

## DR. ASKARI EXAMINES A CENTURY OF MYOSITIS

There's a great deal about myositis that remains a mystery to this day, but a look back at the early days of diagnosing and treating myositis illuminates the struggle to understand the disease over many years.

Ali D. Askari, MD, professor of medicine and chief of Rheumatology at the Case School of Medicine in Cleveland, gave a fascinating glimpse of myositis history at the Annual Conference, beginning with three fatal cases at the end of the 19<sup>th</sup> century.

In 1887, Drs. Ernst Wagner and Heinrich Unverricht wrote about three patients who died of a strange disease affecting multiple muscles. They labeled it polymyositis. Several years later, the German doctors found that some of the patients who seemed to have polymyositis also had skin symptoms that included inflamed patches and rashes. They used the term dermatomyositis. The physicians, both well-respected in Germany and Eastern Europe, were honored by some of their colleagues calling the disease with skin involvement after the two doctors: "Wagner-Unverricht Syndrome."

Early in the 20<sup>th</sup> century, W. Steiner reviewed 28 cases of polymyositis and noted that three patients did not have the skin lesions. Names like pseudotrichinosis, menopausal dystrophy, and late onset muscular dystrophy were used for these cases, Askari said. Not much more was written until the '50s, when FJ Nattrass suggested that some cases of late onset muscular dystrophy were actually polymyositis. By 1958, J.

Walton and R. Adams summarized the situation, saying that polymyositis and dermatomyositis can occur independently. They described the proximal muscle weakness, the pattern of one-time or chronic courses, and also the related medical problems that can occur along with the disease.

Finally, in 1975, A. Bohan and J. Peter established the diagnostic criteria that has been used for decades: symmetrical proximal muscle weakness with or without dysphagia and respiratory weakness; elevation of the muscle enzymes in the blood; the changes observed by electromyography and biopsy; and (in the case of dermatomyositis) the typical skin rash.

If the understanding of the disease process seems vague, treatment was haphazard at best, Askari said. Up until the 1940s, without the arsenal of modern corticosteroids, immunosuppressants and immunomodulators, physicians battled the disease with antibiotics, wheat germ (for its high vitamin content), quinidine (an anti-malarial found in certain trees and similar to quinine), and neostigmine (a muscle stimulant).

In 1951, after the discovery of cortisone, G. Shy and D. McEachern

reported dramatic improvement in five patients receiving cortisone after being diagnosed with "menopausal muscular dystrophy." In 1958, Walton and Adams suggested the use of steroids in every patient with polymyositis.

Steroids quickly became the accepted treatment, and physicians worked for the effective level in individual patients. In 1979, P. Hudson and Walton suggested high doses (80 mg) of prednisone each day for treatment of polymyositis and dermatomyositis, saying lower doses and shorter periods were unpredictable.

Along with advances in treatment were advances in diagnosis. In 1950, E. Christensen and H. Levison described observing inflammation in the muscle biopsy; and by 1958 Walton and Adams emphasized the significance of biopsy findings and description in making a diagnosis of myositis.

In 1984, Arahata described distinctions between polymyositis and dermatomyositis in the muscle biopsy, discovering critical differences that would allow later drugs to have more specific targets. In 1991, Dr. Marinos Dalakas refined the criteria by Bohan; and the criteria continues to be refined.





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Dear Reader:

This issue of *The OutLook* highlights some of the very interesting sessions of TMA's 2005 Annual Conference. We will soon be mailing our *Extra* issue of *The OutLook*, which will focus on the Conference's Medical Panel presentations and other sessions that conveyed information about myositis and treatments.

However, in this issue we cover the sessions that focused on the emotional impact of the disease; the history of myositis and its treatments; how the National Institutes of Health handles myositis research; and how humor can be an effective therapy for myositis and other chronic diseases.

Because many TMA members are physically not able to travel to the Annual Conference or afford the trip, we hope this issue and the *OutLook Extra* will communicate some of the valuable information and insights and give you a feel for what the Conference was like for those in attendance.

We are now making plans for the 2006 Annual Conference and expect to announce the location and dates early in 2006. We will try to make it as convenient and affordable for as many as possible. If you have suggestions or questions, please let us know.

We hope to see many readers of *The OutLook* at the Annual Conference in 2006!

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



# Dr. Buckman on humor, coping, kindness

Humor is an acknowledgement that we have shared experiences, Dr. Robert Buckman told an enthusiastic breakfast crowd at TMA's Annual Conference. Buckman, a humanist, actor, physician and dermatomyositis patient, explained that common understanding of what is usual or expected is necessary before we can depart from it. "This departure is what makes it humor," Buckman said. He told a simple child's joke: "instead of 1,2,3,4, a child might say 1,2,3, banana, and think it's a great joke." This shows an early understanding that breaking an expected sequence is funny. The child's joke also reflects the very human desire to find delight and surprise in words and stories.

In our response to humor we confirm that we know what's expected and so recognize the joke, or the unexpected. But it gets more complicated than that, he said. A joke: If a man speaks alone in the forest with no woman around, is he still wrong? This joke works only if everyone understands that many women are in the habit of correcting men; and only because the butt of the joke (men, he says) are not a group that has suffered more than others from hatred or persecution. Another joke: "Everyone, everywhere has a sense of humor unless, of course, they're Scottish." Funny because everyone has an image of the earnest Scot – probably more so in Britain, where Buckman grew up – but also because no one seriously hates Scottish people. Humor also works best when we are trying to deal with something that frightens, frustrates or fascinates us: airline travel, illness, sex or even mothers-in-law. Especially when things frighten us, humor helps us to somehow get a

handle on them, he said. In his work as an oncologist, he's observed cancer patients who find comfort in joking about their disease or treatment. He tells a story: "A breast cancer patient found that swimming relieved some of the pain after her mastectomy, and she had an artificial breast fitted into her swim suit. During one of her sessions in the pool, it dislodged and was bobbing about in the pool. 'It's doing the breast stroke,' the amused patient responded when an embarrassed friend pointed this out."

Once we understand humor, how do we go about using it as one of the tools to improving our life with chronic disease? "Laughter actually releases endorphins that decrease pain," Buckman said. "Once when I

was very ill, I hobbled to the cinema and spent 90 minutes free of pain." A great many symptoms of a number of diseases are temporarily relieved by humor and laughter, he said, not only by the endorphins but sim-

ply because of the distraction. He rejects the notion that laughter or other responses to humor are able to change the disease course, however: "This type of thinking ends up being harmful to the patient. When he or she hears that other people have conquered their cancer by spending hours in a 'humor room' or otherwise being entertained by funny films or books, the patient ends up feeling like a failure because this doesn't work in his case. It's just another thing that he's to blame for."

During his long, serious battle with dermatomyositis, Buckman said he found it helpful to find irony in his own situation. For instance, at one point in late Fall his doctor confided in his wife that he might die before Christmas. When his wife talked this

over with him, his first thought was "this will certainly spoil the holidays." His second thought was to mock himself for this reaction: "Hey, I'm Jewish and an atheist – what on earth brought on that response?" Buckman observed that when we're trapped in a situation where we have no control, finding the humor in it restores a little control, letting us step back and see ourselves in a bigger picture.

As a physician, he often jokes with his patients, he said, but only after they've had a great deal of evidence that he takes their disease very seriously. One couple came in with a list of questions: what about diet, what about exercise, what about sex? Buckman spent a great deal of time seriously answering the first two questions, when it came to sex, he said "That's the best offer I've had all day," and the couple cracked up. He explained that it would have been entirely inappropriate for him to make that remark early on: "I couldn't have done this until I had won their trust in terms of my concern about the illness," he said. "As it was, this became a wonderful joke that we laughed about each time I saw them." In most cases, he said, the physician should take his cues from the patient about whether humor should enter the relationship.

Buckman believes that humor is a way in which we also acknowledge our own growth and perspective as we go through our lives. A question from the audience asked him what you should do when someone appears to be insulting your deepest beliefs with a joke: "Try once just not to be offended," he said. "You'll find eventually that you'll be able to see humor in a non-threatening way. There really is nothing in life that can't be examined from a humorous point of view, and perhaps our deepest beliefs are the ones that require the most humor."





# Life with chronic illness: searching for meaning

Chronic illness can put the patient in a vicious circle: stress makes almost every illness worse, but chronic illness is one of the greatest sources of stress we're likely to face in our lifetime, and its impact is daily. What's a patient to do? Two Ohio psychologists with a deep interest in mind and body medicine provided some insight at the Annual Conference in Cleveland.

Dr. Kathleen Ashton, health psychologist at the Cleveland Clinic Foundation and representative from the American Psychological Association's new campaign about Mind-Body Health, explained that Mind-Body Health is the effective balance of physical and psychological health, and emphasized the physical manifestation of stress. It's linked to the six leading causes of death — heart disease, cancer, lung ailments, accidents, cirrhosis of the liver, and suicide, she said, and 43% of all adults suffer adverse health effects from stress. Two-thirds of all office visits to family physicians are due to stress-related symptoms, according to the American Academy of Family Physicians.

What happens when your body is flooded with the chemical byproducts of stress? Adrenaline increases, muscle tension increases, heart rate and blood pressure increase, breathing increases, and blood flows to your large muscle groups, Ashton said. Both she and Dr. Craig Travis, director of behavioral sciences at Mount Carmel Family Medicine Residency in Columbus and chairman of the Ohio Psychological Association Professional Practice Committee, examined the understandable stressful effects of knowing you have a chronic illness.

"There is no disease that you either have or don't have — except perhaps sudden death and rabies. All other diseases you either have a little or a lot of," said Dr. Craig Travis, quoting famous epidemiologist Geoffrey Rose. It's all relative, but the chronic illness — whether you have a little or a lot — has distinguishing features: It's permanent, it's the cause of frequent and costly

medical intervention, and it causes enormous change in almost every area of your life, in your job, your relationships, your interests, your position in the family and your goals.

Except for cooperating in your treatment, chances are there's not much you can do about your disease itself, Travis said, but your attitude will influence the ways your disease affects your feelings about yourself. The painful questions you have at diagnosis and in many stages afterwards are about your future, in particular your dignity, self-image, sense of control and independence. Other fears are even more hurtful: rejection and abandonment, isolation and death.

**"If you are distressed by anything external, the pain is not due to the thing itself but to your own estimate of it; and this you have the power to revoke at any moment." — Marcus Aurelius**

When you first learn about your diagnosis, your biggest fear is likely to be about your mortality, but usually that's followed by a time where you're optimistic but just not sure how to proceed, Travis said. On the one hand, it's healthy to try to carry on with normal life, but there's the risk of over-extending your self. On the other hand, feelings of helplessness might eventually lead you to become overly dependent. Sometimes quickly, sometimes more slowly, patients find their way through, using remarkably similar steps:

- They find meaning in understanding the scientific basis of their illness.
- They rethink priorities.
- They regain sense of control by managing their own treatment and symptoms.
- They restore their own self-esteem, often by understanding that others also have terrible burdens.

Travis cautioned patients about spending their dwindling store of energy on wishing that the disease hadn't happened. He said moving towards adaptation means avoiding some of the myths that we commonly hold about illness — that your life is defined by your illness; that being healthy means being alone; that feeling pain means being destroyed by

## NOTES FROM DR. TRAVIS

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|--|--|
| <b>M</b> Manage your symptoms and emotions       | <b>A</b> Acceptance of your symptoms & yourself          |
| <b>Y</b> You are the best judge of how you feel  | <b>T</b> Treatment (get actively involved; take control) |
| <b>O</b> Optimism—Positivity mind set            | <b>T</b> Take care of yourself                           |
| <b>S</b> Support—count on others                 | <b>I</b> Maintain your Integrity                         |
| <b>I</b> Integration of body-mind-spirit         | <b>T</b> Take Time to adjust                             |
| <b>T</b> Transition—your roles will change       | <b>U</b> Understand your emotions                        |
| <b>I</b> Identity—you are MORE than your illness | <b>D</b> Develop adaptive coping strategies              |
| <b>S</b> Self-interest is important              | <b>E</b> Express yourself                                |



pain; that all illness is the result of negativity and that true change is impossible.

The antidote to these negative myths is to rediscover a sense of meaning in something outside complete health. Create a work, perform a worthwhile deed, have a new experience or a new relationship.

The attitude we take toward unavoidable suffering actually causes personal growth, Travis said. Many people experience deepening self-knowledge, discover a previously ignored relationship with God, find the opportunity to grow spiritually beyond themselves, find their relationships with others are deeper, and learn to live within the mysteries of life. But it's a huge journey to get to these areas of personal growth, he acknowledges, with physical and emotional burdens weighing down every step, including fatigue, sleeping problems, family complications and other factors born of both the illness and the

## **"Pain is inevitable, suffering is optional."**

— Anonymous

accompanying stress. Pain itself is not just a symptom, but can also cause further physical and emotional complications, and can sometimes be modified by the patient's reaction. This belief — that your mind can increase or reduce the way your body experiences pain — has a long history. Travis quoted a couple of famous sayings, highlighted on these pages.

The placebo effect is not just a control in a medical trial, but a time-honored acknowledgement that we can sometimes improve our physical condition simply by believing that we can. By the same token, the placebo has an "evil twin," Travis said. The placebo effect harnesses the power of positive thinking and helps heal; the "nocebo" refers to the effect of negative beliefs and expectations, which can actually cause harm, whether in a specific illness or just as a general

approach to life. Travis used another quote: "Belief sickens, belief kills, belief heals," by Robert Hahn, writing in 1995 in *Sickness and Healing*.

To shorten the time that you're affected by any adverse event, Ashton talked about developing resilience, the ability to "bounce back" (see box) after a stressful event. Although psychologists recognize that some people seem to have more resilience than others, it's possible to increase your own resilience by developing caring and supportive relationships, nurturing your capacity to make realistic plans, keeping a positive view of yourself, honing your problem-solving skills, and working toward healthy management of strong emotions.

Suppose you find yourself "stuck" in a negative cycle, either expecting the worst known outcome or even what Travis calls "catastrophizing" or expecting an outcome that's many times worse than the one your health care team predicts. You may benefit

from what psychologists call "cognitive-behavioral therapy," taught by a psy-

chologist, usually in a group setting meeting regularly for a month or two. These organized sessions help patients learn about their own emotions and gently lead them away from an obsession with "what if" back to the reality of their situation and the things they can control in their lives. If a patient finds he/she is remaining in a depressed or anxious state, the therapy can be very helpful.

One technique for people with chronic illness to move toward a fulfilling life is to know exactly what their goals are, said Travis. Regardless of what their lifetime goals were and continue to be, they have some goals in common concerning their illness: to improve their functioning as much as possible, to minimize distressing symptoms, to cope with the psychosocial stress of pain and disability and to prolong

their lives with treatment of their disease and prevention of other diseases and injuries.

It is important to understand that chronic illness is a big, powerful thing, Travis said, but you can learn skills to help you be in control rather than out of control. "You can be a participant, or you can be a victim; you get to choose which. Choose wisely."



## **PRACTICE YOUR BOUNCE**

*Tips from Dr. Ashton*

### **Make connections**

- Develop good relationships with family and friends
- Communicate your feelings

### **Accept change as part of living**

- Accept limitations
- Avoid seeing crises as insurmountable problems
- Look to the future and how to implement changes
- Develop realistic goals and move toward them
- Visualize your goals
- Give yourself reinforcement for accomplishing small tasks toward a goal
- Don't focus on what you can't change

### **Nurture a positive self-image**

- Focus on your strengths
- Look for opportunities for self-discovery

### **Keep things in perspective**

- Consider the broader context
- Maintain a hopeful outlook
- Expect that good things will happen

### **Take care of yourself**

- Exercise
- Eat healthy
- Pace yourself
- Relax



# Music as a time-honored therapy

When musicians set up their woodwinds and strings in the wards of veterans' hospitals during World Wars I and II, their idea was to entertain the soldiers suffering from physical and emotional injuries, kind of like an extension of the USO clubs. It didn't take long for both the patients and the musicians to realize the visits accomplished more than filling the empty hours: Soldiers reported feeling less pain, sleeping better, and generally feeling as though they were healing faster. With the amazing growth in technology and pharmaceutical intervention, the relationship between emotional well-being, pain and healing had been slowly forgotten. The soldiers' experiences were widely discussed, and the use of music as a healing tool was formalized when the first degree program for music therapists began at Michigan State University in 1944.

Now there are dozens of approved music therapy courses at colleges and universities. Music therapists pass an exam to qualify as MT-BC (Music Therapist-Board Certified.) In music therapy, patients do more than just listen to music. Music therapists also guide them in writing music or lyrics, discussing music they like or respond to, and helping them select the music that helps them with relaxation or energy, said Lalene Kay MT-BC, director of the Cleveland Music Therapy Consortium. Part of music's appeal, said Kay, is its presence in our lives from a very young age. "We use music in celebrations of all kinds, large and small," Kay said in her lunch-time presentation at the Annual

Conference. Kay explained that pain becomes more intense when it is the patient's only focus; and she talked about using music in settings where uncomfortable, painful or boring procedures take place. "In these settings, music is a distraction," she said. "It gives the patients something to focus on, as well as lifting their spirits."

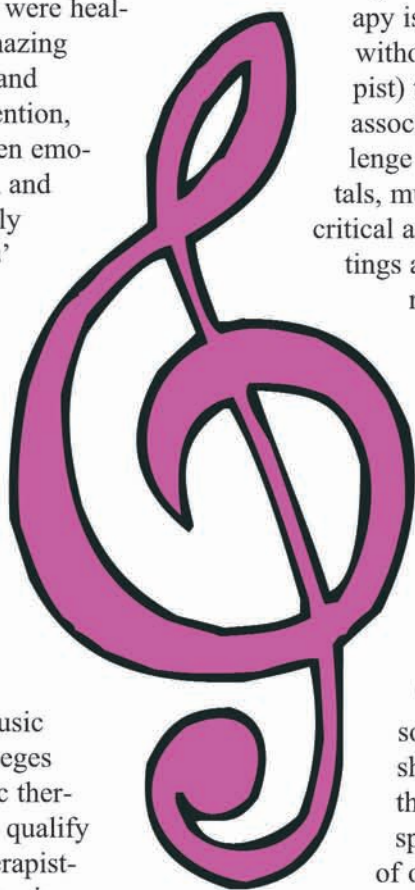
In people with chronic illness or disability – whether or not they have pain – music therapy is often used (with or without the help of a therapist) to manage the stress associated with any challenge to health. In hospitals, music is often used in critical and intensive care settings and labor rooms and nurseries as a calming influence. Studies

have also shown the value of music therapy as an effective stress-reducing and calming intervention in patients about to undergo surgery.

There are many reasons, apart from the sheer beauty of music, that music lifts our spirits. "It reminds us of our connection with other people, which is in itself healing," Kay said. The

American Music Therapy Association says music therapy has been applied in conjunction with standard medical therapy to improve a patient's overall well-being and mood, in chronic diseases like AIDS, cancer, brain injuries, and Alzheimer's Disease.

For information on music therapy, or on how to find a music therapist, go to [www.musictherapy.org](http://www.musictherapy.org); or call 301-589-3300.



## MUSIC HELPS TENSION AND PAIN

Two studies just published, one conducted in China and one in the United States, tested patients recovering from painful surgery. In both studies, patients could elect to have music played during the time immediately following their operations. Those who made the musical choice reported less anxiety and pain and lower blood-pressure readings.

Another study was done in the delivery room of a Taiwan hospital. Sixty-four women needing cesarean delivery were divided into an experimental and a control group. The group that received music therapy as well as routine care reported significantly lower anxiety and a higher level of satisfaction.

## Century,

continued from cover

Meanwhile, inclusion-body myositis was lumped in with polymyositis or a variety of other illnesses until the mid-sixties, when researchers noticed "inclusions" in the biopsies of patients thought to have polymyositis. In 1971, J. Unis and F. Sumaha coined the term "inclusion body myositis" to describe the presence of vacuoles; and in 1978, J. Carpenter described the clinical spectrum of IBM. In 1991 J.R. Mendell and others noted congo red positive material in muscle fibers, indicating that they were amyloid deposits. In 1996, Amato indicated that repeated biopsies might be necessary for the correct diagnosis of IBM.

Looking at myositis from a historical perspective increased his appreciation for what physicians have done for the past century or so, Dr. Askari said. "As you know, this is still going on," he said.





# Understanding the National Institutes of Health

TMA members often mention “NIH” in their bulletin board posts, prompting the reply “what is NIH” from newer members of the myositis community. That’s the question John D. Porter, PhD, Program Director for Neuromuscular Disease, National Institute of Neurological Disorders and Stroke (NINDS), sought to answer in his presentation at the Annual Conference. His goal was to leave his audience with a better understanding of how the National Institutes of Health is organized; how grants are evaluated; what institutes are relevant to myositis; and how investigators, advocacy groups, and patients can best interact with NIH.

So what is NIH? The National Institutes of Health is a federal agency of the Department of Health and Human Services that focuses on medical research. The 27 institutes and centers making up NIH, including the one where Porter works (NINDS), each has its own mission, budget and activities, though there are some similarities from one institute to the next. A typical institute has a director overseeing extramural (grants and contracts) and intramural (laboratory and clinical studies) activities.

“NIH is helping to lead the way toward important medical discoveries that improve people’s health and save lives,” said Porter. NIH-supported researchers investigate the causes, treatments and cures for both common and rare diseases, and look into ways to prevent these diseases. Much of this NIH-supported research is not carried out in NIH’s facility in Bethesda, MD, but in research centers around the country.

## Deciding research funding

Researchers from around the world submit about 80,000 applications to NIH each year for funding. Choosing which ones to fund is a daunting but important task, so there are specific criteria for evaluating each application.

For the first level, peer reviewers determine the technical and scientific merit of a proposed study. Important questions considered are:

- Does the proposed study address an important problem?
- Is the design of the study well-developed and appropriate?
- Are the concepts original and innovative?
- Is the researcher appropriately trained?
- Does the scientific environment contribute to the probability of success?

The second step involves a council made up of scientists and lay persons to evaluate the relevance and need for the specific research. Institute staff members then follow up with their own evaluation of the study’s relevance.

## From research to therapies

Project grants for mechanistic studies lead to a better understanding of different diseases, including myositis. For example, Steven Greenberg at Harvard received a grant from NINDS for a new model of DM. One goal of this particular study is to gain a better perspective of the disease mechanisms in DM.

Another type of research, translational research, focuses on the steps required by the Food and Drug Administration (FDA) to develop new medicines. The clinical trials look at specific treatments in a specific group. Anthony Amato, M.D., another Harvard researcher, is studying etanercept to treat DM, using 40 patients at different medical centers for his clinical study.

The different types of research are essential to finding answers to the many questions still left unanswered about all forms of myositis. Institutes and centers within the structure of NIH have varying interests, and several of these institutes play a role in the study of myositis – NIAMS (National Institute of Arthritis and

Musculoskeletal and Skin Diseases), NIEHS (National Institute of Environmental Health Sciences), NIAID (National Institute of Allergy and Infectious Diseases), and NINDS, to name just a few.

## Working with outside agencies

Program Directors like Porter work toward advancing research in a number of ways. They must keep an eye on the field and recognize the needs and opportunities that arise. Armed with this information, they contact research applicants and the appropriate institutes to develop what’s needed to move forward. Working with advocacy groups, the community, and other federal agencies remains an essential piece of every director’s job to most effectively develop and advance exciting research opportunities.

## Working with NIH

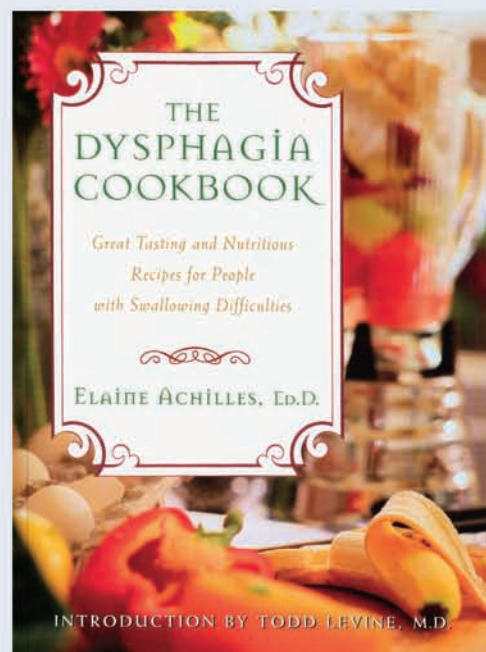
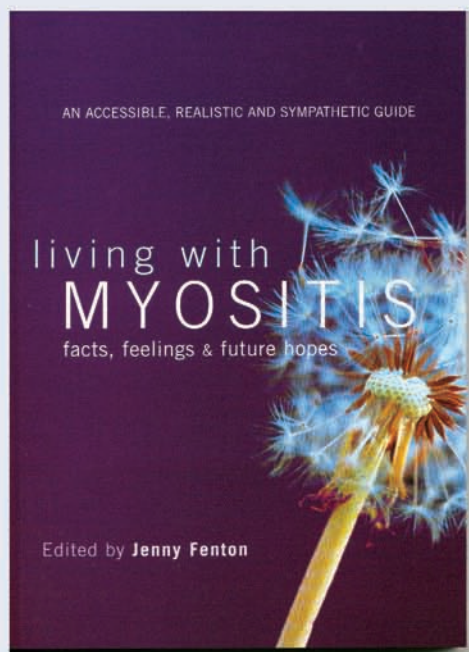
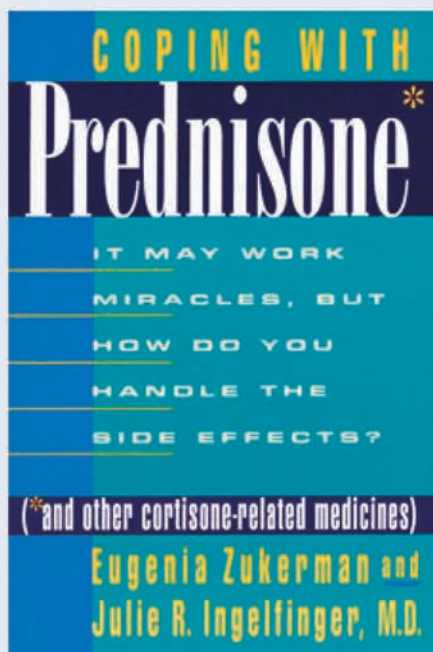
In the Summer issues of the *OutLook* and *JM Companion*, we wrote about the National Institutes of Health Clinical Center. As these articles suggested, scientists working on clinical studies rely on your help. Whether you have myositis or are a relative, researchers call for study participants to test their theories on different aspects of myositis or related diseases. Without you, research couldn’t take the next step toward answering the important and yet-unanswered questions about myositis.



## RESEARCH ONLINE

The Myositis Association lists clinical trials currently enrolling participants on its website, [www.myositis.org](http://www.myositis.org). Many of these trials are supported by NIH or take place on the NIH campus. We encourage you to look into the various studies and the possibilities that come with participating in a research study – to help you and the myositis community.





These are just a few of the great books that are available in the online marketplace. Visit TMA's website, [www.myositis.org](http://www.myositis.org), to find these and other books, t-shirts and awareness items such as ribbons and pins. Or call 1-800-821-7356 to order.



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