



THE OUTLOOK

SPRING 2006

For the inflammatory myopathies

Locate an occupational therapist

Occupational therapists work in many settings, including private offices, hospitals, clinics, nursing homes and schools. Your occupational therapist may want to come to your home to see your own circumstances and make recommendations.

Check with your physician or hospital, or ask people you know who have had a good experience with an occupational therapist. You may also check under "Occupational Therapists" in the yellow pages of your phone book, or call professional organizations for assistance in identifying member providers. States have a Board for Occupational Therapy, but they cannot refer you to a specific practitioner. Each state does keep an online registry that will allow you to see if a practitioner is licensed. Occupational therapists, like other health professionals, are required to display their licenses in a visible place in their place of business.

Many occupational therapists participate in health care plans. To make sure this service will be covered, check with your health care plan before making an appointment. Once you schedule an appointment with an occupational therapist, think about what you would like to accomplish. There are things you can do to make sure you have a productive experience with your occupational therapist:

- answer all health-related questions completely and accurately;
- ask questions to help you understand your evaluation and treatment plan;
- express your opinions and personal values to help your occupational therapist develop a program that will meet your needs.



GETTING ON WITH THE OCCUPATION OF LIVING

Mary Jane De Lauder signed up for regular testing at the National Institutes of Health (NIH) hoping she'd add to the understanding of inclusion-body myositis and benefit future patients. "But I'm the one who learned," De Lauder said. "I can't say enough about the help I've received at NIH." De Lauder was part of both the ongoing longitudinal study of IBM at NIH and, later, the Campath drug trial.

One of the most positive parts of making the trip many times from Florida to Bethesda was De Lauder's visits with Fran Oakley, her occupational therapist. "Fran worked with both of us," she said, referring to her husband Dick. "She taught Dick how to block my feet with his when he helped me get up from a seated position, so my legs wouldn't slide out from under me." She also taught him to transfer his weight as he lifted her, protecting his back and stability at the same time he protected her from falling.

Occupational therapy helps people with limitations carry out the meaningful activities of daily life, like attending to their needs, going to their jobs, continuing their education, and engaging in an active family and social life.

For instance, Fran Oakley put De Lauder in a makeshift kitchen and watched as the IBM patient prepared a simple meal. "That way, she could see firsthand what

I was having trouble with," De Lauder said. "We went through all the details of my daily routine, and she was able to suggest things that helped me in every room, with every task, either by making adjustments to the way I accomplished things or aids that really made my life easier."

Occupational therapists study human growth and development, with specific emphasis on the social, emotional and physical effects of illness and injury. They help people with disabilities get on with their "occupations" of living.

If you're already working with several health professionals, you may wonder where does the occupational therapist fit in? While others on your health care "team" may monitor your health and physical condition, the occupational therapist will ask, "What activities are vital for you to remain an active participant in your own life?"



WANT TO LEARN MORE?

There will be several sessions with an occupational therapist at the Annual Conference August 31-September 3 in Orlando. To register, go to www.myositis.org.

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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

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ABOUT TMA

TMA Board Adds Two New Members

The Myositis Association, a 501 (c)(3) nonprofit tax-exempt organization, is governed by a Board of Directors made up of nine volunteers. Because TMA's bylaws limit service on the Board to no more than five consecutive years, 2005 Board Chair Ed Grass and Board Vice President and Treasurer Richard Bullard III vacated their seats December 31, 2005.

Two new members—Sandra Dunphy and Keith Merritt—joined the Board on January 1. Ms. Dunphy's husband has IBM and Mr. Merritt is a lawyer who brings his legal judgement to the Board. Janet Schuler became the Chair of TMA's Board for 2006 on Jan. 1. Ms. Schuler's husband has IBM, and her family has organized a golf tournament and walkathon in Indiana for several years.

One member of TMA's Medical Advisory Board serves on the Board of Directors. Other Board members have a form of myositis or are connected to someone who does.

Serving on the Board is open to anyone. For the last three years, at least one new member of the Board has been a TMA member who expressed interest in serving. Because of the nature of myositis, it is sometimes a challenge to find people with the time and energy to be Board members. Nevertheless, TMA has found enthusiastic and skilled Board members in the past and invites other members to express their interest.

TMA's Executive Committee, serving as the Nominating Committee, recommends those they believe are best suited to fill TMA's needs. Those approved by a vote of the Board of Directors serve an initial term of one year and are eligible for two consecutive two-year terms,

then must leave the Board to allow others to serve.

Members of the Board are not compensated for their service and commit at least 48 volunteer hours each year, so service on the Board is not for everyone. If you have a desire to serve on TMA's Board of Directors, let us know and you will be contacted for further information.

A CLOSER LOOK

Sandra Dunphy, from Kingwood, Texas, is a civil engineer who graduated from the University of Delaware and worked for Exxon and other international companies. She now works part-time and is an active volunteer. Sandra is married to Ken Dunphy, an IBM patient. She's played a role in the last two Conferences, presenting short exercise programs and has worked with the Houston TMA KIT (Keep In Touch) group's golf tournament, raising \$18,000 in 2005. She also coordinated a fund-raiser for breast cancer.

Sande is on the Development Committee and wants to be "the energy behind the next idea that brings significant funding to TMA."

Keith Merritt was born in Utica, NY and moved with his family to Charlotte, North Carolina, the next year. He attended public schools in Charlotte and graduated from the University of North Carolina-Chapel Hill with a degree in political science and economics. Keith's law degree is also from UNC-Chapel Hill. He began his law practice in 1990 and has practiced law ever since. He is married and has two children: Ryan, age 5; and Megan, age 2.

Keith's wife is a professor at UNC-Charlotte in the Department of Physics and Optical Sciences.



SPOTLIGHT ON RESEARCH

Interstitial lung disease: Risks, treatment and prospects for myositis patients

Interstitial lung disease is a term that includes dozens of chronic lung disorders. It damages lung tissues, inflames the air sacs, and can permanently scar the tissues between the air sacs. Scarring of these tissues can eventually cause the lung to become stiff.

Researchers find that lung disease may be more common in patients with polymyositis and dermatomyositis than they previously believed. Writing in *Current Opinion in Rheumatology*, Dr. Maryam Fathi and Dr. Ingrid Lundberg say that high-resolution computerized tomography combined with pulmonary function tests gives the physician better tools for detecting interstitial lung disease, often before the patient exhibits any of the typical symptoms.

Using these diagnostic tools routinely on new PM and DM patients, a recent study found that as many as two-thirds had signs of interstitial lung disease, even though all the patients were in early stages of myositis. PM and DM patients seem to have about the same risk, and the disease is rarely associated with inclusion-body myositis. Recent studies show that patients with amyopathic dermatomyositis (dermatomyositis without the muscle symptoms) are also at risk for lung disease.

There are ways that physicians can predict the likelihood of myositis patients developing interstitial lung disease. Patients with anti-Jo1 antibodies are thought to be at a much higher risk, Drs. Fathi and Lundberg report. Myositis patients with anti-Jo1 antibodies are also more likely to have arthritis, fever, Raynaud's phenomenon, and mechanic's hands.

Detecting the presence of lung disease sooner rather than when symptoms are well established is very

important because appropriate treatment may prevent the disease from becoming chronic. In the chronic stage, interstitial lung disease is often called chronic pulmonary fibrosis. Treatment is a complex and individual process, varying according to the patient.

Treatments that appear to be effective, according to Drs. Fathi and Lundberg:

Tacrolimus led to stabilization or improvement in four of five anti-Jo1 antibody-positive patients with polymyositis. These observations were confirmed in a larger patient cohort of 13 patients.

Tumor necrosis factor α (TNF- α) inhibitors have also been mentioned as promising agents for treatment of both myositis and interstitial lung disease.

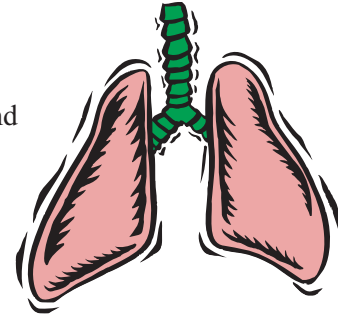
If you are newly diagnosed with PM or DM, or report any lung-related changes, your doctor may order **pulmonary function tests**, a number of tests that measure how well the lungs take in and push air out and how efficiently they get oxygen into the blood.

Chest x-rays help physicians detect complications of lung disease and also can identify how the disease is progressing. Fathi and Lundberg note that these tests are not always able to detect early interstitial lung disease, and recommend **high-resolution computerized tomography**, now widely used for detecting interstitial lung disease, to identify the severity of the disease, and to distinguish between fibrotic disease and active inflammation in the lungs.

Bronchoalveolar lavage is a safe and noninvasive procedure that identifies other causes of interstitial lung disease like infections, drug-induced

pneumonitis, and sarcoidosis.

You or your physician may be interested in the full report by Drs. Fathi and Lundberg at www.myositis.org.



TMA AWARDS THREE NEW RESEARCH GRANTS

Since 2002, TMA has awarded \$2.2 million in research grants and fellowships for innovative medical research related to myositis, and awarded grants to the following in January, 2006:

Hanns Lochmueller, MD, of the Friedrich-Baur-Institute, at the Ludwig-Maximilians-University in Munich, \$164,048 over two years to study the molecular pathogenesis of inclusion-body myositis.

Ingrid Lundberg, MD, PhD, Karolinska University Hospital, Stockholm, \$100,000 a year for two years to study how the immune system affects muscle function in patients with polymyositis and dermatomyositis.

Nicola Ruperto, MD, of the Instituto Gaslini in Genova, Italy, a \$50,000 one-year grant to recruit patients and medical centers from 46 countries for a randomized five-year clinical trial to determine the treatment associated with the lowest occurrence of flare and the lowest drug-related toxicity in juvenile dermatomyositis.

ASK THE DOCTOR

Medical Advisors answer questions from IBM patients

The supplement to *Neurology*, based on the TMA-sponsored “think tank” last year, inspired many questions from members on TMA’s IBM bulletin board and in emails. TMA medical advisors were asked to address the most common questions. Their answers should further illuminate what’s ahead in possible treatment for IBM.

QUESTION: Dr. (Valerie)

Askanas mentions a “cocktail royal” taken as possible protection by a 73-year-old man for eight years, with daily high doses: L-carnitine (900 mg 5X), Co-Q10 (100 mg 4X), B-1 (100 mg), B-2 (100 mg), B-6 (100 mg), E (1000 mg 3X), and B-12 (1 mg). What is the man’s situation today, and would you advise the same cocktail for all IBM patients?

ANSWER: The described patient is still taking it, since 1997, without side effects. As of early March he considers he was initially improved and then non-progressive for about six years; for the following three years he has been using a cane; and for the past year he uses a walker intermittently and is having difficulty getting up from low chairs or chairs without arms. Opening car and dryer doors with his fingers is still better than before treatment. Whether his apparent benefit has been truly treatment-related, unique to the treatment in this patient, or has a wider applicability is not certain. Whether other IBM patients should use this “cocktail” should be determined by each patient’s own physician.

QUESTION: Dr. Askanas writes, “A good treatment of s-IBM should produce increased strength, because muscle fibers (cells) can repair and regen-

erate. The overall difficulty is that in s-IBM the regenerative fibers do not seem to get a chance for sustained, effective rematuration, probably because they become afflicted by the basic degenerative process.”

What does happen to the muscle fibers when IBM patients exercise? Do they not respond at all, or do they just



respond in a way that can’t overcome the degenerative process? Is it pointless for s-IBM patients to exercise?

ANSWER: We do not know the actual cellular details of the effect of exercise on muscle fibers in s-IBM patients. We consider that mild exercise is probably beneficial, at least for muscle fibers not yet involved, or perhaps ones only minimally involved. Intuitively, vigorous exercise that causes muscle-fiber discomfort, pain or fatigue may be detrimental.

QUESTION: Dr. (Marcus) Finch suggests that studies look for clues to IBM in past histories of inflammation and diet. Does this mean that someone with long-term inflammation is more at risk for IBM? What about diet? Does it make sense for someone with s-IBM to restrict calories?

ANSWER: Regarding “long-term inflammation,” we are not certain what the correspondent means. We do not recall chronic infection as a factor in any s-IBM patient. Regarding calorie restriction, it seems logical that one should try to maintain an ideal body weight—being overweight has many disadvantages. We do not know whether being overweight can aggravate the s-IBM, but certainly it increases the load that weakening muscles must move.

QUESTION: Dr. Finch mentions aspirin and other NSAIDs as being protective against the disease process in AD. Should s-IBM patients consider taking aspirin or ibuprofen as a way to protect themselves? What about statins—we know that statins have been suspected as causing myositis-like symptoms, even long-term, so the relationship with cholesterol and IBM must be quite complicated. Would you advise s-IBM patients to reduce cholesterol via statins or diet?

ANSWER: Cholesterol reduction via diet seems reasonable, but is unstudied regarding its effect on s-IBM itself. The relation of statins to s-IBM is undetermined. Regarding aspirin therapy, we do not know whether that would influence s-IBM muscle. Cardiologists often suggest daily aspirin—whether that is appropriate for a specific s-IBM patient must be determined by the patient’s own physician, since aspirin can have side effects.

QUESTION: Dr. (Robert) Griggs mentions that improvement in CK is of little use in measuring improvement in s-IBM. What, then, would constitute improvement?

ANSWER: To indicate improvement, we use increased muscle strength and lessened muscle fatigue, and the converse as reflecting worsening (assuming no other factors are implicated). In the patient's daily life, strength and fatigue can be monitored by such activities as: walking distance, ascending stairs, arising from a chair, exiting or entering an auto, tending to catch the toe when walking, gripping utensils and other things, opening containers, turning keys, writing.

QUESTION: Dr. (Marinos) Dalakas mentions treatments that target T-cells and lists natalizumab. What is its status?

ANSWER: The FDA staff is still concerned and hesitant about re-approving natalizumab (Tysabri) because of its rare but very serious side effects, specifically "a rare and often fatal brain infection [PML]", according to the Wall Street Journal (3-7-06); the FDA staff is concerned that "the drug could be prescribed to patients where the potential clinical

benefits have not been demonstrated to justify the potential risk of PML." Whether it eventually will be considered safe and effective for s-IBM patients remains to be determined.

QUESTION: What is the connection between IBM and HIV? Dr. Dalakas mentions a definite association—13 cases so far. Does this mean that IBM is another of the many manifestations of this disease that devastates the entire immune system?

ANSWER: Regarding the rarely-reported cases of HIV with s-IBM, muscle-biopsy and other studies may reveal more unreported cases. Hypothetical mechanisms are: the HIV virus can damage the muscle fibers and "foreignize" them, making them interpreted by the normal immune system as foreigners to be eliminated; or alter the immune system itself such that it becomes programmed to attack normal muscle fibers. It is also unknown whether the currently-used HIV anti-viral drugs can enhance or diminish the chance

of s-IBM development. Studies of some of the increasing legions of HIV patients could help clarify these points. If the s-IBM in the few reported HIV patients (see Dalakas, in the Supplement) and in the very few HTLV-1 virus patients (see Engel and Askanas, in the Supplement), is due to the named virus, that phenomenon could be a model for a yet-unidentified hypothetical virus causing the far more common idiopathic s-IBM, which we think is possible.



WANT TO LEARN MORE?

There will be several sessions with myositis specialists at the Annual Conference August 31-September 3 in Orlando. For more information, turn to page 8 of this publication. To register, go to www.myositis.org, or call 800-821-7356

HISTORIC SUPPLEMENT DRAWS ATTENTION TO TMA'S MISSION

The *Neurology* Supplement on sporadic inclusion-body myositis (s-IBM), an historic collaborative effort, was published a year after physicians on TMA's medical advisory board invited experts from all over the world to work on the puzzling problem of s-IBM. The two-day meeting brought clinicians as well as basic scientists together and was unique in many regards. Some of the scientists knew each other well from devoting countless hours to IBM research and treatment, or from serving on TMA's medical advisory board. Since the organizers chose to tap the knowledge of scientists working in the tangential fields of aging, the ubiquitin system, protein folding and others,

some at the meeting were completely new to IBM, and were able to tackle its complexities from new angles. This was intentional, and the diversity of approaches in the final publication attests to its success.

TMA believes the supplement is a powerful advocacy and educational tool. As you share it with your family physician and specialists, please also include information about TMA's programs and services so colleagues in the health professions will learn about TMA's support and patient education services as well as its sponsorship of top-level scientific events like the one that produced this compilation.

If you're not sure your health professionals are getting TMA's quarterly mailings about new trends in research and treatment as well as information about clinical trials, special events and conferences for their myositis patients, please send TMA the names and email addresses of the health professionals who serve you. We also send electronic copies of the *OutLook* and *Companion* to interested health professionals.

The full supplement, written for neurologists, is available for sale from TMA for \$10 or you can view the online abstracts, both available through www.myositis.org. To order by phone, call 1-800-821-7356.



WHAT WOULD YOU DO?

Members help new patient face a realistic and fulfilling future

Last February, a 40-year-old man named Brian Hill signed on The Myositis Association Bulletin Board with a heartfelt introduction. Brian had just been diagnosed with inclusion-body myositis, and, frankly, he was frightened. He had a young family, a home he loved, and what he thought were to be the best years of his life ahead of him. As Brian learned more about his disease, he knew he'd need to make plans for the future. He asked the veteran patients who visit the bulletin boards for advice. The question he posed: If you knew at the time of diagnosis what you know now, what would you do differently?

Brian came to the right place. His request released a flood of empathy and welcome and, most important, some of the best guidance available for facing a chronic, progressive disease. "This is exactly what the newly diagnosed need," Brian said. "Someone they can reach out to who has walked down the path."

Plan ahead

Brian lives in an older, three-story home that he and his family love. TMA members advised him to think seriously about this situation and to consider either moving to a one-story house or finding a way to adapt the downstairs to future needs. One member suggested that, as long as there is sufficient room for Brian's needs on an accessible floor, the family might be able to remain in their home. Generally, veteran TMA members made this point: plan ahead rather than reacting when an emergency arises.

Members offer the same advice about insurance. To protect health and life insurance, they advised a discus-

sion with a good financial planner. Brian was urged to communicate his financial and emotional concerns to people in his own family as well as to financial advisors and health professionals.

Other members had tips for Brian's physical well-being: "Develop the strength in the muscles you have left by gentle exercise," one wrote. "Dedicate yourself to becoming more fit." Members recommended walking as he was able, exercising in the water, taking antioxidant vitamins, and eating healthy, natural foods with as little sugar and refined foods as possible. They counseled him against getting overtired, overstressed and overwhelmed. They told him to enjoy each day, and to spend time teaching his children the things he enjoyed as a child.

React quickly to hints of the future

Mike (IBM) in San Diego said: "My plan has been to react quickly when I had even a hint that the next stage of weakness was coming. When I was diagnosed in 1996 at the age of 55, I was still playing golf, tennis and doing some very slow jogging. I had trouble believing the diagnosis. But over the next year I began falling—on the tennis court, on the jogging trail—and realized I needed to protect myself. So in 1997, I got a scooter for 'walking' any distance and stopped the more risky behavior. That year we moved into a one-story condominium after I had two serious falls on the stairs of our previous home. By 1998 I was falling in the house and at my office. So I purchased full leg braces for use at work and a wheelchair for getting around in the house.

"By 2004, I had some falls when I

would go from the driver's seat of our van around to the back to get the scooter (with a Bruno Curbsider lift). So I traded the van for one with an IMS conversion. Now I can just drive in and transfer to the driver's seat. Right now I'm trying to decide what to do about the fact that I can no longer get off the floor if I should fall and that I can no longer safely transfer to our toilet."

Don't forget the ride itself

Brad (IBM) wrote: "Don't let the disease define who you are or who you were before diagnosis. I think a large part of what you're really asking us is, 'how do I adapt to become a patient?' Certainly a worthy question but the answers are many and unique as they pertain to each of us. One thing is for sure, doctors don't know the first thing about being a patient. Let's put a little perspective on our situation. Instead of having IBM, let's say you were hit by a car, waking in a hospital, learning you were permanently disabled. What would you do then about your job, insurance, housing and all the rest? I'm sure you would have been clueless, as would have I and everyone else on this board. Think about all those folks out there, living fairly normal lives, who were confronted with that exact situation but chose to keep going. If there weren't so many, we wouldn't have needed ADA laws. Take it as a wonderful gift you've been allowed to enter our world of disability with slow progression, not forced into making immediate decisions. The fantastic growth and availability of medical aids and equipment can't be overlooked. My wife and I took two outstanding cruises well after diagnosis."

See Members help on next page

Members help,
continued from previous page

Know what you can control and what you can't

Tenayahh wrote: "Assess the factors you can control within your new and future reality. At some point you may want to use a scooter, so you need to have halls and doorways that are wide enough, and you'll need sufficient turning radius. I found it very useful to look at a lot of model homes with these points in mind to practice in assessing them for suitability. If you buy an existing home, be sure that anything that doesn't currently fit the accessibility needs can be altered or remodeled. Maybe a wall can be taken down or doorway widened. Can a ramp be installed in the garage or at one of the easily-reached outside doors? Can a bathroom shower be altered if you need a roll-in shower? Is there enough room to maneuver with a wheelchair or scooter in the

future? Can you put a transfer seat across a tub? Then, after you take care of your present and future physical needs, you can relax and have some fun! There are lots of places to travel even with limited physical ability.

You are wise to watch what you eat, not totally pitching your favorite foods, but eating in moderation. As physical activity is curtailed, you want to do everything you can to avoid gaining a lot of weight. This will help you feel better and make it much less of a physical strain for your family to care for you. It's important to protect their health, too."



FIND RESOURCES

Find books, support, and ideas for independent living at www.myositis.org.

EASY MONEY BENEFITS TMA

Ever wish you had a penny for every time you made an Internet search?

A new search engine called GoodSearch is donating half of its advertising revenue to charities like TMA. It looks like Google and is powered by Yahoo. The difference is that GoodSearch makes a donation for your clicks.

Launched at the end of November, 2005, GoodSearch already has more than 900,000 charities and schools listed, including The Myositis Association.

For each search about a penny is donated to TMA, which you choose from the drop-down menu.


A feature of GoodSearch is the ability to keep track of the amount a charity has raised. Users only have to enter "The Myositis Association" and click the "amount raised" icon on the GoodSearch homepage.




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Fabio fighting for families with myositis

The one and only Fabio—cover model for thousands of romantic novels, actor and author—has added the fight against myositis to his causes. Fabio is a unique worldwide personality,

and through the experience of a close family friend who has inclusion-body myositis, Fabio learned the hardships this disease can place on a family.

After becoming aware of the challenges a small organization representing a rare disease faces in trying to create awareness and raise funds for research, Fabio readily agreed to help



The Myositis Association however he can. Fabio is no stranger to philanthropy and fighting for causes. He has raised funds for other health charities and is currently planning a motorcycle rally in Los Angeles to honor and help the families of those who died in the 9/11 attacks and those who have children serving in Iraq and Afghanistan.

The addition of Fabio's help to TMA's efforts in Washington and elsewhere will attract more media attention to the needs of those living

with myositis. Other recent events, such as the inclusion of a child with juvenile dermatomyositis at the Hollywood film premiere of "Akeelah and the Bee" (see article in attached *Companion*) and TMA's legislative efforts in Washington, DC, will hasten the day when myositis is no longer a disease only known to the families unfortunate enough to be affected by it.

TMA will be announcing later exactly how Fabio will be helping. We are grateful for his willingness to pitch in, and we thank all you who, in your own way, continue to work to let others know of myositis.



Discover new energy and new friends in Orlando August 31 - September 3

Interactive, upbeat sessions with focus on health and fitness for patients, families and caregivers. What you learn may change your life, including:

- New, nationwide research that tracks promising new treatments
- How exercise can beat fatigue, depression and stiffness, regardless of disease level
- How to eat better, cope better, enjoy life more
- How fitness fanatics cope with myositis
- How to make technology work for you
- How to be an advocate with schools, jobs, health care providers and insurance companies

PLUS: joining a study • improving your swallowing • following your dreams • modifying your home • access to care • learning the basics • inspirational stories

2006 Annual Conference
O R L A N D O

THE OUTLOOK