

## Annual Conference features NIH, exercise

This edition of the OutLook has articles about the new clinical research center at the National Institutes of Health and recommendations on exercise, both from NIH experts and members of The Myositis Association. These articles introduce subjects that will be explored in much greater length at the Annual Conference in Cleveland, October 6-9.

**Michael Harris Love**, the medical advisory board member who contributed to the exercise article, will talk about what a review of recent research tells us about the importance of an exercise program in the life of a myositis patient. His session will also recommend some basic exercise strategies for people at every level of ability. He'll be accompanied in this session by **Carrie Baldwin**, a certified aquatic therapy instructor. Later in the day, both speakers will demonstrate some basics of aquatic therapy in the hotel pool. Many TMA members rely on aquatic therapy to maintain flexibility, and we hope you will find out how to get started by attending one or both sessions.

**John D. Porter**, a program director in neuromuscular disease at NIH, will present a session on "Understanding the National Institutes of Health," which will further explain what the new center means to patients. He'll also describe other resources available at the world's largest research center.

Register for the Conference at [www.myositis.org](http://www.myositis.org).

## New clinic designed for comfort and collaboration

Myositis patients and their families traveling to NIH have been watching the construction of a dynamic new clinic, one that replaces the 50-year-old clinical center formerly serving as the treatment and research center at the huge complex in the Washington DC suburbs. You won't be rushed to this hospital by ambulance after a car wreck, even if it happens right down the road in Bethesda. Patients volunteer for their stay in the Mark O. Hatfield Clinical Research Center at the National Institutes of Health (NIH). Dozens more visit for part of a day, also as volunteers, and a good number of both outpatients and inpatients are not sick, but offer themselves as the healthy population in clinical trials underway on one of the four expansive levels devoted to patient care units and laboratories.

The Clinical Center's name honors the Oregon senator who championed publicly sponsored medical research during his 30-year career in Congress. The largest research facility in the world is also, after the Pentagon to its south, the largest federal building in the capital area. Its staff and patients form an international community, speaking 40 different languages. The non-denomi-

national chapel comforts and inspires the faithful.

You can see some of the Center's dynamic architectural energy in the two-story alcoves and flexible floor plan. The visible space can be changed to fit the needs – adding hospital beds, labs, or consultation rooms – at short notice. Architects acknowledged that the future needs of research and patient care are partly unknown, and built in the possibility for sweeping changes.

The Center serves as an international example of how the proper use of space can comfort the sick and their families, and encourage dynamic exchange of ideas among the professionals who care for and study them. There are plenty of places to sit and talk in the two-story crossings of the clinical and research wings, encouraging encounters between colleagues involved in the same protocol as well as spontaneous meetings between clinical and basic science staff.

Other changes have to do with efficiency and access, with the different institutes sharing the human resources that make the Center so vital. "It's a paradigm shift in how we conduct medical research at NIH," said Fred Miller, MD, PhD. Miller, TMA Medical Advisor and Chief of the



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Dear Reader:

In this issue of *The Outlook* you will get a firsthand account of the important changes occurring at the National Institutes of Health and learn about the importance of exercise for those who have myositis. You will also read of the real-life experiences of some TMA members with myositis and the ways they use exercise and other therapies to help themselves remain active and mobile despite the disease.

As you read these, you will probably be thinking to yourself “this is nice and encouraging, but where is the cure?” That is the \$64,000 question we all want answered.

Although we don’t have a cure yet (or even fully understand the cause of the disease) there were two milestone events earlier this year at TMA that are much like the opening of the new Clinical Center at NIH. The Myositis Association’s Medical Advisory Board has grown over the years to now include twenty of the foremost experts worldwide, specifically knowledgeable about myositis. Yet, because of the expense and geographic distance, they had never all met face-to-face. Their meetings had been via remote conference calls limited in duration. In early January, 2005, TMA was able to bring all of these experts together face-to-face in Washington for an entire day. Later in the month, we were able to bring together another set of experts to specifically focus on inclusion-body myositis over two days. These meetings were made possible by the generosity of a TMA member who had the financial means and determination to see that these experts had an opportunity to talk in person about myositis and research aimed at finding better treatments and a cure without time constraints.

Neither of these meetings unlocked the key to this mysterious disease. But as I watched these experts interact and share knowledge, it was clear progress was being made. There was information being transferred from one great mind to the next and you could see there were light bulbs going off in the heads of these experts as they discussed possible causes of why things happen the way they do in myositis.

This type of information sharing will now also be facilitated at NIH with the opening of the new Clinical Center.

It is these sorts of formal and informal exchanges among experienced researchers and young investigators that will lead to progress and a cure. It will not happen overnight, but it will happen.

There is hope!

A handwritten signature in black ink, appearing to read 'Bob Goldberg'.

Bob Goldberg  
Executive Director

# MESSAGES FROM MEMBERS

TMA members discuss exercises that work for them

## Benefits of water therapy

I have had severe PM for 13 years and feel that I can benefit both physically and mentally from aquatherapy. Does anyone have any recommendations for me? – *Yvonneh/PM*

I have done aquatic exercise for eight years and highly recommend it. I firmly believe it has kept me mobile. – *Dorris/IBM*

If you find that the insurance won't cover it, I would recommend checking out your local YMCA. I found a great conditioning class at my Y, plus I qualified for an extremely reduced membership rate. As far as I know, most YMCAs have financial aid programs. – *Kristin/DM*

## Yoga

I started yoga four years ago and continue to do it 2-3 times a week. I am in remission (so that helps), but I think it has done me a world of good, both mentally and physically. I started because the yoga was almost exactly the same exercises as my physical therapist was recommending. If you have a good yoga teacher you will stretch almost every muscle in your body. A good yoga teacher will also help you modify every position so that you can do yoga even if you are in miserable shape. I recommend yoga, but I would make sure you have a good teacher and start in a beginners' class. – *Tom/IBM*

I do yoga almost daily and, like some of the others, find it helps me emotionally as well as physically. I too am in remission but started when I wasn't. The increased flexibility and balance were huge for me! – *Pastor Deb/DM*

I'm so glad you mentioned the yoga from our conference (in Las Vegas) because that was something any of us could do. It's not traditional on-the-floor yoga, which made it much easier. If I'm correct everything was done right in your chair! I still do some of the stretches she taught us. They are amazing. I still have problems with the floor exercise; getting up and down after all that stretching was very hard. Maybe time and practice would make a difference. I guess I'm just so satisfied with my water workouts that nothing can compare anymore. My suggestion is to take your time and find what works best for you. – *Kristin/DM*

## Passive exercises

While resistance and muscle-building activities were definitely out, my doctor set me up with therapy that simply worked range of motion and joint movement, no active participation on my part. I found this to be invaluable in regaining my mobility. It didn't help the muscle loss, but it saved my joints that were threatening to become frozen and, as I began to regain strength, allowed me to smoothly resume many movements and activities that had been beyond my ability for a while. It also seemed to help me with the shakes and many aches that were coming from my 'funny' walk, which was based on the joints becoming problematic due to lack of use. – *Sdiedre/PM*

## Help in getting up

In October of last year I went into rehab for 19 days. At that time I could not get off of a surface lower than a bar stool. There were several exercises that they did with me every day that specifically worked on my hips.



One of them was for me to lay on my back on a flat surface and have someone provide resistance to one leg at a time both pushing away from me and pulling towards me (leg in the air). I believe they called this modified squats as I could not squat down a lift back up while standing (still can't). The other exercise was called bridging and I would lay on my back and lift my butt as high as I could attempting to form an arch. This is very difficult when your hips are so weak and at first I had to have a spotter help lift. I would try to do sets of ten and once you get your butt up, hold it for a few seconds. One other thing that I think helped me a lot was pool therapy. In the water you can hold on to the side of the pool and do squats without the fear of falling. I did pool therapy every day. Also, walking forwards, backwards, and sideways several times across the pool will help build you legs back faster than on land. You get resistance in every direction. As always, consult your doctor before trying anything new but these are some things that got me going in the right direction. – *Troy PM*



# PATIENTS AND PROFESSIONALS JOIN FORCES TO LEARN MORE ABOUT EXERCISE AND MYOSITIS

John Matthews is a regular at the Clinical Research Center at NIH, coming in and out so often he's able to greet the staff by name. He's made the long trip from Boulder to Washington, DC, with his wife Carole every six months since his first visit, about a year after John was diagnosed with inclusion-body myositis during the long Rocky Mountain winter of 1999-2000. He sees Michael Harris-Love, PhD, TMA medical advisor and clinical specialist in the physical therapy section of the Rehabilitation Medicine Department, who measures John's muscle strength in the lab.

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**"Every patient is different and the same patient is even different from day to day."**

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Harris-Love uses his own observations as well as sophisticated force-measuring devices to mark the changes in John's muscles. This time, Matthews had agreed to allow a couple of TMA staff members to watch the elbow flexors, one of the tests that's repeated for each patient who participates in the IBM trial led by Marinos Dalakas, MD, Chief of Neuromuscular Diseases at NIH. As Harris-Love helps his patient off the low bench used for testing, I request some ideas on helping an IBM patient stand up. "Ask him," Harris-Love suggests. "Mr. Matthews is the expert. We learn from him."

That's the heart of the matter, says Lisa Christopher-Stine, MD, a rheumatologist and instructor at Johns Hopkins University, who comes to the lab to learn more about muscle strength testing from Harris-Love: "People like Mr. Matthews have taught us what we know about the course of myositis in human

patients." John Matthews is in what's called a "natural history study." Since there are as yet no effective treatments for IBM, the study documents the progress of the disease in hope that the information gathered will lead to a better understanding of IBM.

Matthews told us his initial experience with IBM was dramatic.

"Although I may have been gradually getting weaker, the first real sign that anything was wrong was when I began to fall. There was no warning or anything – I'd just come crashing to the ground. That really got my attention." He was quickly

diagnosed after the falling incidents, put on a short regimen of prednisone, and stopped after experiencing the side effects without improvement.

Seeing that her husband was faced with a rare disease with no treatment options, Carole Matthews searched the Internet for a trial her husband could join. She found the NIH study, made several phone calls, and shortly afterwards, the Matthews were on a plane to Washington. On his first visit, Matthews was examined again, and his diagnosis confirmed. He was a good candidate for the study and agreed to return twice a year. While he was there, he was also given information about his disease, including fall prevention and coping with swallowing difficulties.

Harris-Love and his colleagues at NIH often consult with physical therapists designing exercise programs for myositis patients all over the world. Matthews had worked with a physical therapist at a medical fitness center in Boulder, and his own exercise program was working well for him. "I hadn't exercised for years," he said. "So in some ways I actually

feel in better health than before I was diagnosed." Most days, Matthews puts in an hour or so of gentle exercise followed by a warm shower. "It's mostly stretching and flexion," he said. "I have a walking routine and a routine I do in my home." Matthews had retired from his job as a supervising engineer in 1996. He hurt his ankle in a recent fall, so he also has specific exercises for rehabilitation of that joint. "I am sure the exercises I do help me," Matthews said. "I want to do everything I can to hold onto my muscle strength and keep as flexible as possible as long as possible."

Physicians are becoming more aware of the benefits of exercise for myositis patients, said Harris-Love; still, sometimes it's slow going. "We often see patients whose doctors have never even discussed exercise with them," he said. Harris-Love, Christopher-Stine and Galen Joe, MD, staff physiatrist in the Rehabilitation Medicine Department at the Center, speculated that physical activity temporarily raises blood CPK levels (one of the measures of inflammation) and this may have discouraged physicians from recommending exercise to their myositis patients.

Harris-Love said he's sometimes asked for a set of exercises that will apply to every patient. "That's just not possible," he said. "Every patient is different and the same patient is even different from day to day, depending on fatigue and possible flares." Within reason, every patient – even someone experiencing a flare – can benefit from exercise, even if it's just some gentle stretching, said Joe. The exception might be someone who has calcinosis or a painful skin flare in dermatomyositis made worse by heat or sweat.

Physicians and physical therapists are now encouraging patients to try to

do some physical activity every day. "If you're in a flare, it might be important to do what you can, even if it's greatly modified," Harris-Love said. "Especially when you're taking high doses of prednisone, you'll want to prevent prednisone-related osteoporosis." Physical therapists will ask what a patient must do in the course of a day. "If they are already doing a great deal of physical exercise taking care of a home, a garden, children and a lawn, they'll need to be able to continue to do these things," Harris-Love said. "That's when a physical therapist might take a look and see what might be added to these normal routines." He always recommends starting slowly and gradually building.

How to tell if you are overdoing it? "A good measure is the length of time it takes to recover from the exercise you do. You should be rested after a night's sleep." He suggests that patients ask their physicians for a session with a physical therapist. "In today's climate we try to teach patients the tools to start an exercise program they can stick with at home," Harris-Love said. "We won't be able to keep working with them in most cases (because of insurance coverage), so the important thing is for us to quickly give them the tools they'll need.

*Harris-Love will talk about recent research regarding myositis and exercise and give some exercise basics at the Annual Conference. He'll also present an aquatic exercise class with aquatic specialist Carrie Baldwin.*



#### Web extras

Harris Love's presentation from San Diego: [http://www.myositis.org/pdf/love\\_exercise\\_article.pdf](http://www.myositis.org/pdf/love_exercise_article.pdf)

Yoga – Sandra Dunphy's 2004 Conference presentation: [www.myositis.org/pdf/yoga.pdf](http://www.myositis.org/pdf/yoga.pdf)

## Ancient art has new meaning for those with myositis

*Sandra Dunphy (see "Good Days and Bad," page 7) recommends yoga for those searching for an exercise program and explains a little history, along with the following guidelines.*

Yoga is an ancient art and science from India, originally designed to strengthen and align the body and quiet and focus the mind for meditation. Although more than 5,000 years old, yoga has been successfully adapted to the needs and lifestyles of today's modern world.

The word yoga means, literally, "to yoke or join." In the practice of yoga, we join and integrate the mind, body, and spirit into one aligned and cohesive unit. Contrary to popular belief, there is more to yoga than just sitting around with legs crossed and saying "ummmm" for hours on end. The physical side to yoga usually involves doing poses that challenge you to move muscle and bone in ways that provide an overall benefit to the body.

There are many types of yoga and each should be explored and tried so that you find the "right" yoga for what you are trying to accomplish. Yoga can be an integral part of an overall healthy exercise portfolio - improving strength, flexibility (range of motion), balance and allowing the practitioner to de-stress. It lets the body relax, facilitating sleep, which allows the body to recover from daily activities.

Yoga also enhances and improves our daily activities, providing better body awareness and focus.

In order to begin the practice of yoga, you should consult your physician in advance to determine what precautions you might need to take in order to begin learning yoga.

Yoga classes are available at YMCA's, local athletic clubs, spas, through college programs, and sometimes through churches. How does one find a yoga class suited to one's needs? Take a class at any facility that offers trial classes to see if the class meets your needs. The instructor should ask and be very interested in any special needs that you might have. If your instructor doesn't respond to your questions, find another instructor. The best yoga instructors will want to do research on myositis if you tell them that is what you have. They will be

able to tailor a yoga program to your needs and what you are trying to accomplish.

If you can't find this in a group class, consider taking a couple of private lessons and ask the instructor

to give you a written program of poses you can do on your own. Remember, find a routine you can do every day – on good days AND bad days. Pretty soon you won't even think about whether you're having one or the other because you can handle anything!



## CLINIC, from cover

Environmental Autoimmunity Group at NIEHS, moved into the newly constructed building, along with the other 1300 physicians, dentists, and PhD researchers; 660 nurses; and 570 other health care professionals now on site. Miller explained that “translational research” – findings from research in basic science “translated” into treatment for specific conditions – is the main business of the Center. Every patient there contributes in some way to what researchers know about the natural history and treatment of disease, Miller said.

The Center trains physicians and boosts collaboration in both formal and informal ways. Lisa Christopher-Stine, MD, MPH, a rheumatologist and an instructor in the division of rheumatology at Johns Hopkins University about 50 miles away, often makes the trip around the beltway to observe and assist Michael Harris-Love, PhD, a clinical specialist in the physical therapy section of Rehabilitation Medicine, when he tests myositis patients (see *Exercise*, page 4). She was delighted to find a group of NIH researchers so involved with the rare disease. “When I had three patients with myositis in my first few months as a fellow, it just really got my attention,” Christopher-Stine said. She keeps up with what Harris-Love is doing in measuring muscle strength. Both Plotz and Marinos Dalakas, MD, Chief of Neuromuscular Diseases, NINDS, send patients in their research studies to the lab for Harris-Love and his colleagues to test.

NIH clinicians and researchers routinely serve as resources to colleagues and their patients all over the world, especially in the case of a rare disease like myositis. Miller and Lisa Rider, MD, the Deputy Chief for the Autoimmunity Group, recently played key roles in groups collaborating on criteria for assessing muscle damage and improvement in adult and juvenile

myositis patients. Some of the myositis trials involve no treatment, but simply collect data on the disease progress. This type of study is called “natural history” research.

Researchers sometimes wait a long time to find enough patients with a rare disease to conduct a meaningful study. The NIEHS autoimmunity group currently seeks volunteers for two important studies: one compares twins or siblings with an autoimmune disease like myositis to a twin or other sibling who does not have the disease; another is a natural history study for both adult and juvenile onset myositis.

### What publicly funded research means to you

There’s no question that research into myositis – and other diseases that are rare or unresponsive to treatment – would be tremendously lacking if left to the private sector. When a patient checks into the Clinical Center for a study involving a new drug, he or she will not be receiving those endless and confusing insurance statements and hospital bills in the mail.

Treatment is free, and potential trial participants know exactly what to expect – in fact, many of them made suggestions for the Clinical Center. Families can also find resources for children ([www.childrensinn.org](http://www.childrensinn.org)) and other family members (<http://clinicalcenter.nih.gov/familylodge/index.shtml>). Patients – some of whom have “lived” at the center for almost a year – recommended large, low windows with a view of greenery; adjustable shower heads; Internet access at every bedside; a library; and an exercise room. These were incorporated into patient rooms, which can also be expanded and constricted according to the circumstances.

NIH formerly required physician referral for a patient to enroll in a trial but revised this requirement in response to patient demand, and now

a great many first contacts are made by patients themselves. In some cases, a patient has run out of any other hope for treatment; in others, a patient with a rare disease simply wants to add to the body of knowledge available to scientists.

When you volunteer for a trial, you play a vital part in the process that will end in a cure, like the following research successes supported by patients:

- First cure of a solid tumor with chemotherapy
- First chemotherapy for childhood leukemia and Hodgkin’s disease
- Discovery of evidence of a genetic component in schizophrenia
- First use of nitroglycerin for acute myocardial infarction
- First use of hydroxyurea to treat sickle cell anemia
- First gene therapy
- First successful replacement of a mitral valve
- First use of AZT to treat AIDS
- Development of screening tests for AIDS and hepatitis, which reduced the transmission rate of transfusion-transmitted hepatitis from 30 percent to near zero.

For more information about the Clinical Center, visit [www.cc.nih.gov/ccc/crc](http://www.cc.nih.gov/ccc/crc).



### BEHIND THE SCENES .

A fascinating story of the 50 years in NIH history that changed the course of research is *Building 10 at 50*, and it’s available without charge from [www.nih.gov/news](http://www.nih.gov/news). In it, author Pat McNees records her interviews with hundreds of patients and research scientists, including former NIH director Harold Varmus, who fought for the new Center when the future of research itself was in doubt.

## CURRENT RESEARCH STUDIES AT NIH

The following is a list of myositis studies currently ongoing at the National Institutes of Health (specific center listed). For more information on these and other studies visit the NIH site at <http://clinicalstudies.info.nih.gov> or TMA's listing of current clinical trials at [www.myositis.org](http://www.myositis.org).

*Alemtuzumab and s-IBM:* Effects of a T Cell-Depleting Monoclonal Antibody, Alemtuzumab, in Patients with Inclusion Body myositis: A Pilot Clinicopathological Study; NINDS.

*Twin-Siblings Study:* Pathogenic Studies In Families With Twins Or Siblings Discordant For Systemic Rheumatic Disorders; NIEHS.

*s-IBM:* Study of Immune Dysregulation in Patients with Sporadic Inclusion Body myositis (s-IBM); NINDS.

*Infliximab and DM/PM:* A Randomized, Double-Blind, Placebo-Controlled Trial of Infliximab In Patients With Dermatomyositis and Polymyositis; NIAMS.

*Apheresis:* Collection Of Blood Components Using Apheresis From Patients With Rheumatic Diseases And Healthy Volunteers; NIAMS.

*Dysphagia:* Effect of Task on Oral Pressure Dynamics During Swallowing; Clinical Center.

*Natural History Study:* Studies in the Natural History and Pathogenesis of Childhood Onset and Adult Onset Idiopathic Inflammatory Myopathies; NIEHS.

*Natural History of PM, DM:* Studies on the Natural History and Pathogenesis of Polymyositis, Dermatomyositis, and Related Diseases; NIAMS.

*Rituximab and myositis:* This study is not yet recruiting patients, but check the web sites listed for updates as information becomes available. Recruiting is scheduled to begin in the fall of 2005.

**Contact:** Email [prpl@mail.cc.nih.gov](mailto:prpl@mail.cc.nih.gov) or call 1-800-411-1222.

## Good days and bad: an exercise program that works

Sandra Dunphy, an aerobics and yoga instructor, will be at the Annual Conference in Cleveland in October, to lead a basic exercise class for people of all levels of ability, including those in wheelchairs. Following up on last year's Annual Conference sessions, "Use it or Lose it," presented by Gregg Middleton, MD, who endorsed regular exercise for patients with myositis and other chronic diseases Dunphy reiterates:

- Use it or lose it. Not using your muscles may lead to further muscle loss.
  - Muscles require work to recover; resting does not lead to stronger muscles, it leads to weaker muscles.
  - Develop a routine that you can do on the good days AND the bad days. Don't be tempted to overdo on the good days, but don't slack on the bad days.
  - The less you do, the weaker you get; the more tired you get, the more pain you have.
- Dunphy's "ideal" exercise regimen includes: aerobic training, resistance training, flexibility (range of motion) training, and work on balance. At the conference, she will demonstrate a number of easy-to-learn exercises that can be done almost anywhere. The list of exercises Dunphy recommends will be available in the conference notebooks. Some tips from Dunphy, who also teaches wheelchair exercise to seniors:
- Do what you can. Add repetitions to make the workout more difficult. Don't overdo.
  - More repetitions and less weight give you a great workout without exhausting the muscles.
  - DO NOT WORK YOUR MUSCLES TO EXHAUSTION. You should feel that you could still do a few more repetitions when you finish your workout.
  - Try doing your workout to music. It makes it much more fun.
  - Work out with a partner whenever possible. YUK IT UP !

Check with your doctor before beginning or changing your exercise program.



# Volunteers needed for new diagnostic study

**NAME OF CLINICAL TRIAL/STUDY:**  
Electrical Impedance Myography (EIM)  
in NMD

**PURPOSE AND RATIONALE:**

The Department of Neurology at Beth Israel Deaconess Medical Center in Boston are conducting a research study involving the development of new technology for the assessment of muscle weakness. Their goal is to develop a new, painless, noninvasive, diagnostic technique called "EIM" (electrical impedance myography) that will be a useful tool in initially evaluating and following patients with neuromuscular disease. The investigators expect that this technique will allow them to follow disease progression in a quantitative way that is not currently clinically available.

**STUDY DETAILS:**

Testing will involve a history and physical examination, EIM testing, quantitative strength testing, girth measurements of the affected limbs, and ultrasound of muscles. Participants will be asked to

return every three to six months for approximately four years. Each visit is expected to last two to three hours. Participants will be reimbursed for their time and for parking. There is no reimbursement for travel costs to the study site. Initial results are expected by July 1, 2005.

**TARGET NUMBER OF PARTICIPANTS:** 25-50 patients in each disease classification

**RECRUITMENT STATUS:** Open

**ELIGIBILITY REQUIREMENTS:**

*Inclusion Criteria*

Participants must

- be at least 18 years old
- have one of the listed neuromuscular diseases (polymyositis, dermatomyositis, inclusion body myositis)

*Exclusion Criteria*

Participants must not

- be less than 18 years old

- require hemodialysis or peritoneal dialysis
- have an implanted pacemaker or cardiac defibrillator
- be pregnant

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