

## The search is on: But why start now?

What is myositis? Is it treatable? What medicine will I have to take? How will it affect me? How will my life change?

These are the questions we hear from newly diagnosed patients. It's only later that they begin to ask about equipment and other aids. But sometimes waiting can complicate the process of finding the right tools. Our medical advisors agree. Whenever they address myositis patients, they advise them to use assistive devices to save energy long before they must. In fact, they say, this puts off the time that it becomes a necessity.

"We don't want to give in," says Ann Navan, who's lived with IBM for years. "We don't want to appear different by using equipment that makes illness more visible." Ann encourages myositis patients to explore assistive devices while still strong and independent. Otherwise, she says, you and your helper may struggle needlessly.

Ann has researched equipment on the Internet and through catalogues, and we include many of her resources in this issue. From aids for reaching household items to lift chairs and scooters, Ann has found resources for almost any need.

"The first problem is how and where to find them," says Ann. "The second is admitting you need them and using them."

She admits waiting too long herself to get the equipment she needed – power chair, adapted van, electric bed. With her help, you can find what you need now, and make the best decision about what's right for you.

## Want something extra? You got it!

*As an added benefit to all TMA members, we've added a couple of Outlook Extra editions. This first issue focuses on products to serve myositis patients. The next special issue in November will focus on treatments for myositis.*

We envisioned this supplement to the *Outlook* to be a practical guide for you to learn more about available products and issues of mobility. Our sponsor and advertisers made it possible for us to expand this issue to include much more for you. We've brought together many of the resources, suggestions and ingenious devices collected by the most knowledgeable authorities on living with myositis – patients and their families. From small, homemade modifications to buying the more expensive adaptive devices, many of you shared your own experiences with us. Offering advice on everything from buttonhooks to scooters is a daily pursuit on the TMA Bulletin Board. Many of the hints and products in this issue were originally posted on the Board; other information comes from our own research into new products now on the market or in the pipeline.

The Extra brings these solutions and ideas right to your doorstep.

Each year, we'll pull together your unique creations and personal experiences for the products issue of *Extra* to help guide those facing new challenges with myositis – challenges you may have already found a way to overcome. Be sure to let us know where any products may be purchased or, if it's a do-it-yourself project, include step-by-step plans for duplication and indicate whether it's a job suited for a general tinkerer or an advanced handyperson. Share your stories with us by emailing [tma@myositis.org](mailto:tma@myositis.org), or send them to TMA Extra, 755-C Cantrell Avenue, Harrisonburg, VA 22801.

This year's Annual Conference in Houston will feature the ingenuity of TMA members in addition to the expertise of our medical advisors. We invite you to join us in Houston, where we can all exchange our ideas in person.

Thanks to everyone who made this initial edition of the Extra a comprehensive and invaluable guide for others.

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## Message from the Executive Director

Dear Friends,

This special issue of *OutLook*, which focuses on products useful for living with myositis, is to serve as a resource for myositis patients, but it is also a tribute to your ingenuity. Myositis patients demonstrate incredible creativity and determination in modifying existing products and designing instruments from scratch to help

make life more manageable. It is this spirit of determination and ingenuity that characterizes so many myositis patients, including children with the disease.

It is also satisfying to see that manufacturers are becoming more aware of the disability market as signified by the multitude of products now available to serve those who are physically challenged by neuromuscular diseases such as the inflammatory myopathies.

You will note that we have for the first time included ads in this special issue of *OutLook*, and Bristol-Myers Squibb Company is sponsoring the products issue of *OutLook Extra* as well as the special treatments issue to be published in November. We have invited corporate advertising and sponsorship to show you some of the products useful to myositis patients and to encourage corporations to demonstrate their commitment to helping The Myositis Association serve the myositis community. Corporate financial support allows TMA to expand its services and programs to our members and others concerned about myositis.

If you care to take a moment to write or send an email to these manufacturers to thank them for their support, it will be noticed and will encourage them to continue to support TMA in the future. Addresses for the advertisers and sponsor can be found at the end of this issue.

I hope you will hold on to *OutLook Extra* and refer to it when you need help or are in search of products. You are also always welcome to call or write TMA for help in locating a product or bringing particularly helpful products to the attention of other myositis patients.

Together we will make life more manageable for you as we continue to search for better myositis treatments and, ultimately, a cure for myositis!

A handwritten signature in black ink, appearing to read 'Bob Goldberg', written in a cursive style.

*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.*

# Need a lift? Decide whether you should drive or push

After reading “The search is on,” we hope you’re ready to think about a wheelchair even if you don’t quite need it yet. We thank Ann and the many members who contributed their personal experiences with wheelchairs for the wheelchair and scooter review that follows.

Chances are one of the first decisions you’ll make is whether your wheelchair will be manual, a power chair or a scooter. With one, you’ll push; with the other two, you’ll drive. Each has its own advantages:

## Advantages of a manual wheelchair

Most people prefer to use a manual chair if they can. The biggest factor for myositis patients is strength – you’ll need lots of strength in your arms and shoulders if you plan to use a manual chair. Manual wheelchairs are:

- Lighter in weight. Technology is making wheelchairs lighter all the time, so each new generation of chairs takes less strength and energy to push than the one before.
- Less obvious. Manual wheelchairs are quieter and also quite a bit smaller, so you’re not drawing as much attention to yourself.
- Less expensive initially and less to maintain. There are fewer working parts, and repair is simpler and less expensive, both for materials and labor.
- More flexible. You provide the power, so you’re not dependent on a battery.
- Easier to handle, especially for

small movements.

- Easier for travel. They fit better into an airplane or in the seat or trunk of a car. Usually, a manual chair can be stored more easily since it has parts that break down. You can remove footrests and wheels on newer models.



- More maneuverable. Those who still have strength in arms and shoulders can get around many obstacles.

## Advantages of a power wheelchair

The main advantage of power chairs may be the most vital requirement for many myositis patients. Power wheelchairs and scooters don’t require the strength you need to use a manual chair. Power wheelchairs:

- Go uphill. This is often beyond the capability of someone in a manual chair.
- Provide more independence. The power frees you from the need for assistance from another when going a considerable distance or on a steep surface.

- Make it easy to carry things. You’ll have an arm free to steady things in your lap. See Mike Shirk’s “art scooter” in the scooter section, page 7.

- Tilt, recline, change position. This helps in preventing pressure sores and makes respiration easier for some riders.

Your choice may not be final – you may plan to use a wheelchair today, or a walker inside and a scooter outside, or a power chair once you need assistance inside. Most

patients we talked to believe it is best to use a manual wheelchair as long as you can, keeping in mind the possible future need for a power chair or scooter. For those in flares of DM or PM, the wheelchair – if they can manage it – is by far the best choice since most will find themselves returning to walking after treatment. If you have long-term disability but can walk in places where you can support yourself, you may want to go with the walker-scooter combination used by many IBM patients.



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# WHEELCHAIR USERS HAVE MORE CHOICES THAN EVER BEFORE

Since most wheelchair users keep the same chair for years, you'll want to be very sure that you'll be comfortable and that the chair meets your needs. Paul Browning, a wheelchair user for two decades, suggests that you make a list of everything you need to consider. For instance, will you be keeping the same car, or are you willing to make a vehicle selection based on your wheelchair? There are many places to start gathering the information you'll need to make an intelligent decision.

## First, do your research

If this will be your first wheelchair, you may have trouble knowing where to even start. Richard Baldwin, who writes a syndicated column called "The Mobility Lifestyle Advisor," recommends beginning with the Center for Independent Living in your area. "Almost every city has one," Richard said. "Believe me, no matter what your situation and questions, the staff there will know about a similar case." Myositis, although a rare disease, has many of the same challenges and weaknesses as other muscle diseases, Richard said. "You won't have to reinvent the wheel."

If you're a veteran chair user about to select a new chair, you may view the change as a little frightening. Everyone we talked to recommended that you browse the Internet extensively before ever making an appointment or showing up at a dealer. If you don't have Internet access, it's even more important to talk to the staff at your nearest Center for Independent

Living, or your physical or occupational therapist.

Since most potential buyers are limited in their mobility, wheelchair manufacturers tend to have extensive web sites. Many companies will guide you through the process and post detailed online instructions explaining how to measure yourself (or have someone measure you) for a chair. You'll also find a great many accessories and will need to balance price and quality every step of the way. Browning said that he doesn't recommend actually purchasing your chair online without ever seeing a specialist, but he thinks it helpful to narrow down your search to the two or three chairs that have the features you need. Going through this process in advance also helps you learn what's available and makes you focus on how you will use your chair.

## Know when to fold 'em

You'll need to choose between a rigid, or fixed, frame and a folding frame chair.

Most occupational therapists now recommend the rigid frame chair. George Wilson, a polymyositis patient who normally walks but uses a folding chair when he needs to cover a great deal of area, made the switch recently and said that his newer, rigid frame chair is

much easier to push. Recent advances have actually made them more portable than the folding frame chairs.

Generally, this chair takes up one seat in a car, once you pop off the wheels. Taking the chair apart in this way may be intimidating at first, but users say they get used to it and can snap the wheels on in seconds. The hand strength needed for this is actually less than for folding the chair, Wilson said.

With new materials it's possible to get a very light chair, even if you are a large person. The lighter the chair, the better, as long as the center of gravity doesn't shift.

Another choice: modular or custom? Usually, a dealer will recommend a modular chair for a first-time user. That's because you probably don't know enough yet about the changes in body strength and function and the ways in which you will use your chair. Modular chairs combine ready-made components to a size that will fit a particular buyer. Choosing this type of chair allows you to make adjustments if your situation, size or strength should change. Once you become a veteran chair user, you'll understand what you need completely and may want to order a custom chair with features that are especially suited to your needs.

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In the end, John says, it all boils down to what you need, what you can get and what you can afford.

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## Wheelchair checklist

Veteran wheelchair-user and TMA

Bulletin Board regular John Servinski was kind enough to share his wheelchair checklist. John says that you should definitely take stock of your own accommodations first, noting these variables:

- Width of chair versus width of doorways at home.
- Weight of the chair – some can get pretty heavy. See if you and your spouse can lift it.
- Type of wheels and the type of terrain you'll be on. Compare solid versus air-filled tubes and types of tread. Some work better in dirt; some on hard surfaces.
- Cost of maintenance and parts. There's no sense in buying a wheelchair if you can't get the parts or if they are too expensive.
- Look at the cost. The fancier the chair, the more expensive. Find out if insurance will pay.

## Roll on out

As John suggests, the type of wheel is a big concern for the wheelchair user. What you use in your house on a smooth surface is going to be entirely different from what you may need to go over bumpy surfaces outside. If you live in a city and are negotiating sidewalks and streets, Spinergy wheels are a good choice, Browning says, because of their ability to absorb shock. Wheels with metal spokes can handle a lot of constant wear and tear, and spider wheels are extremely low maintenance.

The most common choice for people in manual wheelchairs is the pneumatic tire with treads. Others choose the lower-maintenance polyurethane tires, but these don't provide a gentle ride on rough surfaces. The smaller front wheels on your chair – the casters – play an important role as the first part of

your wheelchair unit to meet the ground surface and absorb the shock. Aluminum billet wheels and poly tires with aluminum or plastic wheel casters come in different sizes and help you with a smooth ride. The problem with casters that are too large, members tell us, is that they make it hard to navigate smoothly.

## Accessorize, accessorize

John also advises that you think about accessories. Hand brake extension arms help with setting or releasing brakes. Decide whether you want foot supports to be fixed or removable, he suggests: "If they swing out of the way, it makes the width of the chair greater." Decide on cushions – foam are cheaper; gel-filled are nice, but very expensive. You may have to choose between armrests that are fixed and those that are removable.

"You'll want a tote bag for the back of the chair," John says. "You get tired of holding things in your mouth while rolling around." You'll want hand gloves to help grip the wheels and prevent blisters. In the end, John says, it all boils down to what you need, what you can get and what you can afford. For first-time users he suggests talking to occupational and physical therapists, as well as to those who already have wheelchairs so you can learn their good and bad points from people who know firsthand.

Whatever you decide, John says: "Just remember, your wheelchair is going to last you a long time, and you are going to have to live with whatever you decide on. Not too many companies will take back a unit after

a sale is final. Knowledge is power – be informed!"

## Be seated, please

Nothing's more important than the correct seat positioning of your wheelchair, we hear from users. Every wheelchair user sits differently, and you may need some help knowing the best way to sit for the greatest mobility. You may want to see a Certified Rehabilitation Supplier to find people trained and certified in fitting people to their chairs. Be aware that often these people are also salespeople and, armed with the knowledge outlined here, you should be able to clearly express what you want as opposed to what they would like to sell you. You can find other seating experts at rehabilitation centers. If you have a good one at your hospital, you'll find the staff extremely knowledgeable about what kind of seat is right for you.

## Measure twice, sit once

You'll need to know the key measurements: width of hips, buttocks to the back of the leg, back of the leg to the heel, height of the back. Another crucial consideration is the

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# BUYING AND USING YOUR SCOOTER OR POWER CHAIR

Once you've made the decision to go with a power-assisted wheelchair or scooter, you've taken a big step, but you're not through yet. You'll need to choose between the two.

## Weighing the options

This choice will depend a great deal on the space inside your home and your own strength. The power chair is usually guided by a joystick and is the best choice for those without the strength to maneuver a vehicle with a tiller-mounted steering mechanism like those installed in a scooter.

Power chairs also take up less space, often turning in a radius of about 20 inches. The scooter looks like a low motorcycle and takes more space to turn and corner. Many people who get around inside with walkers, canes, and holding on to the walls and furniture find they only need the scooter outside. If you're in a chair most of the time and want extra power to go from room to room inside, the power chair is your best choice.

Charles Boon wrote us about the power chair he recently purchased from The Scooter Store. He's very satisfied with it and with the store's assistance. The Scooter Store made all the arrangements required with both Medicare and Charles's physician, and there was no cost to him. "The Power Chair is very maneuverable and makes it easy to get around in the home," he said. "I recommend it to those who need help in getting around. It is very much more maneuverable than a scooter."

## More choices for scooters

Let's say you've chosen to buy a

scooter: You're still not through with choices. You'll need to consider where your primary use of the scooter will be: indoors, outdoors, for travel, on hard surfaces, on grass or a combination. If you'll be using the scooter indoors, measure the door widths, especially in the bathroom. If you need width for your scooter to pass through, you may buy a set of offset door hinges at your local hardware store instead of having a contractor widen your door openings.

On the other hand, if your primary use is for outdoors or travel, you need to consider how you will transport the equipment. If you are able to lift 23 to 63 pounds, you may disassemble equipment and transport it in your vehicle. If you are able to lift the seat off your scooter (20 to 39 pounds), you can find an interior lift for the trunk of your vehicle, station wagon, truck, sports utility vehicle or van. If you own a van, you may need to remove the rear seat. Also, you can purchase a C-ARM for your van, allowing the scooter to be loaded and unloaded without removing the scooter's heavy seat. If you are unable to lift the seat, or your scooter will not fit into your trunk or van, there are carriers like the Tilt-A-Rack or Harmar AL-100 or 500.

Some automobile manufacturers will reimburse you for the purchase of a lift or ramp: Ford, \$1000, 800-952-2248; Chrysler, \$750 to \$1000, 800-255-9877; General Motors,

\$1000, 800-323-9935; Toyota, \$1000, 800-331-4331; Lexus, \$1000, 800-255-3987; Saturn, 800-553-6000; Volkswagen, 800-374-8389.

## Straight from the experts – you!

Peter, a dermatomyositis patient from Canada, uses his scooter for the outdoors. He writes: "I've had one now for 18 months and call it my 'Freedom Machine' as it enables me to go out on my own without

help. We are fortunate in living within close proximity to most things we need and if I do have to go further then I can take it on a bus or the 'Skytrain' which has a station nearby. Other than that I can call a 'wheelchair' taxi which

is here in a few minutes and is very convenient to use. Thus I've been able to give up the car and save on the insurance to use for cab fare."

Peter chose a scooter made in Australia, an Orion De-Luxe III, which he bought in Vancouver. The doctor recommended a four-wheeler for stability. In the apartment, Peter uses a walker.

Mike Shirk, whose artwork was featured in the June *OutLook*, said that his scooter has been wonderful for painting outdoors, since he can take his supplies into places that are less accessible either by foot or by car. See a picture of his scooter on the next page.

Millie Carrier has had a great deal of experience with scooters. For her it's worked out better to have foam-filled tires than tires with tubes. "The main reason for this," she says, "is if you have tubes (like a bike) you could get a flat. This has happened to me going down the

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Think about all the options you might enjoy!

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road.”

Her next recommendation is to make sure to have a lift seat, which makes transferring easier. Like other scooter users, Millie suggests that you have a charger on board. Gel batteries are also preferable, Millie says, because these are the only kind allowed on airplanes. When you travel, she says, check to see if extra insurance is needed to cover the scooter. Other scooter suggestions, from Millie:

- Be sure to have at least one light to help when you’re outside in the dark. Unlike Peter, Millie prefers a three-wheeler.
- Think about all options you might enjoy. Millie’s family goes camping, so she needed one that could handle being outside in the woods to negotiate rough terrain.
- A basket is a necessary accessory for carrying things.
- Be sure that the scooter fits your weight and height properly.
- Look for a small turning radius.
- Do your homework: most insurance companies will not replace a scooter until after 3 to 5 years.

You’ll also want to consider if you will be doing much traveling. Millie has found that weight is important, but that it’s balanced out by other features. The on-board charger and lift seat add weight, but she thinks they are worth it.

When you use the scooter, remember to protect the forward and backward levers when carrying objects or turning. Millie likes to visit family and friends on her scooter, so she always has a plan for how she’ll negotiate steps. Because she uses her scooter in the house, she chose the three-wheeler with the smaller turning radius. She remains in her scooter, using its seat as her chair, but she’s able to switch

the seat so it faces backward rather than turning the whole scooter around. By doing this, Millie can continue to use her sewing machine. Even though she uses the scooter in the house, she chose it rather than the power chair because she relies on the tiller to rest when she’s tired or needs to lean forward. She also uses the tiller to help her drink or even eat when she’s not at a table. “With the scooter ‘floor’ I am able to carry things around,” she said. She stretches her legs and moves them around to shift her weight and avoid pressure sores, something that would be more difficult in a power chair.



*IBM patient, Mike Shirk has outfitted his scooter with all the supplies he needs to paint while traveling.*

Colorado IBM patient Brad Bent gave us some suggestions for a variety of devices. Brad has planned ahead and tried devices before he actually needed them. Brad’s

strength is mainly in his shoulders, thumb and index finger. He is twenty years into IBM and stopped walking or standing two years ago. He has always bought what he needed before he actually needed it. He bought a portable wheelchair very early, which he says was a great benefit when walking long distances became a problem. “The mistake I made was not looking at other chairs on the market which would have made a difference in later years,” he said.

Brad bought an Amigo scooter after trying one during the Orlando conference in 1996. He didn’t really use it until the next year but it was ready when he needed it. In 1999, Brad got a Jazzy (power chair) via Medicare, gradually using it more than the scooter because of its great maneuverability. There was a drawback, he said: “As I began to spend more time in the Jazzy the seat comfort became less and less...the standard ‘stock’ seat isn’t built for all-day use.”

Last May, Brad bought a new Jazzy 1122 with a pan seat and Roho cushion. By putting it out for bid, he discovered what other members have told us: there was a \$2800 difference

between bidders! Because of the special cushions, “sitting now resembles sitting on marshmallows

*Continued on next page*

– GREAT!” he said. Another valuable purchase was a “Cameleon” shower/commode chair (Rolli Moden Designs). Brad bought it for a cruise in 1999 and said it was fantastic, and he now uses it every day.

Brad started looking into an “EasyStand” standing aid late last year, finally getting a “loaner” in late February. Brad still has it and says that being able to stand for the first time in over two years is beyond description! Here’s how he transfers: “With my wife’s help and transfer board, sliding on to the seat is simple. The arms drop down, my wife pushes the handle (car jack style) and up you go. My right leg is developing a serious contracture so the stretching of my calf muscles seems to be helping. I’m able to stand for about an hour as the bottoms of my feet start hurting more than anything.”

The basic price is about \$2600, and insurance doesn’t cover standing devices. The EasyStand doesn’t come standard with a “back,” so a high or low back is another \$500. Locking castors are another \$115, so the very basic unit Brad is trying comes in at about \$3200, he says.



## Staying on the road: Questions and answers

**Question:** My mother will be staying with us and she uses a scooter to get around. What type of lift will work in my station wagon?

**Answer:** You’ll need to ask more questions before making a decision. What size is her scooter, who will be loading the scooter, how large is your station wagon, do you want to carry the scooter inside or outside, and will this be permanent? Start with your local mobility dealer to check on the products that

are available locally. Make sure you discuss all these questions before making a decision. To find a local dealer, go to [www.nmeda.org](http://www.nmeda.org).

**Question:** I am a long-time manual chair user and it is getting harder to transfer into my car. Are there any transfer seats that might work in my case?

**Answer:** As the population ages, manufacturers like Bruno, Access Unlimited and others are now promoting transfer seats for different vehicles. Most of these modifications require replacement seats because of the integrated seatbelts and automatic tension system found in newer cars. These powered seat bases swivel out towards the door of the car and then extend out past the door jam. In several models, the seat is actually extended and lowered electrically so that you can make a horizontal transfer. The seat base then lifts you up and back into the car, where you manually swivel into a forward-facing position.

Unfortunately, the driver position in most vehicles will not accept this type of adaptation. Access Unlimited has several modifications to assist you in getting into the driver’s position. This is done by way of a small lift platform that folds out and is powered up and down, making the transfer effortless. The small folding platform takes up very little space and fits neatly between the driver seat and door panel. Call your local mobility dealer to confirm if your car is a good match for this type of modification.

Our thanks to Richard Baldwin for answering these questions. Reach Richard at [mobility@intelos.net](mailto:mobility@intelos.net). Richard writes a monthly column, “The Mobile Lifestyle Advisor” for the Disabled Dealer.



## What about walkers and canes?

If you're just starting to notice a loss of mobility, or if you're in a flare of myositis, you may not be ready for bigger purchases like wheelchairs and scooters. "If you're falling a lot, you need to get yourself an attractive cane or walking stick, or a walker to use when you're especially weak," says Lori Fisher, a long-time TMA member and DM patient.

Even with walkers and canes, though, there is a list of questions to answer: How much weight do you need the walker or cane to handle? How high, wide and deep do you want the seat, if you need a seat at all? Will you use one more inside or outside? What "extras" will come in handy? Some walkers or canes will even fold if you travel frequently.

### Canes

The height of the cane is essential. With your shoes on and standing up straight, the top of the cane should be at your wrist. As you hold the cane, your elbow should be slightly bent. Hold the cane in the hand opposite your weaker side.

Canes come in many styles, and how often you use the cane may determine what style best suits your own needs. The Mayo Clinic suggests that a standard cane will support up to 25 percent of your body weight but provides little stability.

Canes come with a variety of handles, including standard, offset, tourist, and fritz. Decide what's most comfortable for you by trying them out first. If you have weaker grip, certain handles, like the traditional style, may be too difficult for you to grasp with comfort and confidence.

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# A couple of classic common-sense solutions

## The Moench Buttonhook

**YOU WILL NEED:** Coat hanger (not heavy wire); pair of ordinary pliers with cutting notch; possibly a vise; file or grit paper

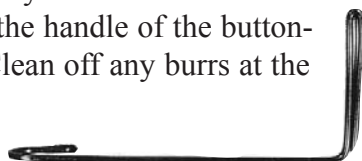
**Step One:** Using a straight piece of coat hanger wire, make a tight end loop. To avoid wear on the buttonhole edges, remove any burrs at the end of the wire. Keep in mind that this must be a tight bend as it will be part of the loop mechanism that must fit *through* the buttonhole. If your hands or fingers are weak, use a vise to tighten the bend.

**Step Two:** Bend the wire into a half loop. The size of the loop can be varied based on the type of button and buttonhole. This loop must fit through the buttonhole both going in and coming out. Regardless of minor variations, it will work!



**Step Three:** With the wire laid out flat and about three and a half inches from the loop, bend the wire up ninety degrees. The loop will need to approach the button from the bottom, so be sure the bend is in the right direction for this.

**Step Four:** At about the one-and-a-half inch point of the last bend, bend the wire back on itself and cut off any excess. This double wire is the handle of the buttonhook. Clean off any burrs at the end.



**To use the Moench buttonhook:** Zip trousers part way up to whatever position is possible. Slip the buttonhook into the buttonhole and then, from the bottom side of the button, catch the button with the loop end of the buttonhook. The ninety-degree handle will keep the buttonhook from sliding and possibly falling to the floor; so you can use two hands to get the loop hooked under the button.

Using the handle of the buttonhook, pull on the buttonhook toward the position of the buttonhole and then outward. This brings the right and left part of the trousers together by way of the lever action of the buttonhook. With the button now approaching at the site of the buttonhole, pull outward and down while, if you can, keeping the top of the trousers upright. The purpose is to align the button with the buttonhole which, when aligned, will then slide through the halfway point, the bottom lip of the button coming over the down edge of the buttonhole.

With the down edge of the button now overlapping the down edge of the buttonhole, simply rotate the buttonhook in a clockwise circle. This will lift the edge of the button fully over the buttonhole. At the end of the circle movement, simply slip off the buttonhook and you are done. (Since the button is the point of leverage, you may need to reinforce it with more thread.)



## Half-step

**YOU WILL NEED:** standard narrow base quad cane; plywood (20 in L x 7 in W x 3/4 in H); one 7-inch 2-x-4 piece of wood; 4 screws

- Round off the corners of the plywood.
- Drill four holes 2 1/4 inches from one short edge of the wood and equally across the 7 inches.
- Cut the 2-x-4 wood for a final product of 1 1/2 inches by 3 by 7.
- Screw this piece onto the plywood at the four drilled holes. This acts as a "leg" for the half-step.
- Drill three or four holes in the metal base plate of the cane.
- Mark the plywood 2 1/2 inches in from one of the short edges of the wood and 3 1/2 inches from the long edges.
- Drill a 7/8-inch diameter hole here. The cane will fit through this hole.
- Attach the cane to the plywood at the holes you drilled in the cane.



## HELPFUL HINTS: MEMBERS SHARE THEIR IDEAS

Please see Resources on page 18 for more information on how to contact the companies listed here. Do you have any suggestions or ideas you'd like to share? Email us at [tma@myositis.org](mailto:tma@myositis.org) with your own buying experiences, creative modifications or handy inventions.

People learn a lot from past experience, and luckily, TMA has members and friends more than willing to share their own. When it comes to making a big purchase, such as a scooter or electric bed, it's important to do your research. It can be just as crucial with smaller items so you're not spending time and money on products that won't get the job done. Here are some of the many helpful hints – both big and small – that you've shared through postings to the TMA Bulletin Board, listservs, phone calls, emails, and letters:

### Household items

In the kitchen, Ann Navan suggests using **long, rigid straws** when lifting a drink becomes more difficult. **Jar openers** ease the burden of always asking for help. One BB user discovered that Craftsman Multi-Purpose Strap Wrenches help open jars of all different sizes. Learn about these and many other household products through Wisdom King, Dynamic Living, Sammons Preston Rolyan, MOMS, and other companies specializing in products designed to help you maintain your independence.

More interested in homemade solutions? Harris Teller, an IBM patient full of ingenious planning ideas, **wraps rubber bands around bottles** to help with grip, for both opening and holding them. Mike

Shirk, who shared some of his own innovations at the 2001 Annual Conference, situates **special hooks** around his house to help open drawers and reach for objects. By fastening a rubber-coated rack hook to a dowel rod then wrapping it with tape, Mike is no longer as limited by his weak fingers. (You can also find ready-made “reachers” at stores listed under *Aids for daily living* in the Resources section.)

Several members' falls led them to consider **emergency alert systems**. Some specific recommendations include: Get Help Now through the American Senior Safety Agency, 888-473-2800; local area Agency on Aging groups; MOMS; Dynamic Living; Fare Thee Well Phones; and other resources available through your doctor. Remember to **carry your portable phone with you** around the house in case of an emergency. “I was fortunate to have carried our cordless phone outside with me,” says Marilyn Townsend, a PM patient who fell while alone outdoors. “Now I carry it wherever I go around the house.” You can also use cell phones, especially now that companies have more flexible and affordable cell plans. Keep emergency contact numbers programmed into your phones so you can call without having to dial the whole number.

Along the same lines, Nancy Fischer's husband installed a **doorbell ringer** on her walker so she could always call him when she needed help. This has a range of about 25 feet. After she shared this advice at a recent TMAConference, others suggested using a **baby monitor** or **walkie-talkie system**.

Other TMA members suggest the **Knox-Box Rapid Entry System**,

which lets emergency crews find your keys and floor plans in a special box in an emergency. You'll need to be sure your local fire department is registered, and check with them for the proper location for installing the box.

### For when you're on the go

Not all of your suggestions came from catalogues and stores. Several people have wondered about **handicapped parking stickers**, embarrassed to ask their doctors or find out more. Shirley Barr, an avid Bulletin Board user, has one if she needs it but doesn't use it very often: “If a parking lot is small or I am not buying much then I leave the spaces for those more disabled than me.” Many others encourage you to visit your local Department of Motor Vehicles office for the right form. “It is better to have it and not need it than to need it and not have it,” adds Franklin, another BB regular.

Do you need help getting out of a car? There are **lift seats** and other useful gadgets. You can order the **handy bar**, offering an extra handle that slides into the door latch in the car's frame, to help you lift yourself from the car.

Pete Randolph, an IBM patient, had his son follow the same concept as the handy bar but chose a longer bar that sticks into the car instead of outside the vehicle. This targeted the muscles needed to make this a successful tool for Pete's individual situation. The bar works on the driver's side, fitting into the door latch bolted to the body of the car. “In order for the bar to be useful, it must





fit to the person using it,” says Pete. “As little as an inch in height can make a significant difference.”

We receive many requests for how to make the popular **half-step**, a device that takes much of the muscle work out of going up and down stairs. This decreases the height of the step you need to take by breaking one stair into two steps. Best of all, it’s portable, so as long as you have some mobility, you can still go places that have stairs or other types of high steps. “My son made me one and I find it useful,” says Richard Gaulke (IBM). “I drive a 4 wheel drive pickup which is higher than the average car. I use the half-step to get into it – otherwise I would have to sell the truck.” You can purchase the EZ-Step, or follow the instructions on page 9 to make your own.

### Everyday advice, straight from your peers

“I’d just like to mention one thing,” writes Peter Stocker (DM). “**Go through all your shoes.** I got rid of a bunch of mine as with walking differently they could catch or just didn’t feel safe.”

“**I would recommend volunteering** in some capacity so that

you’re still involved with the community in a way,” says Bob Foseid (IBM). “In my particular case, I volunteer at one of our major hospitals in Seattle. I work in a rehab area and conduct a class in coping skills and lifestyle changes for patients who are there for the two or three or four weeks that they have to be there. And that is not only helpful for them but it’s certainly helpful for me because I find that it’s been one of the best things that I’ve done.”

“One of the tricks I’ve learned is on my **pants zippers**,” writes Greg Bauer (IBM). “I’ve fastened a fishing swivel. I had lost so much finger strength that I could no longer pull up my zipper. With the swivel attached I can now manage.” Others suggest using a key ring, which gives you a larger pull than a typical zipper.

On another topic, Greg adds: “I also installed a plastic strap with loops at each end on the inside **door handle of my car**. Now I can open the car door without trouble.”

Major General John Moench needed a better way to button his trousers once his fingers became too weak, so he masterfully approached the task of building a better **button-hook**. His device was so ingenious and yet so simple that other TMA members and friends have often asked for the directions. General Moench shared them with us. See page 9.

### Other resources for common-sense ideas

Gene Grosberg, an IBM patient and TMA member, puts his experience as a purchasing director to good use

with his own web site, [www.aids-forhandicapped.com](http://www.aids-forhandicapped.com). After reviewing your own personal needs, Gene seeks the right products for you, at no charge. Visit [www.workshop-solutions.com](http://www.workshop-solutions.com) for Tom Jeary’s problem-solving ideas. Tom launched his site so inventors could freely present their ideas for assistive devices. Workshop Solutions does not produce or sell products but instead provides a forum for imaginative answers. On a similar site, [www.atsolutions.org](http://www.atsolutions.org), John Schafers shares other inventors’ plans for custom-designed solutions.

### Odds and ends

Often, the tidbits that people share are the most useful pieces of advice. Here are some suggestions you’ve given over the years:

- Stack outdoor chairs to have the proper height when rising.
- Wear an apron with pockets for carrying objects around the house.
- Replace top shirt buttons with Velcro for easier dressing.
- Use acrylic cups and cutlery, which are lighter weight than regular ones.
- Change doorknobs to pull or lever handles.
- Throw out all of your mats, small rugs, or other items you can easily catch your toe on.
- Buy a table lamp which you can simply touch to turn on and off.
- Keep commonly used items in the easy-to-reach parts of your cupboard.
- Use the Saran Wrap Quick Covers (different from the cling film) instead of Tupperware tops, which can be difficult to open if you have myositis-affected hands.



# RELIEF FROM DRY SKIN

Many myositis patients, young and old, must deal with extremely dry, itchy skin, especially the cracked and scaly hands known as mechanic's hands. With the helpful advice of others, you can soothe this uncomfortable condition especially common in dermatomyositis (DM) and polymyositis (PM).



**Neutrogena**

## Hand Cream/ Norwegian

**Formula** as popular brands that are frequently recommended by dermatologists. Lotions often contain alcohol, which may cause the skin to dry even more if used too often.

“Even when both skin disease and muscle disease is present, topical cream- and ointment-based medications can be applied to the skin rash in order to minimize the doses of internal medications that are required to control the entire disease,” says Dr. Richard Sontheimer, John S. Strauss Endowed Chair in Dermatology, Professor and Head, Department of Dermatology, University of Iowa College of Medicine, and TMA Medical Advisor.

## Ointments, oils, creams, and lotions

Moisturizers come in different forms – ointments, oils, creams, and lotions. Ointments most effectively trap the moisture in your skin, says Dr. Sontheimer, but they can also leave a greasy feeling. Use **Aquaphor**, **Vaseline Petroleum Jelly**, or another ointment in a small amount on the affected area, and rub it in well to avoid excessive greasiness. Oils, including **baby and mineral oils**, are still effective without being as greasy as ointments. Creams tend to be more popular since they disappear when rubbed in. Dr. Sontheimer lists **Original Eucerin Cream**, **Nivea**, and

## Patient-to-patient recommendations

What do patients themselves recommend to each other when ordinary lotions don't do the trick?

Dale Sjogren, a PM sufferer, stumbled upon **Badger Balm** at his local hardware store. He coats it on his rough spots and covers them with a Band-Aid overnight. “It generally heals a crack within 12 hours,” he says.

Beth, another PM patient and Bulletin Board regular, uses **No-Crack** hand cream she found at [www.restorationhardware.com](http://www.restorationhardware.com). “My fingertips still split and crack at times,” she says. “But not near as much when I am using this.”

Two more frequent posters on the web site's Bulletin Board, Dorris Norris and Lea Jaeger, both praise **MSM Cream**. Dorris spotted this remedy at her health food store; Lea discovered a mail order web site, Kala Health Inc., willing to send it to her in Israel. “I have IBM and also have fingers that split, bleed and get very sore,” says Dorris. “[MSM Cream] heals the places quickly.”

Other Bulletin Board users volunteered these helpful products:

**L'Oreal's Ombrelle 60**, a light, non-greasy, and fragrance-free sunscreen that protects against both UVA and UVB rays;

**Aquaphor**, a fragrance- and preservative-free lotion that comes in original or healing ointments; and **Dermaplast**, a pain relieving spray that numbs and soothes the affected area. You can find most of these products at your local pharmacies, including CVS ([www.cvs.com](http://www.cvs.com)) and Walgreens ([www.walgreens.com](http://www.walgreens.com)); Cheri (DM) came upon L'Oreal's Ombrelle 60 online at [www.feelbest.com](http://www.feelbest.com).

## Scalp solutions

“Because the hair interferes with the application of creams and ointments, the scalp requires a corticosteroid chemical dissolved in other vehicles such as solutions, gels, sprays, or foams,” says Dr. Sontheimer. “A potent corticosteroid solution massaged into the still-moist scalp after shampooing can provide the greatest benefit from this form of therapy.”

In answer to a fellow Bulletin Board user, Jane, a DM patient, recommends **Luxiq** (betamethasone valerate), a topical corticosteroid, for scalp itch. This medicine is available as a prescription foam for scalp rashes. “It actually works like a mousse and gives your hair fullness while helping your scalp,” she says. She also offers fluocinolone acetonide topical solution (also known as **Derma-Smoother/FS**) and desonide ointment, both prescription medications.

## Mummy treatment

Sometimes the substances alone are not enough. For Andrea Clausen, nothing compared to the **wet-pack**, or **mummy treatment** prescribed

by the Mayo Clinic to help her skin more effectively absorb her medicated creams.

Andrea wet dressings of soft, white, 100 percent cotton material with lukewarm water (avoid hot or cold), squeezing out the excess water so the material was damp but

## AVOID DRYING OUT YOUR SKIN EVEN MORE

Besides treating your dry and itchy skin, there are a number of ways to prevent this irritation from getting even worse. The Cleveland Clinic recommends that you:

- Wash your hands and bathe in warm rather than hot water.
- Apply moisturizer immediately and liberally after bathing.
- Use adequate sun protection, choosing waterproof, broad-spectrum sunscreens.
- Avoid soap, which can rob your skin of necessary, natural oils. Use soap only on areas such as underarms, genital areas, and feet.
- Choose cleansers that are gentle and non-drying.
- Wear gloves to protect your hands when you wash dishes, work in the garden, or do any activities that might be hard on your skin.

Dr. Sontheimer suggests you pat dry rather than rub with a towel after bathing.

He further recommends increasing the humidity in your air at home, either through your central heating system or with a portable humidifier.

not dripping. She then applied the prescribed cream to her skin, covering it with the wet dressings. She treated her stubborn rash for thirty minutes twice a day, noticing dramatic results within two weeks. When finished with the treatment, she reapplied the creams or ointments.

If mechanic's hands bother you, try **Dermapak Gloves** to cover the lotion, ointment or cream you choose. Andrea treats her hands when they're irritated, spreading cream over her hands and wearing the gloves to bed until her rash improves. (See page 10 of the September 1999 issue of *The Outlook* for the complete article detailing the mummy treatment.)

## Prevention through sun protection

Protection from the sun's harmful rays guards against drying out your skin even more. Use sunscreen with Sun Protection Factor (SPF) 15 or higher, and apply as much as you would lotion on dry skin. If you don't use the proper amount of sunscreen, the SPF actually decreases. Be aware that certain medications, including methotrexate and tetracycline, increase your sensitivity to the sun, so read the labels carefully.

Using the Bulletin Board to solicit peer advice, Cheri sought information on sunscreens with mexoryl to prevent a sun-induced flare, as recommended by her dermatologist. Liesl Dutro offered **Anthelios "L" SPF 60 Sun Block** as an option, though Chris' response shared his recollection of its strong scent and greasy feeling.

Sun protection is also available in certain cosmetics, including **Dermablend** and **Covermark**. These products blend physical sunscreen with cover-up. Dermablend

Corrective Cosmetics promise natural-looking coverage that won't clog your pores, are fragrance-free, and resist smudges. Even more important to those with skin problems, however, is the SPF 30. Covermark also offers sun protection, with SPF 20 "Face Magic" and SPF 16 "Leg Magic" that won't rub off or smudge. Covermark's cosmetic camouflage is 100 percent waterproof and highly pigmented.

The increasing emphasis on sun safety has spurred companies to create more stylish, comfortable sun-protective clothes - clothes with the protection woven directly into the fabric. You'll find swimwear, business and polo shirts, track pants, hats, driving gloves, canopies, umbrellas, and much more.

It's important to understand the labeling, which the Federal Trade Commission monitors carefully. The Ultraviolet Protection Factor, or UPF, measures how much of the sun's radiation is absorbed by the fabric. So a UPF of 20 means that 1/20th of the radiation passes through the clothing; or in other words, the fabric reduces your exposure by 20 times. A UPF value of 15-24 is considered good protection against UV rays; 25-39, very good; and 40-50, excellent. Some UV protection may be lost if the clothing is overly worn or washed, wet, or stretched out. Enter "sun protective clothing" in your Internet search engine to find a list of companies stocking these products, or see Resources on page 18 for some options.

There are times you may not consider sunscreen to be essential, like while driving or going for a short walk. Windows and car glass do not block the UVA rays, prompting some companies to offer UV

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# TRIED AND TESTED IDEAS FOR BED AND BATH

When you decide you need some adaptive devices around the house, the bathroom and bedroom are logical places to start. There are a number of items, both big and small, that can prove to make life much easier. The first step is learning what products are even out there, then deciding which type best suits your personal needs. You may need to adapt some of these ideas to fit your own circumstances.

## BATHROOMS

Since most bathrooms are fairly small in size, it can be difficult to move around. The first items you may consider are **grab bars** for getting in and out of the shower and on and off the toilet. These are useful elsewhere in the bathroom, too, depending on your own ability to get around. “In order to get into the shower, you don’t want to fall and you want to hang onto something sturdy,” says Bob Fischer, whose wife Nancy suffers from IBM. “So I installed a lot of grab bars two feet apart, so she walks her way into the shower without falling.”

Showers and baths can be dangerous places, especially if you already have some trouble with balance or stability. Use **rubber mats or strips** on the floor of the shower or tub to help prevent unnecessary slips and falls. **Bath seats or benches** are available in a number of sizes and styles to fit your own specific situation. Some extend outside of the tub itself so that you won’t have to lift your leg while standing to get into the tub. Choose **levered faucet handles** rather than

knobs or cross handles, which can be difficult to turn if your grip has been affected by myositis. If you already have knob faucets around your house, Harris Teller (IBM) suggests wrapping rubber bands around them for better grip.



Smaller items and ideas make bathing an easier task for you and your caregiver. Most department or retail stores carry **long-handled sponges or bath puffs** to help you get to hard-to-reach body parts; some stores have long-handled devices for washing your hair, too. Harris suggests using a **handheld showerhead** on the massage setting for a better and safer way to clean yourself. Madeline Sabia installed a shelf in her shower just the right height to rest her elbow while shampooing her hair. “I LOVE my **wall mounted soap dispenser** in the shower,” says Barbie on the Bulletin Board. “No more messing with bottle caps while I’m in the shower. Just press – there is my soap and shampoo.”

## Toilets

The height of your toilet seat can be essential to staying more indepen-

dent. Toilet aids include **boosters or risers**, with or without armrests, that fit on the top of the toilet seat; **toilevators** installed under the base of your existing toilet, raising it 3 1/2 inches; and **lifting commode chairs**, which help users seat and raise themselves through controlled support and lifting. Boosters and risers have the advantage of being portable, but others in your household may find them to be a nuisance as well as being unattractive. The toilevator takes away this annoyance and has a cleaner, less intrusive look. Lift seats are important for those requiring more help rising from a seated position. Some lift seats are motorized, like Phillips’ “Butt Booster” and “Tush Push” models. Others, like the “Uplift Commode Assist,” are self-powered, lifting up to 80 percent of your weight and allowing you to keep some control yourself. Choose the model which best suits your own needs, as well as what you may reasonably expect your future needs to be.

If getting to the bathroom is a problem in itself, there are products on the market for both women and men. **Portable urinals** eliminate the challenge of transferring to the bathroom, or you can use them when you’re traveling, especially on airplanes or other places with small bathrooms. You may find these useful only on certain occasions or on a daily basis. Harris again adds his own advice: “I try to be on the best schedule possible, one which I know exactly when I’m going to have to go.” He schedules his morning to use the toilet immediately before showering, so he can move straight from one to the other.

People find it hard to discuss

these very personal strategies, but our members who are willing to discuss bathroom hygiene have helped other members enormously, and we hope you will continue to share your tips. When leaving the house, Harris carries his “portable toilet,” a special bag that includes a portable urinal and baby wipes. Depending on the urinal model, you can empty your bladder from a seated position and without the help of another.

Other suggestions for making bathroom chores a little easier:

- Wrap your toothbrush, razor or make-up with something to increase the handle’s thickness. This will make gripping much easier.
- Install a magnifying mirror for make-up or shaving.
- Use a toilet tissue holder if reaching is difficult. (Find one model at Dynamic Living.) You can also try a portable or installed bidet for cleansing.
- Try no-rinse shampoos and body washes, allowing you to bathe wherever it’s convenient for you.
- Use large, disposable moistened cloths for daily bathing. These are like giant towelettes that clean you without drying already irritated or dry skin. Ask your hospital, or you can find them at some drugstores. Some members heat them briefly in the microwave and find this kind of waterless “bathing” very soothing.

## BEDROOMS

Getting out of bed can be a daunting task some mornings, but certain adaptive devices can make this a much easier and more comfortable proposition.

Rising from a seated or prone position can be difficult for those with weakened muscles. **Bedrails and stand assists** are some of the simplest and least costly ways to help. Both of these devices help you stand from a seated position on the bed, but you must have at least some upper body strength to lift a portion of your weight.

Consider changing the height of the bed. **Risers** come in a variety of types and sizes. One Bulletin Board user suggested lynx levelers, interlocking blocks typically used to level RVs and campers when parked. These raise your bed to a more suitable height for getting out and are available at RV suppliers or camping stores. Try [www.lynxlevelers.com](http://www.lynxlevelers.com) or [www.campingworld.com](http://www.campingworld.com) for more options. Riser cones tilt chairs and beds to make standing easier or raise tables to provide easier access for those in bed or using wheelchairs. They can also give more clearance under your bed for putting in a more complex lift or hoist system. Stack these cones to the height you need.

## Hoist or lift systems

Depending on your level of weakness, you and your caregiver may decide a **hoist or lift system** best suits your



needs. For Stu Hayward, an IBM patient, a lift was even more appropriate due to his wife’s bad back. They chose a Hoyer Lift since Medicare paid most of the cost for the lift and sling. SureHands also offers systems to help caregivers with transfers, bathing needs, and more. Hoist or lift systems require space for installation, so keep in mind what space you have available. Different companies will offer demonstrations, installation, and training, with upgrades and trade-ins offered by some. If you expect your needs to change over time, check the company’s policy on trade-ins before making this major purchase.

Lift systems are also useful for helping you use the toilet and re-dress. Keep in mind all the possible uses you may have for a lift system as you research what’s best for your own situation:

- Aid to transfer from the bed to the bathroom, with a caregiver’s help
- Means to transfer yourself independent of any outside help
- Tool for dressing yourself
- Assistant for exercises and/or physical therapy
- Aid to reposition yourself when a caregiver is away

These systems come with ceiling-mounted tracks or as more temporary transfer systems. Decide what’s best for you and your caregiver. In the end, **transfer boards** may be adequate for your needs. These boards are designed to help patients go from beds to wheelchairs, for example, with less dependence on another person. Even transfer boards, seemingly simple devices, have a

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# FINDING FUNDING FOR YOUR NEEDS

Computer equipment, assistive devices, and many other products and services are available through different programs helping those with chronic conditions.

## The health insurance maze

If you and your family are covered by a major medical insurance plan, you may already know the benefits available to you. Each plan is different, so be sure to read the details carefully. Your policy should state what is and is not covered for the purchase of durable medical equipment. “Some private insurers are OK,” says Brad Bent, an IBMer and long-time member of TMA. “One of my IBM friends recently got a \$30,000 power chair for which they paid 100%. If you’ve worked for the federal government...they seem to pay 100% of expenses.” Customer service representatives for each company are available to help you unravel any confusing issues.

You may be eligible for other insurance coverage, including Medicare, Medicaid, SCHIP, HIPAA or COBRA.

**Medicare** is divided into two parts: Part A for inpatient hospital services and Part B for outpatient services. Part B covers durable medical equipment that your doctor prescribes for home use for a specific medical reason. This equipment may include commode chairs, lifts, wheelchairs, hospital beds, and canes. The amount of assistance you receive depends on the state you live in and the type of Medicare coverage you have. Be sure your equipment supplier participates in Medicare and has a Medicare supplier number. Visit the Medicare web site at [www.medicare.gov](http://www.medicare.gov) to

find the specific information and phone numbers for your state.

**Medicaid** is available to those with lower incomes and varies from state to state. The Federal government gives broad guidelines for Medicaid coverage, then states set their own standards for coverage. Visit the Centers for Medicare and Medicaid Services (U.S. Department of Health and Human Services) web site at [www.cms.hhs.gov](http://www.cms.hhs.gov), or call 877-267-2323 for more information on both Medicare and Medicaid.

For those families whose income is too high to qualify for Medicaid yet not enough to afford private insurance, the government offers **SCHIP**, or the State Children’s Health Insurance Program. The Federal government gives states flexibility in setting the requirements, but the goal is to insure more of the nation’s uninsured children. Eligibility requirements typically range from those families making 100 to 200 percent of the Federal poverty level. For more information visit [www.cms.hhs.gov/schip](http://www.cms.hhs.gov/schip).

**HIPAA**, or Health Insurance Portability and Accountability Act of 1996, entitles you and your family to protection when you change or lose your job. Contact your State Insurance Department (which is also sometimes called Bureau of Insurance, Division of Insurance, Department of Managed Health Care) for details.

**COBRA**, or Consolidated Omnibus Budget Reconciliation Act of 1986, allows you to temporarily continue the health insurance coverage you currently have through your employer (or that of a spouse) once you or your spouse stop working or reduce your hours. Companies are

only obligated to offer COBRA coverage when they have 20 or more employees, and you must elect coverage within 60 days to be eligible. With COBRA, you pay the premium each month; your employer does not pay any part of this. For a typical situation, coverage is granted for a period up to 18 months. However, if you’re disabled and must discontinue working, you’re entitled to 29 months of coverage; 36 months if you’re eligible for Medicare. For more information, go to [www.cobrainsurance.net](http://www.cobrainsurance.net). Lawyers who specialize in patient advocacy advise patients to say yes to COBRA as a first step – even though the payments seem high.

**SHIBA**, or State Health Insurance Benefits Advisors, is free of charge and helps answer questions about health insurance access and coverage. Call your state’s Office of the Insurance Commissioner to find out if your state has a SHIBA program.

To help navigate the often-confusing issues, Olsten Health Services offers **ACCESS**, or Advocating for Chronic Conditions, Entitlements and Social Services. This program is available to everyone and considers your specific circumstances when searching for the right answers. Call ACCESS at 888-700-7010 for more information on Social Security Disability, health insurance, or other related issues. “A lot of times people fall between the cracks,” says Donna Elliot, a representative from Olsten who spoke at our 2001 Annual Conference. “I don’t have a job anymore, I didn’t accept the COBRA offer, I make too much money from Medicaid, what am I going to do?” She says this is a perfect time to call Access because



they'll review your circumstances, the state you live in, your needs, and your options.

### Other helpful sites include:

**Insure Kids Now**, provided by the U.S. Dept. of Health and Human Services, [www.insurekidsnow.gov](http://www.insurekidsnow.gov) or 877-543-7669

**U.S. Department of Health and Human Services**, [www.hhs.gov](http://www.hhs.gov) or 877-696-6775

**Administration on Aging**, [www.aoa.gov](http://www.aoa.gov) or 202-619-0724; or your local Agency on Aging or League of Older Americans

**National Council on Aging**, [www.ncoa.org](http://www.ncoa.org) or 202-479-1200

**Veterans Administration**, [www.va.gov](http://www.va.gov) or 877-222-8387

### Computers, equipment, etc.

The **Beaumont Foundation of America** donates computer equipment to organizations, schools, and individuals so that more people will have access to today's technology. To contact the Foundation, write to P.O. Box 209000, Austin TX 78720; call 866-505-2667; or visit [www.bmtfoundation.com](http://www.bmtfoundation.com).

The **Muscular Dystrophy Association** (MDA) offers financial assistance for the purchase of wheelchairs, either manual or powered, and leg braces. The guidelines for eligibility include:

- An MDA physician has prescribed the apparatus.
- Your disease is covered in MDA's programs.
- You're registered with your local MDA.
- You have not committed to a vendor before contacting the local MDA Health Care Service Coordinator.

■ All other medical insurance has been billed prior to MDA's assistance being available.

Each year, MDA establishes the amount of assistance available. Call 800-572-1717; or visit [www.mdaua.org](http://www.mdaua.org).

**TMA** now offers a marketplace for used equipment and other adaptive devices. With different forms and stages of myositis, certain types of assistance may not be enough. TMA provides a place on its web site for selling or donating your used equipment to others who need it now and for finding the products you may soon need.

The **eBay** web site also offers a variety of products, new and used. Once you research what products and which manufacturers you prefer, visit [www.ebay.com](http://www.ebay.com) to see what's available. The stock is continuously changing, so check back often for better results.

**Home health care or hospice organizations** can be useful for many patients. These services provide medical equipment delivery and instruction, therapy, help for daily activities, and pharmaceutical services. Visit the Joint Commission on Accreditation of Healthcare Organizations ([www.jcaho.org](http://www.jcaho.org)), a not-for-profit organization, to find out more about the home care organizations in your area.

### Your personal experiences

Brad Bent decided not to wade through the many layers of Medicare when he first bought necessary equipment. Instead, he saved his doctor's prescriptions for these devices and used the purchases as tax deductions. Once he was eligible for Medicare, however, they paid the entire cost for his power chair. Later, he purchased a new chair, receiving \$2,000 in assistance

from MDA. "Almost all equipment which could be classified as a major expense item has funding information in their product information sheets and web sites," he added.



### Enlist your dealer

If you're unsure about whether a piece of equipment you need is covered by Medicare, you can find out first with a Medicare Advanced Beneficiary Notice. The notice enables you to "try out" the system by submitting an advance claim for something you'll need in the future to see if Medicare will cover it when the time comes. Durable medical equipment dealers are experts in this. Larger companies may have an entire insurance department to deal with insurance, and they have plenty of practice in making sure their clients will be reimbursed for necessary purchases.

It's extremely important to speak frankly with your doctor. Ask him or her to fully assess your present and future needs. Armed with his or her advice, sit down with the dealer's representative. Normally, the staff will know a great deal about eligibility guidelines. It's important also for you to understand the difference between dealers who accept Medicare and those who accept Medicare assignment. In a nutshell, the supplier who accepts Medicare and doesn't take assignment can charge you any amount to make up the difference in price. The dealer who accepts assignment takes the Medicare-approved amount – plus your co-insurance – as the full price of the product.

# RESOURCES

**Bristol-Myers Squibb Company:**  
345 Park Avenue, New York NY  
10154-0037; 212-546-4000;  
www.bms.com

## General catalogues, books and web sites

■ **Aids for Handicapped:**  
www.aidsforhandicapped.com

■ **Allabilities:**  
www.allabilities.com

■ **The Centers for Independent Living:**  
www.ilusa.com/links/ilcenters.htm

■ **The Complete Product Guide for People with Disabilities:** 215-675-9133, jefflen@jvleonard.com

■ **Disability Products Postcards:**  
P.O. Box 220, Horsham PA 19044

■ **Dr. Leonard's:** P.O. Box 7821,  
Edison NJ 08818-7821; 800-455-1918;  
www.drleonards.com

■ **Maxi Aids:** macatalog@maxi-aids.com

■ **MOMS:** P.O. Box 922,  
Valencia CA 91355

■ **Rolli-Moden:** Division of  
Manfred Sauer USA, Inc., 12225  
World Trade Dr, Ste T, San Diego  
CA 92128; 800-707-2395;  
www.rolli-moden.com

## Aids for daily living

■ **Dynamic Living:** 428 Hayden  
Station Road, Windsor CT 06095-  
1302; www.dynamic-living.com;  
product-finder@dynamic-living.com

■ **Disability Products:** 5447 East  
Elmwood Street, Mesa AZ 85205;

800-688-6794; www.disabilityproducts.com;  
info@disabilityproducts.com

■ **EZ-Step, Inc.®:** P.O. Box 138,  
Devils Lake ND 58301; 800-741-2568;  
www.ez-step.com

■ **Rand-Scot, Inc.:** 401 Linden  
Center Dr, Fort Collins CO 80524;  
800-467-7967; www.randscot.com  
or www.easypivot.com

■ **Sammons Preston Rolyan:** 4  
Sammons Court, Bolingbrook IL  
60440; www.sammonspreston.com  
(or www.sammonspreston.ca);  
sp@sammonspreston.com

■ **Wisdom King:** www.wisdomking.com

## Do-it-yourself solutions

■ **Assistive Technology Solutions,** 35 Western Ave.,  
Burlington VT 05401; www.at-solutions.org;  
jweisman@vtc.vsc.edu

■ **Workshop Solutions,** 135  
Keats Way Place, Waterloo ON  
N2L 5H4 Canada; www.workshop-solutions.com;  
tlj@golden.net

## Relief from dry skin

■ **Badger Healing Balm:** W.S.  
Badger Co., 625 Route 10, Gilsum  
NH 03448; 800-603-6100;  
www.badgerbalm.com; info@badgerbalm.com

■ **Covermark:** 800-524-1120;  
www.covermark.com

■ **Dermablend** (Division of  
L'Oreal USA): 1135 Pleasant  
View Terrace West, Ridgefield, NJ  
07657; 877-900-6700; www.dermablend.com

■ **Dermpak Gloves:** Dermpak  
International Inc., 3440 Belt Line

Blvd, St. Louis Park MN 55416;  
800-252-0805

■ **Kinesys:** 150 Bellam Blvd,  
Unit 270, San Rafael CA 94901;  
866-453-0747; www.kinesys.com;  
Canada: 3771 Jacombs Road, Unit  
415, Richmond BC V6V2L9; 888-546-3797

■ **Llumar:** 800-255-8627;  
www.llumar.com

■ **MSM Cream:** Kala Health, 108  
Woods Hole Road, Falmouth MA  
02541; 800-998-8813; www.kala-health.com;  
sales@kalahealth.com

■ **No-Crack Hand Cream:**  
Dumont Co., 700 Copeland Ave.,  
La Crosse WI 54603; 888-838-6668;  
www.nocrack.com or  
www.restorationhardware.com

■ **North Solar Screen:** Attn:  
Debby Miller, 9 Bartlet St, Suite  
231, Andover MA 01810; 866-230-4700;  
www.northsolarscreen.com

■ **Southwall Technologies Inc.:**  
3975 East Bayshore Rd, Palo Alto  
CA 94303; 800-365-8794;  
www.southwall.com

## Relief from dry skin, Sun-protective clothing

■ **Coolibar:** 4206 Park Glen Rd,  
St. Louis Park MN 55416, Attn:  
Customer Service; 1-800-926-6509;  
www.coolibar.com

■ **Frogwear Sun Protective Clothing:** 800-328-4440

■ **MasqueRays:** PMB #242, 3525  
Del Mar Heights Rd, San Diego  
CA 92130; 877-786-7848;  
www.sunproof.com

■ **Solar Eclipse:** P.O. Box 13102,  
Scottsdale AZ 85267-3102; 800-

878-9600; [www.solareclipse.com](http://www.solareclipse.com)

■ **Solartex Sun Gear:** P.O. Box 36050, Richmond VA 23235; 877-476-5789; [www.solartex.com](http://www.solartex.com)

■ **Solumbra/Sun Precautions:** 2815 Wetmore Ave, Everett WA 98201; 800-882-7860; [www.sunprecautions.com](http://www.sunprecautions.com)

■ **Sun Clothing, Etc.:** 540-842-4583; [www.sunclothingetc.com](http://www.sunclothingetc.com)

■ **Sun Emporium:** 12 Hermitage Close, Ashmore, Gold Coast, Queensland 4214, Australia; 61-7-5597-0005; [www.sunemporium.com](http://www.sunemporium.com)

■ **Sun Grubbies:** 5519 Clairemont Mesa Blvd #163, San Diego CA 92117; 888-970-1600 (within US); 858-268-1600 (outside US); [www.sungrubbies.com](http://www.sungrubbies.com)

■ **Sun Protective Clothing Ltd:** 598 Norris Ct, Kingston ON K7P 2R9 Canada; 800-353-8778; [www.sunprotectiveclothing.com](http://www.sunprotectiveclothing.com)

## Emergency alert systems and other aids

■ **Dynamic Living:** (see Aids for daily living, on page 18)

■ **Fare Thee Well Phones:** 3463 State St. #330, Santa Barbara CA 93105; 866-892-4387; [www.mobile911alarms.com/Emergency\\_Response\\_Phones/index.html](http://www.mobile911alarms.com/Emergency_Response_Phones/index.html); [info@FareTheeWellPhones.com](mailto:info@FareTheeWellPhones.com)

■ **Knox-Box® Rapid Entry System:** 17672 Armstrong Ave, Irvine CA 92614; 800-552-5669 (General Information) or 866-625-4563 (Customer Service); [www.knoxbox.com](http://www.knoxbox.com)

■ **Sammons Preston Rolyan** (see Aids for daily living, on page 18)

## Wheelchairs, scooters and standing aids (including van conversion sites)

■ **Altimate Medical:** (EasyStand) P.O. Box 180 West 1<sup>st</sup> St, Morton MN 56270; 800-342-8968 (Cust Svc); 877-844-1172 (Funding Info); [www.easystand.com](http://www.easystand.com)

■ **Braun Corporation:** 800-843-5438; [www.braunlift.com](http://www.braunlift.com) (van information)

■ **Freedom Motors USA:** 923 E. Michigan Ave, Battle Creek MI 49014; 888-625-6335; [www.freedommotors.com](http://www.freedommotors.com) (van information)

■ **Independent Mobility Systems Inc.:** 4100 W. Piedras St, Farmington NM 87401; 800-467-8267; [www.ims-vans.com](http://www.ims-vans.com)

■ **Mobility Discount:** 1049 U.S. Bypass 41 S., Venice FL 34292; 800-363-9256; [www.mobilitydiscount.us](http://www.mobilitydiscount.us)

■ **Planet Mobility:** P.O. Box 91, Hazel Park MI 48030; 866-465-4387; [www.planetmobility.com](http://www.planetmobility.com)

■ **Rollx Vans:** 6591 W. Highway 13, Savage MN 55378; 800-956-6668; [www.rollxvans.com](http://www.rollxvans.com)

■ **Scooter City:** 6/1645 Ipswich Rd, Rocklea 4106 Australia; 07-3255-6565; [www.scootercity.com.au](http://www.scootercity.com.au)

■ **The Scooter Store:** 800-723-4535; [www.thescooterstore.com](http://www.thescooterstore.com)

■ **Tilt-a-Rack:** Mesa Verde Manufacturing Inc., P.O. Drawer NN, Cortez CO 81321; 970-564-0497; [www.tiltarack.com](http://www.tiltarack.com)

■ **Vantage Mobility Int'l:** 5202 South 28<sup>th</sup> Place, Phoenix AZ 85040; 800-348-8267; [www.vantagemobility.com](http://www.vantagemobility.com)

## Bedroom and bathroom

■ **Apex Dynamics Healthcare Products:** 332 Reece Road, Dawsonville GA 30534; 800-742-0453

■ **BHM Medical, Inc.:** 2001, Tanguay St, J1X 5A8 Canada; 800-868-0441; [www.bhm-medical.com](http://www.bhm-medical.com)

■ **The Boulevard:** jjMarketing, 1205 Savoy St, Suite 101, San Diego CA 92107; 619-222-8735; [www.blvd.com](http://www.blvd.com)

■ **Clark Medical:** 5510 Ambler Drive, Unit 10, Mississauga ON L4W 2V1 Canada; 800-889-5295; [www.clarkmedical.com](http://www.clarkmedical.com); [info@clarkmedical.com](mailto:info@clarkmedical.com)

■ **Dynamic Living:** (see Aids for daily living, on page 18)

■ **Great Ideas, Inc.:** 1633 Ravine Lane, Highland Park IL 60035; 800-611-5515; [www.bidets.us](http://www.bidets.us)

■ **International Sani-Fem Inc.:** P.O. Box 4117, Downey CA 90241; 800-542-5580; [www.freshette.com](http://www.freshette.com) (sells urine-collection devices)

■ **Jiny Enterprises:** 1521 Via Linda Street, Fullerton CA 92833; 800-989-5098; [www.jiny.com](http://www.jiny.com) (portable bidet)

■ **LCM Distribution Ltd:** 1410 28<sup>th</sup> Street NE, Calgary AB T2A 7W6 Canada; 888-726-4646; [www.lcmdistribution.com](http://www.lcmdistribution.com)

■ **Lynx Levelers:** 800-463-5505; [www.lynxlevelers.com](http://www.lynxlevelers.com)

■ **Maintenance Specialties:** 13288 Ebony Ave, Port Charlotte

*Continued on next page*

## Resources,

*Continued from previous page*

FL 33981; 888-858-7278;  
www.wheelchairparts.com

■ **Mobility Transfer Systems, Inc.:** P.O. Box 253, Medford MA 02155; 888-854-4687; www.bed-mobility.com (carries “The Transfer Handle” and urine-collection devices)

■ **Name Brands Direct:** dba Medical Products Direct, 3945 SE 15<sup>th</sup> St, Suite 200, Del City OK 73115; 800-804-9549; www.medicalproductsdirect.com

■ **New Angle Products:** Box 25641, Chicago IL 60625; 773-478-6779; www.whizzy4you.com

■ **Phillips Lifts:** 8062 College Corner Rd, Centerville IN 47330; 888-429-5438; www.phillipslifts.50megs.com

■ **Preferred Healthcare:** 6615 Waggoner Dr, Dallas TX 75230; 866-553-5319; www.phc-online.com

■ **Sanicare Asia:** Renmin South Road, No. 45, Xiashan District, Zhanjiang, Guangdong, China; 86-759-2360445; www.sanicare.com

■ **Sanicare Europe:** Gesseltweg 4, 6089 NT HEIBLOEM, The Netherlands; 31-0-475-491132; www.sanicare.com

■ **Sanicare US:** 535 South Tenth Street, Las Vegas NV 89101; 888-890-1573; www.sanicare.com

■ **Sure Hands Lift and Care Systems:** 982 Route 1, Pine Island NY 10969; 800-724-5305; www.surehands.com

■ **Up-Lift Technologies:** 125-11 Morris Drive, Dartmouth, NS

B3B 1M2, Canada; 902-422-0804;  
www.up-lift.com

■ **Waverley Glen:** 116 Rayette Rd, Unit 1, Concord ON L4K 2G3 Canada; 800-265-0677; www.waverleyglen.com



## Wheelchair choices,

*Continued from Page 5*

angle of the seat in the wheelchair. Although you may like the casual effect of reclining in your chair, too much reclining will cause pressure sores and perhaps even tip your chair. And the size of the seat can cause discomfort: the wrong size or angle can cause sore spots, or skin and back problems.

As John observes, the correct seat cushion can mean a lot for your comfort. A standard medium-density foam cushion, fitted well to the size of your seat, is a good choice for most. For those with pain or numbness from sitting, a seat made of rubber tubes filled with air will more comfortably spread your weight, but may slip more than the foam cushion. In between is the gel or honeycomb cushion that provides some stability as well as protection from sores. We've also heard from members who use an “active massage” cushion, which heals and prevents pressure sores.

### Putting on the brakes

Brakes should be a concern in your chair selection, members say. Most wheelchairs simply come with scissor locks and push locks. Remember that the brakes are working by creating friction on the tire, so contact is reduced over time with this wear and tear. A newer brake is a hub lock that's mounted

on the hub of the wheel. You can have the handles to operate the brakes mounted wherever it's most convenient for you. Our frequent wheelchair users say that the brakes are very important as you consider how you will be transferring from your chair. They suggest that you also carefully examine the footplates on your chair with an eye toward how you will use them for support when transferring.

### Maintenance

You can maintain your manual chair if you are generally handy. Check to make sure your axles are oiled and clean and that all screws are tight. You should check the air pressure in your tires and have any loose spokes or rips in your cushions repaired right away.



## Walkers and canes,

*Continued from Page 8*

Quad canes, with four legs instead of the standard single leg, offer more stability. One cane is even designed to switch from a quad to a straight cane for those with changing needs. (Visit the Wisdom King web site to see more about the "Duo-Cane Quad Cane" in the mobility section.)

How light do you want the cane to be? How much weight can it hold? The answers to these questions will vary from person to person, but be sure to keep these in mind as you search for the right cane.

Once you decide on the cane, there are accessories available to help even more. Cane holders hook to a table or desk, or to the cane itself, to prevent the cane from sliding off or falling to the floor. Grip assists, or pressure-sensitive strips,

can improve your grip on the cane. Ice grips allow cane users to walk with more confidence on icy or slippery surfaces by cutting into the ice or snow, though it is still not recommended to walk about in these unfavorable conditions.

## Walkers

There are very basic walkers, with all four legs covered with rubber tips, requiring some strength and balance for you to slightly lift the walker to move forward. Some walkers have two wheels in the front with rubber-tipped legs in the back; others have wheels on all four legs of the walker. Decide where you'll use the walker; walkers with wheels may be difficult to maneuver on thicker carpets. Check for brakes on wheeled walkers, which can be hard to stop otherwise.

If you decide on a wheeled walker, the tires can range from 3 inches to 8 inches, with different material for indoor or outdoor use. Be sure the handles can be set to a convenient position for you, and check the strength needed to apply the handbrakes.

Do you need a seat? If so, decide on the height, width and depth that's best suited for your size. The seat height generally varies from 18 to 23 inches off the floor, and some walkers come with a flexible backrest for comfort. Look into how much weight the walker can bear, including the weight capacity of the seat itself. You may need to investigate other measurements depending on how you'll use the walker - check its width for getting through doorways and its size when folded for storage.

Finally, you can choose from a number of accessories to make the walker even more useful, including padded seat cushions, baskets, bags and trays.

## So which one do I get?

Ask others on TMA's Bulletin Board or through your Keep In Touch support group what they've found helpful and why.

"I had a rolling walker with a seat height that conflicted with my knee motion when walking," wrote 'Barbie' on the Bulletin Board. "I didn't realize I was leaning slightly backward to avoid hitting my knee on the walker seat. So here is a word of caution: Try out the walker before you buy [and] decide to keep it."

As always, check to see if any warranty is available for any product you choose. Manufacturers and stores will typically offer at least limited warranties with their products, so read them carefully.



## Dry Skin,

*Continued from Page 13*

**light blocking film.** Fluorescent lights also emit some UV rays, and you can place **acrylic diffusion shields** over the bulbs for protection.

For these protective films and shields, Dr. Sontheimer suggests the following companies: Southwall Technologies Inc., North Solar Screen, and Llummar. The film coatings absorb or reflect from 96 to 99 percent of the sun's harmful UV rays. North Solar Screen shades roll up and down so that you can use them according to your different needs for day and night, and they offer bulb jackets to provide UV protection from fluorescent lights.

If you have any products or ideas you'd like to share with us, email [tma@myositis.org](mailto:tma@myositis.org) or call 540-433-7686 x 15. Sharing your ideas with us will help a host of myositis patients and friends everywhere!



## Bed and bath,

*Continued from Page 15*

number of choices: tapered ends to allow for smoother sliding, rows of balls for easier transfers, notches to lock the board to your wheelchair, and different weights for taking the boards with you wherever you go.

## Electric or hospital-type beds

**Home care beds** are available so that you can more readily reposition yourself. You'll find fully electric, semi-electric, and manual or crank models at different manufacturers. Be sure to check out the specifications, including maximum weight limit and special features you'd like. Is there a warranty for repairs and/or maintenance? Will the company ship and set up the bed in your home? Does the weight limit include just the person or the person and all bedding? Some beds offer interchangeable parts that will transfer from one model to another if your needs change over time. Decide what height you need the bed to be in order to get in and out of bed yourself, or with little help from your caregiver. It may be best to talk to a manufacturer representative to clear up all of these details before investing substantial money.

As always, TMA's Bulletin Board is a great place to find information from those who have used certain products and specific manufacturers. Your *Keep In Touch* support group friends are another great resource for learning about products firsthand; ask at your next meeting or have your Area Representative include your questions in the next email or newsletter. Find out the pros and cons straight from the experts. And share your own knowledge with us so we can include it in next year's products issue of *Extra*.



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- LOW VISION AIDS
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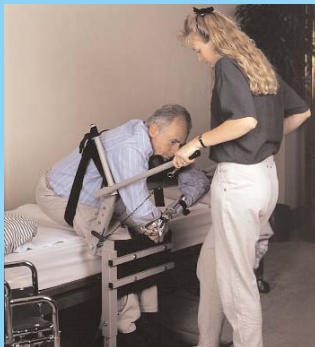


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## TMA Online Marketplace

Have medical equipment you no longer use? Need something but don't want to buy it new? Visit TMA's marketplace online to sell or donate your old equipment: From cushions and lift seats to walkers and wheelchairs, your old equipment will help others.

Or see what's available from other TMA members and friends: Find helpful gadgets or larger products that you need.

Email [tma@myositis.org](mailto:tma@myositis.org) with a full description of the equipment you are selling or donating, and include a picture if you can. Or send your ad to TMA Marketplace, 755-C Cantrell Avenue, Harrisonburg VA 22801.

TMA offers this service as a way for buyers and sellers to connect. We can't make any judgements about the equipment's condition or value. Please be aware that shipping charges may add significantly to the cost of the equipment.

We need your help to make this work!

# October 10-13, 2003 Annual Conference in Houston, TX

## Medical Panel to include:

Richard J. Barohn, MD  
Chairman, Department of Neurology  
University of Kansas Medical Center

Walter G. Bradley, DM, FRCP  
Chairman, Department of Neurology  
University of Miami School of Medicine

Marinos C. Dalakas, MD  
Chief, Neuromuscular Diseases  
NINDS, National Institutes of Health

Frederick W. Miller, MD, PhD  
Chief, Environmental Autoimmunity  
NIEHS, National Institutes of Health

Ann Marie Reed, MD  
Chair, Pediatric Rheumatology  
Mayo Clinic, Rochester

## Location, location, location:

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