those cases where a biopsy with bronchoscopy is too small for a definite diagnosis, your doctor may ask for an open lung biopsy. For this, you will be admitted to the hospital and have general anesthesia. A surgeon will make an incision between two ribs and remove a section of lung that's at least a half-inch long. This is such a small piece of lung tissue that the procedure won't affect your overall lung function. It's almost always enough for a clear diagnosis. After surgery, patients stay in the hospital a few days. In the first week or so after the surgery, you may have some pain around the incision site. Although it is not a particularly risky procedure, it does involve hospitalization, anesthesia and recovery, so it's done only when necessary for a definitive diagnosis.

### Bronchoalveolar Lavage

Once you have a diagnosis of interstitial lung disease, your doctor may

want to determine if your disease is still forming scar tissue or if it is no longer active. This is important because if it's not active, treatment may not be helpful and may have side effects. The surgeon will inject salt water into a section of lung and then remove it immediately by suction. Since this samples a large number of cells, it helps your doctor make decisions about your treatment. It's a safe procedure, it takes no lung tissue, and the risk of complications is low. It can be done with you as an outpatient, and repeated when more information is needed.

### Exercise Testing

Because patients with interstitial lung disease – like all of us – have more shortness of breath when exercising than when at rest, your doctor may wish to test your breathing ability and lung function with exercise. This is usually done on a stationary bicycle or a treadmill. Your doctor may get more detailed information about your heart and lungs with exercise, sometimes by having you breathe into a mouthpiece connected to a computerized lung function machine while you exercise.

## Commonly prescribed drugs

### Cyclophosphamide (cytoxan)

After beginning cytoxan for interstitial lung disease, your doctor will inquire about any side effects or problems. It's usually taken as one dose per day in the morning, and it's important to drink extra fluids while taking cytoxan so that you will urinate more frequently and prevent bladder complications. Like most drugs, cytoxan can cause stomach upset, such as nausea and vomiting, but usually the small doses used for ILD minimize this side effect. Other possible side effects are hair loss, changes in skin, and greater chance of infection. As always, discuss this drug very thoroughly with your doctor and report any side effects, even if they're different from the ones mentioned here.

### Prednisone and methotrexate

Many of you are already taking methotrexate or prednisone, or both. Prednisone has a number of side effects that are all too familiar to myositis patients, including weight gain, mood swings, moon face, bone loss, insomnia and a tendency towards diabetes. If you are new to prednisone, ask your doctor about protecting your bones, following a special diet and spacing the doses for the best possibility for sleeping well. Your doctor will follow your progress and check for side effects. Report any changes or difficulties immediately.

After beginning methotrexate for interstitial lung disease, your doctor will follow you closely and inquire about any side effects or problems with the medicine. This drug is usually prescribed as one dose per week. Once a day of the week has been chosen for methotrexate therapy, the drug should be given on the same day in following weeks. Some side effects of taking methotrexate are a lowered blood count, liver damage, upset stomach and fatigue. Often, doctors prescribe folic acid along with methotrexate to prevent side effects. Report any unusual symptoms to your doctor immediately. Many people tolerate methotrexate well and never have any side effects. Your doctor will tell you to avoid alcohol while taking methotrexate.

### Other treatments

Some of TMA's medical advisors have been watching new treatments for myositis, which include drugs called cyclosporine and tacrolimus. These drugs have been used in some cases where ILD did not respond to other, more commonly used drugs, and also in cases complicated with pneumonitis. Your doctor may discuss these and other experimental drugs with you over the course of your treatment.



# EXPERTS AND MEMBERS SHARE RECIPES FOR HEALTH

Can the roast beef and mashed potatoes you ate last night affect the way you feel this morning? While acute and even subtle food allergies can have a profound short-term effect on your health, your overall diet – what you eat day after day – is more likely to affect your overall health while you cope with the specific symptoms of chronic disease. There is good evidence that excessive weight and the type of diet you follow may influence symptoms of myositis, arthritis, and a host of other chronic illnesses.

Patricia Kendall, PhD, a Colorado dietician who writes frequently on nutrition and chronic disease, warns us to be wary of special diets and nutritional supplements that claim to cure disease. “Unfortunately,” Dr. Kendall says, “most of the claims for these cure-all diets or nutritional supplements have not been scientifically tested to determine if they work and are safe.”

Like arthritis, myositis is a complicated autoimmune disease with no simple nutritional cure. Because there are so many factors and related diseases, there isn’t one single diet plan that will help everyone. What Kendall and other medical and nutrition experts do generally recommend, however, is that people with arthritis follow a diet based on variety, balance and moderation.

“Consuming a variety of different kinds of fruits, vegetables and whole grains is important in addition to moderating the amount of foods high in sugar, salt and saturated fat,” Kendall says. “Eating a well-balanced diet may help you feel better overall, aid in weight control and help prevent other chronic diseases

such as heart disease and cancer.”

Recent research also suggests that consuming omega-3 fatty acids found in cold-water fish and other seafood may reduce joint inflammation in people who have rheumatoid arthritis as well as myositis. In addition, a diet that has both vitamin D and calcium is essential for preventing osteoporosis. Many chronically ill patients develop osteoporosis from lack of exercise and from the inflammation itself as well as medications like prednisone that hasten bone loss. Kendall adds that foods rich in zinc and selenium (lean ground beef, chicken, whole-wheat bread, eggs, almonds, milk and tofu) may be of some help because both of these minerals have anti-inflammatory properties.

Medications also affect your body’s nutrient needs. For example, antacids taken for stomach irritation often have high levels of calcium, sodium and magnesium. Prednisone and other steroids prescribed for

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**You can educate yourself [about diet], make some adjustments, and seek the guidance of your doctor or a registered dietician.**

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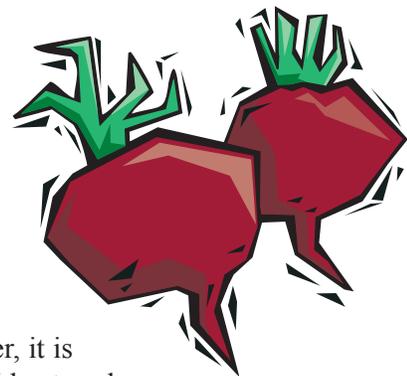
myositis may cause your body to lose potassium and retain sodium. Penicillamine may lower blood levels of copper. Methotrexate, commonly prescribed for myositis, may lower levels of folic acid, and most doctors prescribe a folic acid supplement with this drug. In some cases, eating a variety of foods will provide sufficient levels of these minerals without

added supplementation.

However, it is a good idea to ask your doctor how the medication prescribed for you may affect your nutrient needs and whether a vitamin and mineral supplement may be appropriate for you.

For all chronic disease patients, good nutrition can sometimes be challenging. Weakness, inflammation and fatigue make food preparation more difficult. Medications can take away your appetite and cause stomach upset. Depression – often a concern in people with chronic illness – may also change your eating habits and suppress your appetite. Though you may not be able to control all these factors, you can educate yourself, make some adjustments, and seek the guidance of your doctor or a registered dietician, Kendall says.

For patients taking high levels of prednisone, TMA’s medical advisors often prescribe supplements of calcium and vitamin D as well as a strict diet to counteract the weight gain, water retention and “moon face” associated with high amounts of steroids. TMA Medical Advisor Dr. Richard Barohn asks his prednisone patients to follow a diet that is low-fat, low-salt and low-carbohydrate, with almost no simple sugars. He finds that patients who can follow this difficult regimen are often spared the unpleasant side effects. The diet is basically an anti-diabetes diet, since diabetes is another common side effect of long-term prednisone use. Marianne Connolly, a polymyositis patient, was determined not to gain the weight that was sure to accompany her high-dose pred-



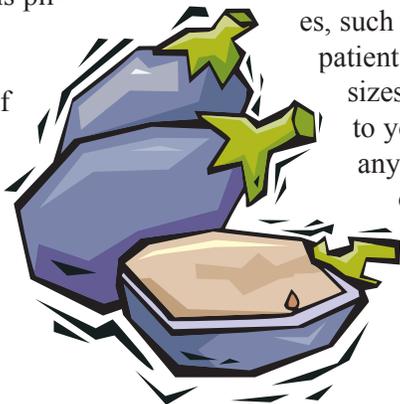
nisone intake – 60 mgs – prescribed to control the pain, weakness and lung symptoms of her disease.

Marianne’s rheumatologist prescribed a prednisone diet – no salt, no sugar, and low carbohydrates. Marianne worked with a dietician, who also encouraged her to eliminate cheese and all dairy products as well as processed foods and additives from her diet. “We were actually following an elimination diet,” Marianne said. “Eliminating processed foods, additives like dyes and chemicals, and milk products removed several possible sources of allergic reaction that could have been adding to the inflammation.”

Marianne found that her choice of food did help her avoid the side effects of prednisone, and it also contributed to her general well being. Now down to 5 mg of prednisone, she still follows her diet because she enjoys it and loves the way she feels when she eats only fresh, unprocessed foods. “I’m not saying I don’t have a piece of pie or a small piece of cheese every now and then,” she said. “But it’s very rare.”

Like Marianne, Mark Roberts made a conscious effort to eat foods that give his body what it needs to work properly and avoid foods that don’t contribute to his health.

Mark’s story is dramatic. He had been especially fit all his life. Then came the typical rash and muscle weakness of dermatomyositis (DM). He went from rollerblading 10 miles a day to not being able to lift his head from his pillow, all in three weeks’ time. After a course of prednisone and a successful regimen of IVIg, Mark was able to return to work and take only a



small maintenance dose of prednisone to stay relatively healthy.

Mark has removed all refined foods, like flours and sugars, from his diet, choosing only fresh, whole foods and limiting coffee. For snacks, he eats fruit, carrots and aged cheeses. “We eat high fiber, nutrient rich foods that are processed as little as possible,” he says. Mark also takes a number of supplements. “I can tell you it is much easier to lead a healthy lifestyle than to be sick and tired all the time,” he says.

Others have altered their diets to a lesser extent. Richard Gaulke, an IBMer and long-time TMA member, says, “I went on a diet soon after finding out that I had myositis. My reason at the time was that my MD did not want me to take a lipid medicine and I have a history of elevated cholesterol and triglycerides.” Richard now follows the Atkins diet. He avoids breads and pastas, other than the soy variety, and has lost more weight. “The lower weight is a great plus as my legs get weaker in time with IBM,” he says. More important, he has seen a noticeable change in his health – for the good. The colds that bothered him year after year are no longer an issue. He’s even been able to stop taking medicines for his sinus problems. He’s continued to feel good throughout the three years he has been watching what he eats, he says.

Lori Love, MD PhD, a DM patient, restricts her diet to mostly plant-based foods, adding different herbs to her food for specific purposes, such as ginger for digestion. As a patient and physician, she emphasizes the importance of speaking to your doctor before making any major changes to your diet or other routines, and recommends that you work together to find the best overall treatment for you.

## Messages, Cont’d from page 3

have found that I have had to put my pride in my pocket and ask for assistance where I need it and to keep trying to help myself where I can. I think that there is a time when I only frustrate myself and my family by not asking for help. My family has said to me that they often want to help when they see me battling to do something but they do not want to be accused of interfering. I have reached an agreement with them in that I will ask for help when I need it and before I get frustrated and angry because I can’t accomplish what I set out to do. I think that most family and friends do not understand the severity of the disease because it is so slowly progressive and the subtle changes in our condition and what we can do are not easily noticeable.

- Roly/IBM



## Contribute to Extra

We’ve received rave reviews about both 2003 issues of *OutLook Extra*, and we have you to thank for much of it. We’re working on the second edition of the Special Products issue, and we need your thoughts and ideas. Are there any unique gadgets you use daily or larger devices that help you get around? Big or small, we’re looking for all of the products that make things easier for you.

Send your suggestions to us, and be sure to include any drawings, photos or detailed directions for do-it-yourself projects or modifications. Email [tma@myositis.org](mailto:tma@myositis.org) or write to us at 1233 20th Street NW, Suite 402, Washington, DC 20036. We’d like to hear from you by April 30, 2004.



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