THE OUTLOOK

For the inflammatory myopathies

Myositis in the news

SPRING 2007

Recent developments have increased knowledge of myositis in the health care and patient communities:

An article in *The New York Times* on March 27 discussed the possible connection between some forms of myositis and cancer. To answer patient concerns about cancer and myositis, TMA has posted recent research on this connection on its web site under Complications.

A **Good Morning America** story aired March 29, talking about the difficulty of diagnosing myositis because of its complex symptoms and tendency to mimic other diseases.

An upcoming article in *Arthritis Today* will discuss the difficulty in diagnosing myositis.

Reviews of TMA's book Myositis and You are scheduled to appear in publications targeted to rheumatologists, pediatric social workers and JM families.

Publicity about the **Johns Hopkins Myositis Center** led to some of the above recognition and also inspired a couple of local television broadcasts in the Baltimore-Washington area.

TMA Bulletin Board users led campaigns seeking recognition of myositis from national health writers and international television personalities.

For more on recent myositis publicity, including ways in which you can help, see pages 4 and 5.

. . .

Myositis Center model for rare disease care delivery

Dermatomyositis patient Nancy Paugh remembers vividly the first months of her illness: "I couldn't even dress myself," she said. Paugh, who lives in West Virginia, was lucky enough to get a quick diagnosis and prompt care. Still, she found that going about the business of being a patient with a chronic illness was "horribly exhausting."

Being a patient sometimes seems like a full-time job, says Jerry Fritz, a Maryland man who has had polymyositis for four years. Between trips to the lab for blood and muscle tests, to the rheumatologist for treatment, and to the lung specialist who treats a related lung disease, he sometimes feels he has little time for anything else. Then there are sessions with his regular physician and with the pharmacist filling multiple prescriptions.

Their stories are familiar to anyone with a complex, chronic disease, especially a rare one where specialists are few and scattered. Both Paugh and Fritz are looking forward to their appointments at the new Myositis Center at Johns Hopkins. The Baltimore hospital is adding myositis to its list of chronic diseases with centralized delivery. "We'll be a kind of 'one-stop clinical shopping center," said Dr. Lisa Christopher-Stine of The Johns Hopkins Myositis Center, which opened in March at the Johns Hopkins Bayview Campus. This is an interdisciplinary center for patients with inflammatory and druginduced muscle conditions:

polymyositis, dermatomyositis, inclusion-body myositis, and statininduced myopathies.

The Hopkins plan assembles the staff all in one place for a Friday clinic, rather than sending the patient around to multiple specialists. A nurse-manager is also available by phone on other days to make appointments and answer questions.

The Myositis Center duplicates a model used by Hopkins to deal with other complex, relatively rare diseases, said Dr. Antony Rosen, director of the Division of Rheumatology. It's been very successful in diseases like lupus, scleroderma, rheumatoid arthritis and vasculitis. Not only does it make life easier for the patients, Rosen said, but the physicians develop significant expertise in the disease and make appropriate collaborations.

Getting to this point has been a long and complex process, say codirectors Christopher-Stine and Dr. Andy Mammen. The two directors started working together because their different backgrounds-hers is in rheumatology, his in neurologymeant they were consulting with each other on specific patients. For instance, Mammen is more familiar with electrodiagnostic testing (EMG/nerve conductions) and is trained to read the muscle biopsies that diagnose and track the progress of myositis treatment. Christopher-Stine has a strong background in drug-induced muscle disease. Both

Published by: TMA, Inc. THE MYOSITIS ASSOCIATION

1233 20th Street, NW, Suite 402 Washington, DC 20036

P: 202-887-0088 P: 800-821-7356 F: 202-466-8940 Email: tma@myositis.org Web: www.myositis.org

Executive Director: Bob Goldberg Editors: Theresa Reynolds Curry Kathryn Spooner

BOARD OF DIRECTORS

Janet Schuler, *Chairman* Jay Shinn, *Vice Chairman* Sandra Dunphy, *Secretary* Keith John Merritt, *Treasurer* Chester V. Oddis, MD, *MAB Liaison* Janice Goodell Andrea Macher Monica Pedano Patrick Zenner

MEDICAL ADVISORY BOARD

Richard Barohn, MD, Chairman Robert L. Wortmann, MD, Vice Chairman Anthony A. Amato, MD Valerie Askanas, MD, PhD Walter Bradley, DM, FRCP Marinos Dalakas, MD W. King Engel, MD Lawrence Kagen, MD Michael Harris-Love, DSc, MPT Ingrid Lundberg, MD Frederick W. Miller, MD, PhD Kanneboyina Nagaraju, PhD Chester V. Oddis, MD Lauren Pachman, MD Lawrence H. Phillips II, MD Lisa Rider, MD Ann Marie Reed, MD Rup Tandan, MD, FRCP Victoria P. Werth, MD

STAFF

Sandra Claudio, *Office Assistant* Theresa Curry, *Communications Manager* Bob Goldberg, *Executive Director* Jami Latham, *Operations Manager* Kathryn Spooner, *Programs Manager*

MAA Founder: Betty Curry

TMA welcomes new board members, medical advisors

The Myositis Association welcomes two new board members in 2007.

Monica Pedano comes to the Board with a strong financial background, having worked as a financial consultant and advisor since her 1993 graduation from Villanova University. She has been committed to finding answers and a cure for myositis since her oldest son, Joseph, was diagnosed with juvenile dermatomyositis at 18 months. Read more about Monica and her family on the cover of JM Companion.

Patrick J. Zenner is a 32-year veteran of the pharmaceutical industry and retired from his position as president and chief executive officer of Hoffmann-La Roche Inc., North America, and member of the global Pharmaceutical Executive

Committee. He works as an industry consultant and serves on numerous corporate boards. In his long career, he served in an array of leadership positions in the pharmaceutical industry and is presently on the

Board of Trustees of Creighton University and Fairleigh Dickinson University, where he serves as Chairman. His wife, Peggy, was diagnosed with inclusion-body myositis last year.

TMA also added three distinguished scientists to its medical advisory board at the MAB's annual meeting in January 2007.

Lawrence J. Kagen, MD, is an attending physician at The Hospital for Special Surgery and The New York Hospital, both in New York City. He also serves as the director of the Laboratory of Clinical Immunology and the director of Occupational Health Services for The Hospital for Special Surgery. He has a long-time interest in myositis, has written extensively about it and has been the editor of several distinguished professional publications. He is also a professor of medicine at Cornell University Medical College.

Jerry R. Mendell, MD, is the director of the Center for Gene Therapy, Columbus Children's Research Institute, Division of Molecular Medicine, Department of Pediatrics, Columbus Children's Hospital and Ohio State University College of Medicine. He has served as an editor for many distinguished journals, including Muscle and



Nerve, Neuromuscular Disorders, Annals of Neurology and Neurology. He is presently an editor at Nature Clinical Practice. Dr. Mendell returns to the MAB having previously served as a TMA medical advisor for a number of years.

Kanneboyina Nagaraju, DVM, PhD, is the director of the Murine preclinical drug testing facility and an associate professor of pediatrics at the Center for Genetic Medicine in Washington, DC. He is a Doctor of Veterinary Medicine and has a PhD in Immunology. He has served as an assistant professor of medicine at Johns Hopkins University in the Division of Rheumatology and is a former TMA-funded researcher.

TMA funds fifth cycle of research proposals

TMA's Board of Directors approved funding for five new research projects in January, 2007. The projects funded this year are very different and are largely focused on therapies:

Two of the proposals selected build on the similarities between IBM

and Alzheimer's Disease: one by exploring medications that have been approved and successful in Alzheimer's patients; the other will examine the nutritional and exercise

interventions that also seem to have benefit in preventing and slowing Alzheimer's. A third project will test the effectiveness of a high-tech "smart" brace's potential use for IBM patients; and the fourth proposal funded takes a look at genetic therapy in IBM. The fifth project seeks to better classify the condition of myositis patients worldwide to assist researchers in treating myositis.

The proposals funded were those recommended by the Research Committee of TMA's Medical Advisory Board, and their diversity indicates the coming-of-age of TMA's young program. "The variety and scope of the projects we have funded are very encouraging, and they indicate that TMA plays an important role in furthering knowledge about myositis," said Dr. Lawrence Phillips, Chairman of the Research Committee.

Dr. Valerie Askansas, MD, PhD, Professor of Neurology and Pathology at the University of Southern California Keck School of Medicine, has published dozens of research articles on IBM and continues to look for more clues to the disease process. Unlike polymyositis and dermatomyositis, IBM does not respond to medications that treat the inflammatory process. Her recent studies have focused instead on the degenerative mechanisms in IBM muscle fibers. Askanas has demonstrated the similarities between the Alzheimer's Disease brain and IBM muscle.

> She now proposes to study a type of drug that improves cognition in Alzheimer's patients and reduces amyloid-beta pathology in experimental models to see whether it will also work to reduce the effects of amyloid-beta in her lab's IBM-experimental human muscle culture model.

Christa M. Studzinski, a PhD candidate at the University of Kentucky, was awarded a research fellowship to examine how changes in diet and exercise will affect transgenic mice. Both diet and exercise. Studzinski notes, have been found to improve function in animal models of Alzheimer's Disease. Studzinski's mice will be put on a special low-carbohydrate, high-fat (ketogenic) diet and given a measured exercise program. The ability of diet and exercise to prevent, halt, or reverse the disease process of IBM will be tested using a variety of behavioral and laboratory markers.

Ingrid Lundberg, MD, PhD, Karolinska University Hospital, Karolinska Institute, Stockholm, Sweden, was awarded a one-year grant for a project to better classify the present condition of myositis patients worldwide to determine the most effective treatments.

Terry Oh, MD, an assistant professor of physical medicine and rehabilitation at Mayo Clinic, Rochester, MN, will study whether "Stance Control Orthosis" is effective for people with IBM and knee instability. This brace may provide the necessary stability while overcoming the restricted lower leg movement and tiring effects of traditional braces.

Drs. **Brian Kaspar, PhD**, and **Jerry Mendell, MD**, both of the Columbus Children's Research Institute, have successfully enlarged and strengthened the quadriceps muscle in mice by using a common virus to carry a follistatin gene into the quadriceps muscle. Because follistatin blocks myostatin, which is associated with loss of muscle mass, Drs. Kaspar and Mendell will test whether such gene therapy might be used to help humans who have IBM and lose muscle mass and strength.

This is the fifth year that TMA has funded myositis research. TMA has now approved 24 projects totaling \$2.7 million. For a complete listing of TMA-funded researchers and related research reports, go to the TMA web site at www.myositis.org.

Myositis Center, continued from cover

have backgrounds in research as well as patient care. They are both wellversed in other muscle diseases, an important factor in myositis, where diagnosis is often made by ruling out other possibilities.

"I'm sure our patients will get used to us calling each other over and saying, 'Hey, look at this. What do you think?' " said Christopher-Stine. Mammen said that would happen with other members of both departments with special expertise. And a lung specialist will join them each week at the clinic. Dr. Sonye Danoff, a pulmonologist, specializes in interstitial lung disease, the type of pulmonary disease often seen in myositis patients.

Appointments with the Myositis Center physicians can be made by calling the center at 410-550-MYO2 or 410-550-6962.



0 0a



Myositis in the News

Myositis featured on Healthline

On January 26, Retirement Living, a new cable television channel devoted to adult education and health, aired a show on myositis. On camera was dermatomyositis patient Cindy Buhl, a congressional aide who was a featured speaker at TMA's congressional briefing to promote Myositis Awareness Day last fall. Buhl spoke eloquently about her own experience with myositis, as did Dick Edell, former University of Maryland lacrosse coach, who has IBM. Myositis experts Drs. Lisa Christopher-Stine and Paul Plotz provided medical commentary for the half-hour segment of RLTV's "Healthline."

Those in the Mid-Atlantic area were able to watch the show when it aired. Due to many requests by TMA members, the station has made the entire broadcast available online, and RLTV's medical expert has fielded several inquiries from myositis patients. Those with Internet access can find it online at www.rl.tv. There's also a direct link posted on TMA's web site.

Currently, all RLTV shows are available on DirecTV Channel 238 and the Comcast Network, which primarily serves Mid-Atlantic and New England states. CN8 has a zip code look-up to find the channel in your area (http://cn8.tv/). TMA will let members know when the show is rebroadcast by posting the time and date on TMA's web site.

Battling both radiation and PM

Polymyositis patient Michelle Thomas of St. George, Nevada, has found herself in the national news, from the *Los Angeles Times* to the *Discovery Channel* for her outspoken criticism of nuclear weapons testing in her home town. For Thomas, as for many others who were around when nuclear tests blew an ill wind into St. George decades ago, the thought of another blast is a reminder of former government duplicity. Thomas, 54, has had full-blown cancer twice, just like many others who were children when the tests were done, and has had other pre-cancerous lesions removed.

The cancer rates near St. George became so high that the community has its own cancer hospital. "Believe me, cancer isn't the only thing that came from those tests," Thomas told the *OutLook*. "Autoimmune diseases here are common. 'Rare' diseases aren't so rare in St. George."

Ever since Thomas became too sick to work as a teacher, she has spent much of her time on anti-nuclear activism. "I've also had to educate my doctors," she said. "My whole life has been a lesson in having to stand up for yourself." Reassurances that the new bomb to be tested would be conventional, rather than nuclear. have not reassured her: "Fool me once, shame on you. Fool me twice, shame on me," she told The Washington Post. Thomas believes that her public exposure might be helpful to drawing attention to myositis patients as well as sparing the townspeople from more possible damage. "We don't need any more disease," she said.

9/11 firefighter disabled by PM

New York Fire Department Lieutenant Martin Fullam rushed to ground zero and worked in a cloud of poisonous smoke following the 9/11 attack on the Twin Towers. He lost many of his men in that battle, and now he's fighting another one. Fullam has polymyositis, complicated by severe lung disease that's left his family \$50,000 or so in debt. Fullam was invited by New York's congressional delegation to attend the State of the Union address in Washington, DC. He and others are advocating for a \$1.9 billion infusion of federal money over five years to fund medical treatment

for rescue workers sickened by the poisonous fumes and dust following the terrorist attacks. Fullam said that he was familiar with polymyositis, even before he was diagnosed: "It's not so rare among firefighters."

Aggies' Assistant coach strikes chord with DM patients

The Texas A&M Aggies' men's basketball team has some new fans-dermatomyositis patients from around the country-thanks to Al Johnson. Johnson, a 30-year-old who was promoted to assistant coach just this year, invited everyone to learn more about his personal struggle with DM by sharing his story with Texas newspaper reporters. When posted online, these articles reached thousands of readers, including basketball enthusiasts who wrote about Johnson on their blogs, and DM patients and friends who understand his story firsthand. Commentators for a recent ESPN-televised contest between Texas A&M and Kansas briefly discussed Johnson's diagnosis on the air.

TMA members and friends from TMA's online bulletin boards reached out to Johnson, offering words of encouragement as well as thanking him for bringing attention to the littleknown disease. Many of them commented that the articles really hit home as Johnson detailed the exact symptoms they had experienced in the beginning. Family members of a young girl with juvenile myositis contacted Johnson to say they were touched by his story.

He's feeling better now, able to return to the bench to coach one of the top college teams in the nation. With his welcoming yet unassuming personality, Al Johnson has introduced many new people to the complexity of DM.

Advocacy in the information age

Use your web site for advocacy

Many TMA members have web sites connected with their business, hobbies or family interests. Even if your web site is not about your disease, by mentioning you have myositis and linking to TMA, you can educate those who visit your site.

If you link pages with similar sites, you'll attract people who might also be interested in you. Reciprocal linking, where you add a link to your pages that sends your visitors to another site, and the other site links back to you, means that other people who are interested in autoimmune disease, patients' rights or chronic illness will learn a little more about myositis. Make sure that all your business materials include your name and web address.

Use your newspaper's blogs to talk about myositis

Of the top 100 newspapers in the U.S., more than 90 now seek reader interaction. The most common way is in the form of blogs, usually written by a senior writer or journalist, that ask for reader response. This is becoming a very effective way for people with special interests to get exposure. For instance, if you read an interesting article about better access in public buildings, this is your chance to weigh in with the challenges of your disease. While you're at it, link to your blog, your web site, and TMA's web site.

As you become an active participant in local news, you'll gather a readership if you follow some simple rules:

■ Shorter is better. Keep your online comments to less than 300 words, providing links as necessary to longer commentaries you've written on the topic.

■ Informal is fine. Whether you're posting your answer to an editor's

question or disagreeing with another reader, be brief, informal and very specific.

• Know your stuff. Editors and other readers get extremely impatient with those spouting ignorant rhetoric, vilifying public officials without facts, or promoting doubtful theories. To make your point and win respect, be specific, include facts and interesting information, and limit your comments to your own experience, so it's clear that you know what you're talking about.

Commenting often and answering questions in a helpful way may win you status as a local expert. One phenomenon of the Internet age is that traditional media, both broadcast and print, are finding stories and subjects online. Some newsrooms have reporters assigned to sift through blogs and reader posts every day. When you become a frequent presence online, you may find that traditional news sources will begin to contact you for information.

Use the bells and whistles

Members of nonprofit organizations are increasingly using buttons and badges on My Space and Facebook, as well as on their own web sites and in their blogs, to spread the word about the organizations they believe in, and encouraging those who visit their space to donate. There are very inexpensive tools for this purpose. Some banners are simply graphics that direct the reader to associations like TMA: others give readers a way to donate to a cause with a touch of a button that then refers them to a secure site. You don't have to be a graphic designer to do this. Places like bannermakerpro.com have preset strings of code available for your use.



JOIN THE BLOGOSPHERE

"Blog" is short for "web log," an online journal usually written in a series of short items with the most recent entries at the top. There are two kinds of blogs—an online diary that chronicles a person's life; and more news-related blogs with links to other websites and commentary on the news. Many are combinations of both, with personal information mixed in with news and links of interest.

Because of the widespread availability of this publishing form, there has been an explosion in the number of bloggers. One website, technorati.com, tracked more than three million weblogs recently, an increase from 100,000 just two years ago. Free software is available at places like blogger.com.

Weblogs are about as many different subjects and opinions as there are people writing them. Some blogs are highly influential and have enormous readership, while others are primarily a way to keep in touch with family and friends. Generally, once a blog is determined to be trustworthy or of interest to a particular group, it gets the most Internet traffic.

These formal and informal online journals, and the online links they use, are replacing traditional sources for sharing news. New blogs pop up daily. If you are a blogger who writes about life with myositis, here are some tips:

- Provide a link to TMA's site.
- Link to other TMA bloggers.

Respond to questions as quickly as possible regarding myositis.

Put up something new almost every day.

If you have any questions or need fresh material for your blog, email tma@myositis.org.

Good advice shared on TMA's message boards

Be your own best friend

I overdid it since Christmas...too much running the kids around, activities, etc., and I started to feel tired and not so good. I noticed some soreness in weird spots, like my abdomen for the past 3 weeks. I ignored it...shouldn't have.

I continued on...and it caught up with me last Thursday. I felt better on Saturday, then kind of overdid it again because my daughter's 15th birthday party was that night. I didn't want to disappoint her. My friends are saying cancel, we will take out the kids. Of course, I declined. I am okay. I can do it.

I have learned my lesson. I will listen to my body, and I am not Super Mom or Super Wife!

Michelle, DM

It really is a hard lesson to learn, and unfortunately, it won't necessarily take just this incident to do that. It's a lot of two steps forward, one step back...but as long as you're going in the right direction, that's the ticket!

Beth, DM

I think when we feel good we all try to pretend nothing is wrong and prove to ourselves we can do it. I have just finished one hour of house cleaning as I feel more able to do more each day; however, I am now sitting down for an hour or two so I can get back up later and do some more. I am going to break down and have a friend who offered to help anytime come in and clean my shower—I have no strength in my arms or hands to scrub the sides.

Zara, DM/PM

It's easy to push beyond your limits, but the problem I find with this disease is that sometimes you don't know what's too far until you are already there. I suppose I'm still trying to find that balance, as it seems you are too. And honestly, sometimes the consequences are a fair trade for the enjoyment. But I'll be nobody's hero if I relapse.

Carla, DM

There is a lot more to come, so try and pace a bit more. Think of what you would say to your best friend if she was overdoing it a lot and suffering for it. Now be your own best friend.

Elizabeth, DM

Quality time with family, friends

I'm sure many of you can relate. I had a bad day today and I am really feeling quite down about this whole thing. My emotions are all over the place. One minute I feel I can deal with this and then the next I'm in tears. I am the mother of a 3-year-old and I don't want her to see her mommy sick. I fear the future. Any words of encouragement out there?

Katie, DM

Believe me, you are not alone. As the mother of a 6-year-old and an 8-yearold, I can completely empathize with how you're feeling. Guilt is a very heavy burden to carry—about all you can't do but want to do.

Let me give you some immediate relief about your daughter, which has been given to me time and time again...she loves you no matter what. Get her to climb up on your lap, read her a book. Ultimately, it comes down to the quality of time you spend with them, and in our case, just the *actual* time. If I just sat next to my kids for a bit, not trying to do the laundry before I collapse, trying to get dinner ready, reading my e-mails, etc., they would be thrilled.

Two final short-term fixes for you too: a good laugh and a good cry (not necessarily in that order). Arm yourself with accurate information, good doctors and take it one day at a time. Knowledge is power and laughter is always the best medicine for your soul. We are all here for you and to help one another through this struggle.

Vicki, DM

Be strong, be heard

There is hope and you have to be strong and determined to turn this around. I am now driving, exercising, and almost all that I did before but at a slower pace. This past September we went on our first cruise and hope to go again in a few months. This is a great site and so many caring and supportive people are here to guide you and give you encouragement. You will get there; it just takes time and the right frame of mind.

Fay, PM

I was diagnosed last June with PM and all of my symptoms were similar to yours. I made several mistakes. Many of us live in smaller areas and our doctors just don't see enough PM or DM to know the best ways to treat it or be aggressive enough with the treatment. You really have to take charge and challenge you treatment. This site is a great resource and the experiences of everyone here have been invaluable to me. You're teaching me I have to learn it and direct my own treatment—nobody cares as much as I do. Thanks for your support.

Carla, PM

Don't miss the support, encouragement and practical advice shared on TMA's message boards. If you've never been and need help, email tma@myositis.org.

Notes of interest

Injection studied as alternative to IVIG infusion therapy

By pinpointing the mechanism through which an intravenous therapy combats chronic inflammatory diseases, researchers at The Hospital for Special Surgery (HSS) in New York City have discovered that they may be able to replace the time-consuming infusion therapy with an injection that could be given during a quick office visit.

Investigators at HSS discovered that intravenous immune globulin (IVIG) or antibody therapy works, in part, by attaching to a receptor known as FcãRIII and blocking the function of interferon gamma, a major inflammatory factor. Only a small component of the IVIG solution, 0.5%, is responsible for blocking this receptor.

"The study suggests that it's not the whole preparation itself, but the immune complexes within the preparation that are causing the therapeutic effect," said Lionel Ivashkiv, MD, director of basic research at HSS, who led the study. Instead of using IVIG, which is pooled from thousands of blood donors, clinicians may be able to use small amounts of so-called immune complexes, or even design synthetic drugs that will avoid problems, such as potential exposure to infectious agents, that are associated with using blood products.

"The recently reported research, indicating that a small component of these preparations may be responsible for its beneficial effect, offers promise of making this therapy available in a more convenient, and perhaps less expensive form," said Dr. Lawrence Kagen, TMA Medical Advisory Board member, also of HSS. "In addition, the insight presented into its mechanism of action may allow development of different and novel agents with greater efficacy. This basic research is important. It points the way to clinical investigations. Until then, we are hopeful but cautious."

The study appears in the January issue of the journal *Immunity*.

Caffeine Cuts Muscle Soreness

A small study found moderate doses of caffeine equal to 2 cups of coffee could reduce muscle pain. Researchers suggest caffeine may block the body's receptors for adenosine, a chemical released in response to inflammation.

Can Prunes Reverse Bone Loss?

Could a handful of nutrient-rich dried plums each day help keep the doctor away by actually reversing bone loss in women with osteoporosis or osteoarthritis? A unique clinical study under way in the Florida State University College of Human Sciences in Tallahassee means to find out.

Why prunes? "While drug therapies are available for the treatment of osteoporosis, they can be prohibitively expensive and are not without side effects; hence long-term adherence to these therapies is low," said Bahram Arjmandi, FSU professor and the study's principal investigator. "Furthermore, many women prefer to modify their lifestyle and dietary practices in order to prevent fracture due to osteoporosis."

In a 2004 study he led while at Oklahoma State University, Arjmandi found that a diet supplemented with dried plums produced significant restoration of bone mass in female rats whose ovaries had been surgically removed. "I've never seen results that were more consistent," he said. "If the findings from FSU's human study are similarly positive and reproducible, they could help researchers isolate the compounds responsible. From there, it may be possible to create a safe, low-cost alternative or adjunct to prescription medications for osteoporosis."

Women who are two to 10 years postmenopausal and wish to learn more about participation in Arjmandi's dried plum study can call 800-951-4490. To learn more, visit the web site at www.chs.fsu.edu.

Operating Funds are Important Too

Richard Friedland, a TMA member, in response to the news that members are being asked to donate to research for the \$500,000 matching research challenge writes, "I am stewing a bit about the emphasis on reallocating contributions to research at the obvious expense of funds for operationsthe life-blood of the organization. I'm all for finding a cure, or better treatment options, but we cannot risk losing the funding for operations which allows the organization to exist and serve patients, physicians and researchers. Enclosed is my check for \$500 which I wish to designate to operations and ask that you publicize this issue and challenge other donors to match my check, or better. Thank you."

As noted, donations to TMA for the matching research challenge are restricted solely to research, as are the matching funds that will be provided. Unrestricted funds continue to be needed to provide capital for TMA to provide all its other services and activities -- educational materials, annual conference, newsletters, website, support groups, advocacy, etc.

You will be receiving a mid-year appeal in the mail from TMA in the next two months that will ask for donations to support these other activities. Please keep Mr. Friedland's request in mind and help support these other important activities of TMA.

Chat Schedule

How TMA decides which research to fund

Thursday, April 5, 4 p.m.

Lawrence H. Phillips, II, MD, professor of neurology at the University of Virginia School of Medicine, is the chairman of the research committee of TMA's medical advisory board. Dr. Phillips will also take questions about the electro-diagnostic tests that are used to diagnose myositis.

(Transcript available to members online in My TMA.)

Exercise for myositis patients

Tuesday, May 22, 4 p.m.

Michael Harris-Love, DSc, MPT, CSCS, is Assistant Professor, Program in Physical Therapy at the George Washington University School of Medicine and Health Sciences and Visiting Researcher, Environmental Autoimmunity Group, NIEHS, NIH. **Joseph Shrader,** PT, CPed, works with myositis patients at NIH on the natural history of strength and functional impairments in patients with idiopathic inflammatory myopathies, teaches physical therapy, and has a private practice.

Juvenile myositis

Thursday, June 14, 8 p.m.

Janalee Taylor, RN, MSN, CNS, is Clinical Nurse Specialist and Associate Clinical Director at Cincinnati Children's Hospital Medical Center. She will discuss how children develop toward independence throughout the course of juvenile myositis.

Statins and myositis: what's the connection?

August 15, 4 p.m.

Dr. Lisa Christopher-Stine is co-director of the Myositis Center at Johns Hopkins University Hospital, and has written articles on the relationship between myositis and statin drugs. Dr. Christopher-Stine will also take questions about the Center, which opened in March, 2007.

PM, **DM** and cancer October 16, 2 p.m.

Dr. Andrew Mammen is co-director of the Myositis Center at Johns Hopkins University Hospital and has a special interest in the connection between myositis and cancer.



For the inflammatory myopathies