



THE OUTLOOK

FALL 2003

For the inflammatory myopathies

Chat with the Experts

On Thursday September 4, TMA hosted its first online "Chat with the Experts" with Dr. Walter Bradley, Chairman of TMA's Research Committee and Professor of Neurology at the University of Miami, School of Medicine. Dr. Bradley chatted for more than an hour with 15 to 20 TMA members representing every disease type. He answered questions ranging from how to properly position walkers to prevent falls to new anti-T-lymphocyte therapy for IBM to when we might expect to see significant advances in gene therapy for neuromuscular diseases. An edited transcript of Dr. Bradley's chat is available on TMA's web site.



The chat with Dr. Bradley took place in TMA's Community Forum, which includes disease-specific, general and caregivers' Bulletin Boards and informal chat rooms. This was the first in a series of chats with distinguished myositis experts that TMA plans.

Dr. Anthony Amato is scheduled to answer questions in TMA's next "Chat with the Experts." We hope you can join us and take advantage of this exciting new service.

To participate in TMA chats, register with the Community Forum at www.myositis.org.

Renowned researchers and physicians at Annual Conference

TMA is honored to present some of the world's leaders in myositis knowledge, research and treatment on Sunday, October 12, at the Annual Conference in Houston. You may recognize our medical panel members as scientists working on the front lines. Members have responded to this significant gathering of top-level scientists by registering for the Conference in unprecedented numbers. The panel members are long-time friends of TMA, active in establishing and nurturing both the organization and research program. Panel members will speak about current research and treatment; the TMA-funded research program; promising research in the pipeline; and new developments in our understanding of the disease process.

The panel meets Sunday morning to address everyone and in the afternoon with disease-specific groups to answer your questions. Please formulate your questions now and send them to t@myositis.org. We ask that you keep your questions general, rather than on the details of your particular illness. We will summarize these sessions in the special November *OutLook Extra*, focusing on myositis treatment.

Dr. Marinos Dalakas is a neurologist and Chair of the 2003 Annual Conference medical panel. Dr. Dalakas played an indispensable role in the birth of TMA. He is the head of the Neuromuscular Diseases

Section of the National Institutes of Health. His IBM clinic at NIH forms the basis for much of what other neurologists know about managing IBM. Dr. Dalakas is the Chairman of TMA's Medical Advisory Board, has spoken at several Annual Conferences, published a huge body of research on myositis diagnosis and management, and just published a summary of treatment and future treatment options for the myopathies.

Dr. Fred Miller will moderate the panel. Dr. Miller is a rheumatologist and immunologist. He is the chief of the Environmental Autoimmunity Group, a clinical and basic research group he is establishing on the NIH campus to study genetic and environmental risk factors for myositis and other autoimmune diseases. Like Dr. Dalakas, he's been involved with TMA for years, and is known to members by his appearances at conferences and his frequent answers to your questions. He is the Vice Chairman of TMA's Medical Advisory Board and a member of TMA's Board of Directors.

Dr. Richard Barohn is a neurologist and chairman of the Department of Neurology at the University of Kansas Medical Center. He maintains a neurology practice and treats a number of myositis patients. Dr. Barohn has a strong interest in teaching young doctors about myositis - both in his position at the University of Kansas and at the American Academy of Neurology - and is active with TMA's

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Published by: TMA, Inc.

THE MYOSITIS ASSOCIATION

1233 20th St., NW, Suite 402
Washington, DC 20036

P: 800-821-7356
F: 202-466-8940

Email: tma@myositis.org
Web: www.myositis.org

Executive Director: Bob Goldberg
Editor: Theresa Reynolds Curry
Staff Writer: Kathryn Spooner
Graphic Design: Jami Latham

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Dear Friends,

Research is in the news lately, and this issue of *OutLook* highlights some of the latest developments. As with any other recently announced research findings, it is best not to jump to conclusions until the news has been digested and critically reviewed by other myositis experts.

Nevertheless, I encourage you to read the research abstracts in this issue and - for those coming to the Annual Conference - please bring your questions for the Medical Panel. TMA has also recently started online chats with experts, and there will be opportunities in these chats to have some of the preeminent experts answer your questions.

For those attending the Conference, we profile this year's Medical Panel to let you know more about our distinguished speakers. In addition to the Panel, there will be two-hour breakout sessions for those with the same type of myositis to address questions to the medical panelist who is the expert in that form.

Juvenile myositis patients and their parents can attend special sessions geared specifically toward JM at this year's Conference as TMA continues to explore how best to serve the juvenile community. A TMA JM Steering Committee is helping develop a new juvenile division and Juvenile Council within TMA and has met several times with good progress. You can expect further announcements in the near future.

Other events scheduled for October, in addition to the Annual Conference, include announcement of the second round of research grants to be issued by TMA, update of TMA's strategic plan, release of TMA's Commemorative Anniversary Scrapbook, and planning sessions between the leaders of TMA's Medical Advisory Board and Board of Directors to examine the strategic direction of our research program and how TMA can hasten the day when there is a cure for myositis.

We have a busy time ahead and will include TMA members in these events. As always, we welcome your input.

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

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POSTINGS FROM MEMBERS...

Q: For those of you who have the Medic Alert bracelets, what exactly do you put on them? Do you put your myositis diagnosis and then let them call for the other info?

A: TMA members suggest including the names of all medicines you're taking on your medical alert bracelet so emergency personnel will know, for example, if you're on medicines aimed to suppress your immune system. Even if they don't know what myositis is, this information may prove to be very helpful.

"I signed up through the Medic Alert web site (www.medicalert.org)," says Cindy, a polymyositis patient. "I have an online file that I update regularly as my meds change. The information is only a phone call away." The bracelet includes a Medic Alert ID number, a phone number to call collect, and an 800 number under the words "Call immediately." Her doctors change her medicine dosages frequently, and this system updates her file with these changes. Remember to include diagnoses, emergency contacts, doctors, allergies, etc.

"I do wear a medic alert necklace that says diabetes, takes steroids, and lists other meds and has polymyositis," adds Franklin. "I know that EMTs may not know what polymyositis is but it is there for doctors too in case of emergency."

Remember to have these IDs with you when you travel or go out alone. You may also want to take a more detailed list of your medicines, doses (including times), and doctor information while traveling. Also include any allergies you have and any other over-the-counter medicines or vitamins you take.

To contact MedicAlert: 2323 Colorado Avenue, Turlock CA 95382; 888-633-4298 or 209-668-3333 (outside US); customer_service@medicalert.org. Visit the web site for more

information about MedicAlert in countries around the world.

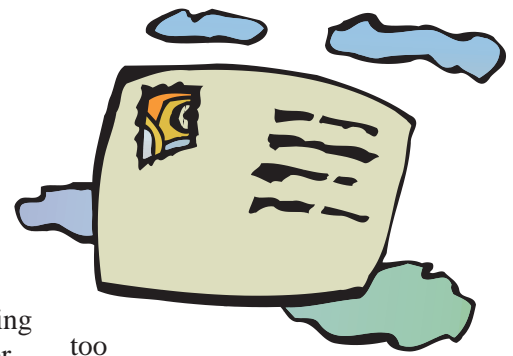
Q: I have PM and my legs are still weak. I recently read about using arm and leg weights. It sounds interesting but does anyone out there know if using weights can hurt?

A: First, get your doctor's approval before starting any exercise program. Though there hasn't been much research on exercise and myositis, reports tell us that stretching, strengthening and general exercises, like walking, are good for myositis patients. Be careful if you're in an active flare of myositis, as it may take your muscles longer to heal after exercise, and be sure to drink plenty of water. Exercising may not rebuild your damaged muscle, but it can help the muscles you have keep their strength and flexibility. Choose exercises that are right for you in your stage of the disease. Your doctor or physical therapist can help.

Randal Gerdes (PM) says, "Be careful with your weight lifting as it can cause your CK to go up and can cause you to flare up if you do too much. Only do it in moderation." Don't exercise the day or two before having blood tests because it can affect the results.

"If not in a flare appropriate exercise is a plus," adds Greg Fountain (DM). "If you exercise and overdo it you will know it. So start out real slow and increase the exercise until your body says quit. After getting started then increase the exercise a little each week or so. Quantifying muscle gain is very difficult for me. I feel the same as I did a year or so ago. However, I have not fallen in at least a year and a half, so there must be some progress."

"I think that overuse certainly has short term negative consequences," says Richard Gaulke (IBM). "Lifting



too heavy a weight might not only make you feel tired and achy the next day, it might actually do some harm."

Other members recommend water exercises to relieve some of the pressure on your joints. You can use different equipment for resistance, which is similar to weight training without the stress on your body.

Attitude Adjustment

People often promote having a positive attitude when dealing with chronic disease. One recent string on TMA's Bulletin Board explored the pros and cons of this subject. Here are some of your thoughts:

"This is a very touchy area because your mental state so affects your body. Sometimes all we can offer someone is a positive attitude and hope." (Shirley, DM)

"You are absolutely correct in that our positive attitude doesn't guarantee a successful struggle with myositis. I do believe though that some days are better than others because of my attitude." (Franklin, PM)

"I urge those who preach positive attitude to also preach acceptance (gotta deal with life on life's terms) and gratitude (for those healthy times as well as small pleasures)." (Valerie, PM)

"A positive attitude may mean different things to different people. For me, a positive attitude means dwelling on the good things in life and taking one day at a time. I do have some down days, but I try hard to make them few and far between." (Dorris, IBM)



PLANES, TRAINS, AUTOMOBILES, HOTELS AND MORE: TRAVEL TIPS FOR EVERY OCCASION

Traveling to new places should be fun and exciting, but unexpected hurdles can take some of the joy out of it. Whether you're traveling by car, plane, bus or train, you'll want to do some advance planning for any special needs you may have.

Help with hotels

Using your own car may be the simplest way to travel since you already have at least some of the modifications you need. However, you'll still need a place to stay. Hotels will often claim to be ADA-compliant, but this compliance may not meet your own specific needs. Explain in detail your particular concerns and challenges. Hotels tend to be responsive when given more information, so the more you can share with the hotel staff, the better they may be able to accommodate you during your stay.

Here are some more tips on reserving hotel rooms:

- Talk directly to the hotel where you plan to stay. The 800 numbers typically direct your call to a national reservations office, where the representatives most likely have not visited the particular hotel in person. They will only know the hotel's layout from a written description. As we found out from planning conferences, this usually isn't enough to make judgments about accessibility.
- When you call the hotel itself, make sure the person you talk to has actually seen the handicapped-accessible room. If they can't answer specific questions about the rooms, ask to speak with the Reservations Manager. Be very specific about your needs, and don't be embarrassed to ask

the hotel for a detailed description of the room, especially the bathroom. Get a guarantee that the reservation is for the accessible room, not just a request for this type of room. If the hotel offers shuttle service, check its accessibility, too.

- Write down your confirmation number. Keep a list of the names of all hotel staff members you talk to on the phone, and make sure to take this with you when checking into the hotel.
- Talk to the right person. Make sure you're speaking to someone who has the authority to guarantee your reservation. Be careful not to assume anything.
- Confirm your reservations a few days in advance. Give them your confirmation or reservation number, making sure your reservation is for the room type you requested. If there are any problems, you can try to fix them and avoid last-minute surprises. Ask for the Reservations Manager if you aren't satisfied with the reservations. Again, write down the names of all hotel staff and place this with the other materials to take with you.
- If there are problems when you arrive, keep calm but be persistent. Again, be sure you're talking to the right person from the beginning so you won't have to explain the problems more than once. If you're not sure if the room will be suitable, ask to see it before you sign anything. If the hotel cannot meet your needs, ask them to help you find a more accessible room in a nearby hotel.

Cruising on your vacation

Newer hotels tend to be more

accessible, including rooms, shuttle services, and dining areas. The same is true for newer ships if you're planning a cruise. You can find more information about cruise ships by visiting their web sites. Princess, Caribbean, and other lines offer special cruises for all interests, and most are clear about the services they will provide for you.

Some people with special medical needs prefer cruises since medical professionals are on board throughout the trip. Know the limitations of the ship itself, though, so that you won't be surprised. Explain your needs carefully to the representative and to the crew before you ship off. Cruises pamper their passengers, but try to get specific information about how they can help. Visit Access-Able Travel Source (see details on page 7) for more information on specific cruise lines and ships.

Traveling by plane or train

When taking a train, determine which stations you'll be using and find out if they're accessible. Different stations may have different methods for helping you board the train with a wheelchair. Ask to speak with a Customer Service Agent at the station itself instead of the Reservations Agent if you have more specific questions or concerns about the facilities.

For airplane travel, ask for bulkhead seats, but there aren't many on each flight, and those traveling with wheelchairs as well as those with small children often request these seats. Be sure the airline knows you'll need assistance when boarding and deplaning or moving during the flight so

they'll be better prepared.

"I recommend nonstop flights whenever possible," says Bob Foseid (IBM). This isn't always an option, though, so you need to plan ahead. Harris Teller (IBM) suggests contacting the airline's disabled desk or department. "I

have them fax me at home what we have agreed they're going to

do," he says. "And I take that to the airport with me." If you want them to meet you at the gate with a scooter, for example, have them put this in writing. "I found that every time I gave in and every time that I said 'Okay, I can see it's a problem'," adds Harris. "It became a bigger problem."

Jan Scholten and his wife have traveled many times within Europe: "I booked my flights via a travel agent and informed them that I had a wheelchair (folded type), gave the dimensions and weight and that I required assistance only from the gate to the airplane, because I could walk with crutches inside the plane." He warns that airlines now make more thorough security checks that take some time, especially with extras like wheelchairs or crutches. He uses the cushion

from his wheelchair on the airplane seat to provide extra height – enough to allow him to rotate and stand with little assistance.

For use at his destination, he adds: "We took an air cushion with a small pump and filled it at site with air, placed this on top of

the chair which enabled me to stand up by myself." Take any portable items you think will

make your trip easier for you and your caregiver.

You don't want to tire yourself out before the journey begins.

Taking your scooter or wheelchair along

If you plan to take your scooter or chair, you'll need to be sure you have any repair items you may need on hand. Millie Carrier (PM) recommends gel batteries for your scooter, especially if you're flying, so that airlines will not have to re-pack the batteries in leak-proof containers. If you're traveling abroad, remember to pack an appropriate converter to recharge your battery. Call the scooter manufacturer to get its recommendations for the proper type.

Label your scooter parts carefully in case the crew has to disassemble the scooter or unplug any connections, and leave detailed instructions on how to put it back together once you reach your destination. No matter where you go and how you plan to get there, be sure your scooter is working properly before you leave. Get a general "check-up" for your scooter to repair even minor problems.

Take along a bag for your scooter or wheelchair accessories, including wheelchair leg supports and portable cushions. These items are likely to fall off or get

lost during the bustle of packing and unpacking the plane or vehicle.

Arrive early at airports to be sure an aisle chair will be available to take you to your seat once you've given them your own wheelchair or scooter. If you don't have a caregiver or friend with you, explain to the airline staff how to best help you into the seat.

General travel tips

Rent a wheelchair or scooter at your destination, suggests Dorris Norris, an IBM patient. If you're staying in a hotel, staff there may be able to help you with these arrangements, then have it waiting for you when you arrive.

How accessible is the place you're visiting? "When you call the concierge [at the hotel], ask about the curb cuts," says Dorris. Also check the city's web site. Most attractions will let you know what accommodations they have. Some may offer special pricing or times for those needing any type of special assistance. Contact the local Center for Independent Living for recommendations.

"Take frequent breaks," adds Franklin, a PM patient. "And don't think you have to wait in a line for anything. Most places will let you go to the front in a wheelchair." You don't want to tire yourself out before the journey begins.

"I now ride in the back seat of the car with a small pillow for my neck, or where ever I feel needs a bit of support, and a larger soft pillow under my knees" says 'Tubby G,' a DM patient who frequently posts on the Bulletin Board.

If you have special dietary needs, let hotels, airlines, trains, and others know about this ahead of time so they can prepare.

Safety first

When you travel, be sure your medicines are carefully labeled and packed.

Keep a list of the time schedule and dosage for your medicines, and wear a medical alert bracelet if you have one. (See Messages from Members, page 3.)



Myositis research promises hope, questions some diagnoses

Journal articles published over the summer offer hopeful news for patients with inclusion-body myositis, dermatomyositis and polymyositis, and pose some interesting questions about the diagnosis of polymyositis.

A promising future: TMA Medical Advisory Board Chair Dr. Marinos Dalakas reviews treatments for myositis in the June edition of *Seminars in Neurology*. Dr. Dalakas is chief of Neuromuscular Diseases at the National Institutes of Health, and a founding TMA medical advisor. In his article, Dr. Dalakas predicts more effective treatments in the future from studies of factors that activate T-cells. He predicts IBM treatment will benefit from the newly developed immunotherapies, some of which he is planning to use. As for PM, Dr. Dalakas describes it as being quite uncommon and misdiagnosed frequently because of the difficulty distinguishing it from IBM and other inflammatory muscle diseases.

Drs. Anthony Amato and Robert Griggs comment on the over diagnosis of PM in an editorial in the August issue of *Neurology*. In *Unicorns, Dragons, Polymyositis and other Mythological Beasts*, the two myositis experts remark on a study in the same issue by a Dutch team who, like Dr. Dalakas, believes that PM is actually quite rare. Amato and Griggs propose that many cases believed to be PM are actually IBM, myositis associated with a connective tissue disorder, dystrophies with inflammation, or perhaps even DM without the skin symptoms. The Dutch scientists found nine of 165 patients given a diagnosis of an inflammatory myopathy using up-to-date criteria were initially believed to have polymyositis. Using the older but still commonly used Bohan and Peter criteria, 76 of these patients would have been diag-

nosed with polymyositis. On follow-up, only five of the nine initially thought to have polymyositis actually had the disease when they were re-evaluated. Four of the nine diagnoses were changed to IBM. Thus, the overall frequency of polymyositis was five of 165 (five of 238 if one includes all the IBM patients).

TMA board member Dr. Fred Miller, the Chief of Environmental Autoimmunity at the National Institutes of Health, said the recent discussion of PM diagnosis is not surprising to those in the field, but suggests the problem lies not in the diagnostic criteria, but in their interpretation and application. Dr. Miller said the Bohan and Peter criteria clearly require a full evaluation using the most up-to-date methods to rule out all other forms of myopathy, which apparently was not done in these studies. In contrast with the new pathologic criteria for PM and DM, which some neurologists are proposing in these papers, an international multidisciplinary group of more than 100 experts on myositis has recently come to a consensus that the Bohan and Peter criteria for definite PM and DM are appropriate to use for classification and entry of patients into clinical trials, Dr. Miller said. "We all agree that new criteria for all forms of myositis are needed, but the problem is that the studies needed to define more sensitive and specific criteria using all the new genetic, immunopathologic, electron micro-

scopic, antibody and other testing of perhaps 200 to 300 consecutive subjects with weakness in a variety of clinics would be very expensive and one that no one seems to be willing to support now."

Since this discussion has profound implications for PM patients, TMA scheduled a chat with Dr. Anthony Amato - who has written extensively on this topic - as part of its "Chat with the Experts" series on the TMA web site (www.myositis.org).

More good news for future IBM treatment comes from a Swedish report of anti-T-lymphocyte globulin treatment. In an open, randomized study, a multidisciplinary team of physicians at Sahlgrenska Neuromuscular Center in Gothenberg, led by Dr. C. Lindberg, published a study in the July edition of *Neurology*. The study's authors compared five patients who were given a year's treatment with methotrexate to six patients who received a year of the same treatment after also receiving seven days of anti-T-lymphocyte immunoglobulin treatment. At a year's follow up, patients who received the immunoglobulin and methotrexate treatment were found to have increased mean muscle strength by 1.4% compared with the methotrexate only group, whose muscle strength decreased by 11.1%. Dr. Walter Bradley, Chair of TMA's research committee, believes this study has

Continued on next page

Dutch scientists found that nine of 165 patients given a diagnosis of an inflammatory myopathy using up-to-date criteria were initially believed to have polymyositis. Using the older but still commonly used Bohan and Peter criteria, 76 of these patients would have been diagnosed with polymyositis. On follow-up, only five of these nine initially thought to have polymyositis actually had the disease when they were re-evaluated. Four of the nine diagnoses were changed to IBM. Thus, the overall frequency of polymyositis was five of 165 (five of 238 if one includes the IBM patients). Since this discussion has profound implications for PM patients, TMA scheduled a chat with Dr. Anthony Amato - who has written extensively on this topic - as part of its "Chat with the Experts" series on the TMA web site.

Research hope, questions

Continued from previous page

very positive implications for IBM treatment. However, the anti-T-lymphocyte immunoglobulin treatment is not without risk, said Dr. Bradley, and more research is needed to further assess these results.

A small Dutch study of one dermatomyositis and one polymyositis patient treated with anti-tumor-necrosis-factor-alpha (with infliximab) in The Netherlands, led by Dr. G.J. Hengstman at the Neuromuscular Centre Nijmegen, found that both patients demonstrated a marked and sustained subjective and objective improvement without any side effects. The authors say that these preliminary results suggest anti-TNF-alpha treatment with infliximab is a safe and rapidly effective therapy for myositis.

We'll hear more about these promising new treatments as well as the PM discussion at the Annual Conference. Attend the Conference to hear the news as it develops.



Medical Panel

Continued from front

Kansas *Keep In Touch* (KIT) support group. He has spoken previously at TMA conferences and is a member of TMA's Medical Advisory Board.

Dr. Walter Bradley is a neurologist, the Chairman of TMA's Medical Advisory Board's Research Committee, and a professor and chairman of the neurology department at the University of Miami. Dr. Bradley has published hundreds of research articles on chronic neuromuscular disease, including myositis, and is a founding editor of the journal *Muscle, Nerve*. Dr. Bradley spoke last year at TMA's Annual Conference and will report on the progress of TMA's research program at this year's Conference.

Dr. Ann Marie Reed is a pediatric rheumatologist and head of pediatric

rheumatology and associate professor of pediatrics at the Mayo Clinic in Rochester, Minnesota. Dr. Reed was a founding physician member of TMA, serves on TMA's Medical Advisory Board, and has spoken at previous conferences. She has a long-time interest in juvenile myositis, childhood immune diseases, and osteoporosis.



Travel Tips

Continued from page 5

Greg Fountain, a DM patient, suggests talking with your doctor about getting a prescription for a general antibiotic in case you get ill while you're away.

Your trip may depend largely on the staff at the hotels, airlines, cruise ships, trains, and other places. What one friend may have experienced can be completely different from your own. However, finding out what has worked for others can still be a great benefit to you. Visit TMA's Bulletin Board or ask your *Keep In Touch* support group members for advice.

The more you plan ahead, the better your trip is likely to be.

Resources and tour planners

Accessible Journeys: www.disabilitytravel.com; 800-846-4537

Access-Able Travel Source: www.access-able.com; 303-232-2979

Amtrak: www.amtrak.com; 800-872-7245

Center for Independent Living: www.ilusa.com (go to Links then Directory of ILCs)

Flying Wheels: www.flyingwheelstravel.com; 800-535-6790

Travel Turtle Tours: www.travelintalk.net; 800-453-9195



More on WAMO!

Working Against Myositis for Others (WAMO!) is a catchy acronym but it is more than just that. It is a recognition and belief that those with myositis cannot shoulder the burden of combating myositis and raising awareness without the help of those who do not have the disease. WAMO! is a campaign and program to organize volunteers to help raise funds for research and to enable The Myositis Association to offer more services and benefits to its members.

WAMO! is also an acknowledgment of the importance of family and friends in helping those that they love to live full and enriched lives despite myositis.

TMA will be recruiting WAMO! members at the grassroots level and will identify WAMO! Representatives locally who can help organize and lead local fundraising efforts. As part of this effort to increase fundraising for TMA that is not primarily dependent on those with myositis, TMA is hiring a Development Director to help organize national TMA campaigns and assist local grassroots efforts to raise funds.

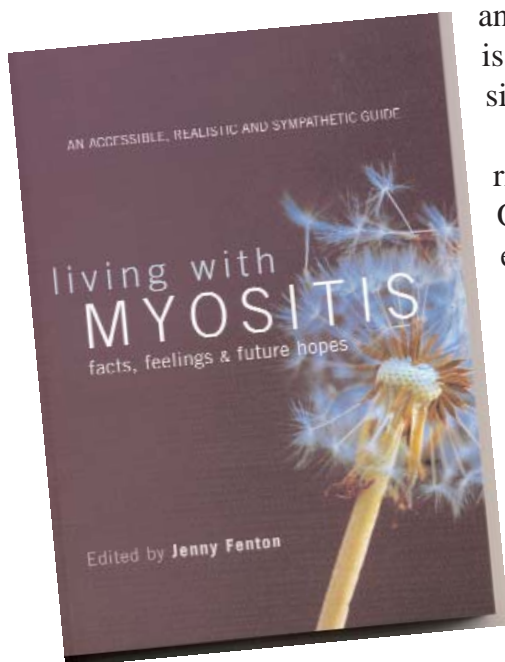
WAMO! can also be a fun way to honor and celebrate those who help others. TMA will be issuing WAMO! awards to individuals and corporations who make a difference in the lives of those with myositis. Become a WAMO! winner!

Keep an eye out for more information about this program on our web site, in TMA publications, and at the Annual Conference as we further develop this new, exciting initiative.

Together We Will! and WAMO! Will Help.

Living with Myositis, a book by and for patients

With humor, compassion and common sense, London dermatomyositis patient Jenny Fenton has written and edited *Living with Myositis: facts, feelings and future hopes*. She calls it an accessible, realistic and sympathetic guide, and readers will find it lives up to her description. Jenny includes patients with every kind of myositis and from both sides of the Atlantic - and also incorporates commentary and advice from experts about every aspect of the disease: emotional issues, practical challenges, complications, nutrition, exercise, prognosis and coping with drugs.



Jenny was a very active mother of three daughters when she experienced more than a year of troubling symptoms several years ago. Once she was correctly diagnosed, Jenny felt relief and set out to do everything she could to recover quickly.

Needless to say, it wasn't as easy as she thought, and she relates her story with humor. Jenny tackled all the difficult chores of putting a layman's medical book together, including dealing with experts who didn't want their work simplified, continuing on through the dark days following her mother's death, and ultimately using her graphic design skills and contacts to produce an attractive, well-designed book.

Jenny's book will be available at the TMA Annual Conference and through TMA's web site Marketplace at www.myositis.org.



THE MYOSITIS ASSOCIATION

755-C Cantrell Avenue
Harrisonburg, VA 22801

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