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Looking ahead:

Coming in Spring *OutLook*

- Myositis Center opens at Johns Hopkins
- TMA awards new round of research grants
- Research: seeking understanding and a cure

Also, coming soon!

- Chats are back! Watch for news at www.myositis.org.

Myositis research gaining momentum, attracting international attention

This is a new era of myositis research, with multi-center studies and international collaboration. That was the message delivered by The Myositis Association medical panel at the Annual Conference. Medical Advisory Board Chair Richard Barohn, MD, University of Kansas, said TMA made the right decision when TMA-funded research money was opened up to the international myositis community. "We've funded investigators from Germany, Japan and Sweden," Dr. Barohn said; and by the same token people come from all over the world to donate their time for the important work of evaluating myositis research proposals.

Dr. Barohn reviewed the two ways TMA funds research: The cash grants he defines as "seed money" are \$50,000 one-year grants to get a project off the ground. "With the kind of research we need, it's amazing how quickly you can go through this much money," he told myositis patients and families. Most investigators use the grants from TMA to get started, with the ultimate goal of interesting a larger agency to help them continue the research.

Also very important are the fellowships designed to train the next wave of investigators. "There's nothing else out there for a young investigator who may be interested in myositis but has finished his or her residency," Dr. Barohn said. He praised the diversity of the myositis

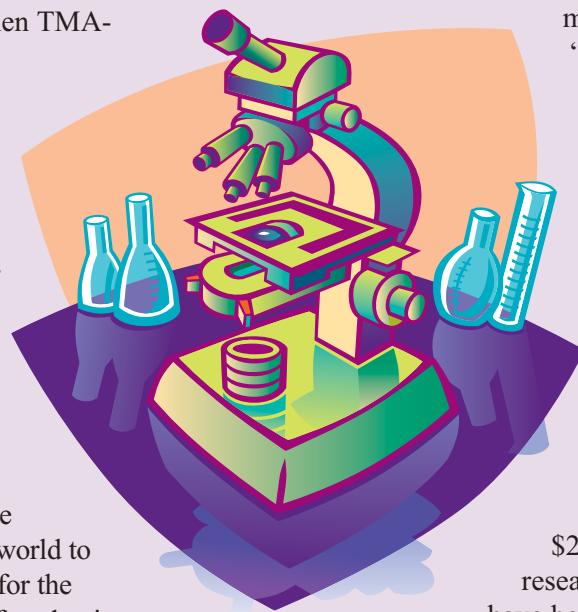
scientific community:

"There are some PhDs, some MDs; some running clinical trials and some concentrating on basic science," he said.

"More than \$2 million in research funds have been raised through your blood, sweat

and tears, and TMA has been an important funding source since the beginning of its research program four years ago. As someone who works in this field, I thank you."

Dr. Barohn noted that TMA does not presently suggest specific topics for research (called "directed research") but some larger agencies set aside a certain portion of resources to make sure promising avenues are pursued. "We're probably



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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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Research,

Continued from cover

not big enough to do this,” he said.

Find Dr. Barohn's full presentation online at www.myositis.org.

Clues in proteins and genes

In his New England neurology practice, TMA Medical Advisor Anthony Amato, MD, Brigham and Women's Hospital, Boston, is always looking for clues. “This basic science is very important,” he said. Dr. Amato looks at a great many biopsies, not just for myositis but for muscular dystrophies. “I’m always asking if we can look at genes and proteins to see if we can’t classify things better,” he said. He’s been a leader in questioning conventional ways of classifying myositis.

Dr. Amato hopes to find “genetic fingerprints” that will point not only to the prognosis, but to the best treatments. “We know there is a fingerprint that will predict interstitial lung disease, and one that predicts myositis-associated cancer,” he said, “but we still need to find them.” Work in the lab will also lead to easier diagnoses. As science moves forward, Dr. Amato predicts a day when biopsies will be obsolete and physicians will be able to rule out or identify myositis with a blood test.

He’s keeping an eye on IBM in the laboratory as well: “This is harder because we still really don’t know how much of it is degeneration and how much is inflammation,” he said. “We’ve got a special laser microscope lasering out the inclusions to figure out what they are made of—possibly misfolded proteins,” he said. “We’ve progressed a lot in the last couple of years to the point where I’m really excited about the basic science.” Dr.

Amato noted that he and Dr. Barohn are developing a pilot study for an experimental IBM drug.

Multi-center myositis trials

Dr. Amato is leading trials using **Enbrel (etanercept) for dermatomyositis**; trials that are calling for patients who are recently diagnosed and those who are experiencing a flare. “We’re trying to see if we can get quicker, better results with Enbrel,” he said. This trial is being conducted in centers here and in Canada and needs patients to enroll. Centers are in Illinois, Kansas, Massachusetts, Maryland, New York, North Carolina, Ontario, Texas, British Columbia, Ontario and Quebec.

Dan Lovell, MD, MPH, Cincinnati Children's Hospital, spoke about multi-center studies using **Rituxan (rituximab) for adults and children**. Adults with dermatomyositis and polymyositis and children with juvenile dermatomyositis are needed for this investigation, led by TMA Medical Advisors Drs. Chet Oddis (University of Pittsburgh) and Ann Reed (Mayo Clinic Rochester). The study will begin by testing rituximab in adults with myositis. Once rituximab is shown to be safely tolerated by adults, the study will begin enrolling children with JM. All the participants in this randomized, double-blind, placebo-controlled trial will eventually receive the treatment. This study is innovative in a number of ways: It is the first to combine adult and pediatric physicians in a single study of a rare muscle disease; the first to use the new measures of improvement, disease activity, and disease damage recently proposed for use in myositis trials; and the first to use the randomized placebo phase

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design that allows all patients to receive the active drug. There are centers in Arizona, Kansas, Kentucky, Massachusetts, Minnesota, New York, Michigan, Pennsylvania, Texas and Wisconsin.

Go to www.clinicaltrials.gov for more on joining one of these trials.

Focus on JM

Dr. Lovell shared his optimism about the direction juvenile myositis research is heading, citing the rituximab trial and an international effort mounted by The Paediatric Rheumatology International Trials Organisation (PRINTO). This group studies new therapeutic approaches to treating rheumatic diseases like juvenile myositis. PRINTO's network includes 185 centers from 46 countries currently involved in the international treatment trial for JM. Dr. Lovell praises the innovative design of this study as it takes a straightforward and economical approach to research. For research applications to succeed to the funding stage, he says, applicants must show hard evidence that the treatment they plan to study has a solid chance of benefiting the patients.

PRINTO's model simply uses what doctors are already doing—treating their patients—and encourages the doctors to add their clinical and observational findings to the research database as they follow their normal course of treatment, gathering much more information than a typical clinical study while maintaining a realistic budget. The practical design of this trial has implications for future trials into adult forms of myositis as it avoids the need to justify the use of a particular treatment, an expensive and time-consuming process. In the current PRINTO trial, the researchers expect combination therapy (prednisone plus one other medicine) early in the treatment plan to be more effective and safer than using prednisone alone. To

test this, they designed the study to give all newly diagnosed patients three daily pulses of intravenous methylprednisolone at 30 mg/kg/pulse then randomize them into one of the following three groups:

- Prednisone at 2 mg/kg/day
- Prednisone at 2 mg/kg/day plus cyclosporine at 5 mg/kg/day (split into two doses)
- Prednisone at 2 mg/kg/day plus methotrexate at 15-20 mg/m² once weekly

The researchers plan to enroll 162 participants for the 2-year trial and 5-year follow-up.

For complete information about this trial, go to www.clinicaltrials.gov.

Find Dr. Lovell's full presentation online at www.myositis.org.



Exercise research: a call to action

TMA Medical Advisor Michael Harris-Love, DSc, MPT, George Washington University, made a compelling case for the need for more research specifically investigating exercise and myositis, first by showing the absence of strength training studies in recent years; and then by explaining the obstacles to exercise research for the treatment of myositis. The approach used in drug trials doesn't work in rehabilitation research, Dr. Harris-Love explained. Studies can't be designed that account

for all the variables, nor can outcomes be assessed without measuring critical parameters or fully defining the treatment. "Researchers need a different approach than they use for drug trials," Dr. Harris-Love said, "if we are to intervene in effective ways and improve care for myositis patients."

To be effective in using exercise for myositis treatment, researchers must address some important questions:

- What is the best mode of exercise for people with dermatomyositis and polymyositis (isometric, isotonic, etc.)?
- How should exercise intensity and volume vary with disease severity?
- What is the best way to increase exercise intensity?

Dr. Harris-Love argued for intervention principles rather than an "effectiveness" approach to exercise trials. His recommendations:

- That The Myositis Association ask for proposals specifically targeting Phase II exercise research;
- That the existing collaborative structure of several key myositis studies add a subgroup of investigators willing to participate in multi-center exercise research;
- That TMA and other advocates communicate the need to allocate funds for myositis exercise research to the National Institutes of Health.

Dr. Harris-Love also talked about new research into the force and gait of older people with IBM.

For Dr. Harris-Love's full presentation, please go to www.myositis.org.



Exercise: necessary and possible for every level

A diagram of three intersecting circles—age, myositis, and inactivity—illustrates an important point, said Dr. Michael Harris-Love and Joseph Shrader, PT, CPed, Rehabilitation Medicine Department, National Institutes of Health. Where all these conditions are present, the threat of disability increases. This is true even if there are only the two intersecting circles of age and inactivity: Not only myositis patients, but everyone who is aging can benefit from exercise. In fact, the importance of exercise goes beyond enhancing good health. It's at the root of many of the chronic illnesses that are causing long-term disability, untimely death, and the loss of productivity.

Drs. Harris-Love and Shrader have both worked extensively with myositis patients and have yet to see or hear of a study that has found exercise harmful, so long as the exercise is appropriate for the level of function. This is in line, Dr. Harris-Love said, with the benefits of exercise on the aging population in general. Studies find that the elderly—even people in their 90s—have a response to weight training that is very much like the response of young adults.

Myositis patients, particularly as they age, have the same vulnerabilities to health and life as the general population, in addition to their worries about weakness, drug side effects and syndromes associated with myositis. This increases the challenge, since those with general weakness, with an assistive device for walking, or in a wheelchair or scooter obviously don't have all the same exercise options as the general population. But with a little ingenuity and professional guidance, exercise is possible and beneficial for everybody.

Slides from the session, given at the Annual Conference, are on the TMA's web site. Some highlights:

Observe all three phases when exercising

For each training session, there are three phases, and each one is important. The warm-up phase minimizes any possible strain on the heart, gradually increases the blood flow, and decreases the blood pressure response to initial exercise. Especially in older adults, the sudden increase in workload may increase the risk of a heart attack. The second phase of physical training should reach a rate of exertion that you perceive as "somewhat hard," and the third, or "cool down," phase allows for a gradual recovery.

It is generally agreed that almost all adults—unless they have chest pains, severe muscle pain, or unstable joint or uncontrolled high blood pressure—benefit from 30 minutes of moderate exercise most

days. When physical therapists monitor an ongoing exercise program, they generally recommend increases in the length and repetitions of each set of exercise before they increase the intensity. The final phase, or "cool down," maintains adequate blood flow and provides for a gradual dissipation of body heat.

Can't find the time or the endurance to exercise for 30 minutes? Multiple short exercise sessions may have the same training effect as a single longer exercise session of the same total duration.

Guidelines for strength and mobility

To preserve muscular strength, therapists usually recommend one set of 8-10 different exercises, each repeated 10-12 times, 2-3 times a week. For joint flexibility, try static and dynamic range-of-motion stretches, using

four repetitions daily or at least twice a week. Barriers to exercise may be fear of falling, long recovery time, pain or a host of other problems. The key is to adapt, changing the exercise, changing how you do it, or shortening the time until it becomes an activity appropriate for your own situation. Ask: "Can I restore function or should I accommodate the problem?" When pain interferes, seek ways to support the problem area to continue the activity. Another key: Find what you like to do, whether resistance training, gardening, hiking or chores in the home. For strength training, you don't need fancy equipment. Look around and see what home items—canes, rubber balls, rolled up blankets and towels—can provide resistance and support.

Find your level

Patients who don't use a gait aid (like a cane or a walker) have a variety of options. Besides sports and outdoor activities, they can use isotonic free weights, core strengthening, and a variety of aerobic and hip strengthening exercise. Those who do use gait aids have many of the same options and may find that elastic bands provide a safe method of resistance. Those who use powered mobility aids can work with special equipment, work with a professional or a trained relative, use elastic bands or towels, and employ simple props like a table for assistance in reaching.

Function-specific exercise

Sitting, standing, rolling, climbing stairs—all challenges to myositis patients—can be exercises in themselves. To continue your ability to perform these simple functions, find the safest way to do them and repeat the function many times.

The tale of two patients

The importance of exercise, both for strengthening and weight control, has an enormous impact on the quality of

Find what you like to do, whether resistance training, gardening, hiking or chores in the home.

life and independence. Consider two patients, both the same height, same disease, same disease duration and same patterns of weakness. One needs help with many daily activities, cannot work, cannot climb stairs; the other works full time, walks with a cane, is independent and can climb stairs. The difference: 80 pounds of weight separate these two, a load that makes every aspect of daily living more difficult.

The future of serial strength assessment

Trials prove the effectiveness of drugs and other treatments to reverse or slow down the weakness of myositis patients. Measurements are made by strength assessment at different stages. Investigators use objective isometric strength measurement, maximum voluntary isometric contraction and fixed dynamometry, which is becoming more popular. The more exactly investigators can measure strength gain or loss, the more we'll know about treatments for myositis. Fixed dynamometry has been used to measure outcomes in six drug trials and will be used in another this year.

3 simple tips for exercising

When leading her exercise sessions at each Conference, Sande Dunphy, member, TMA Board of Directors and certified fitness instructor, tries to get across three simple messages:

- Do gentle exercises every day.
- Find a routine that you can do on both good and bad days.
- Don't overdo exercise on the good days; don't skip exercises on bad days.

She focuses on stretching and strengthening muscles without much equipment or time.

Sande and her fellow Houston *Keep In Touch* members recently filmed an instructional exercise video specifically for myositis. Call TMA at 1-800-821-7356 for more information on obtaining a copy.



Experts answer questions

Polymyositis and dermatomyositis patients question drugs, diagnosis

In the question-and-answer sessions, some polymyositis patients told Dr. Richard Barohn that despite many drugs, weakness was progressing and unpleasant side effects made continuing treatment of questionable value. Dr. Barohn suggested some steps PM patients in this category could take. "Don't take yourself off drugs, of course," he said, noting the danger of abruptly stopping a treatment regimen, especially with prednisone. He also counseled them to get an up-to-date biopsy. "We're finding a lot of PM patients who don't respond to treatment actually have IBM," he said. "Find someone who is an expert in reading biopsies to confirm a diagnosis made long ago," he said. Other drug-related questions:

■ **Why does someone who responded well to IVIG suddenly stop responding?** "The answer is, we just don't know," he said. "We don't even know why it works when it does." He suggests making a decision with your doctor to either increase the dose, increase the frequency or to go off IVIG altogether. "Whatever you do, monitor your response very carefully."

■ **How can I avoid the bloating and weight gain of prednisone?** "There is a way, but it's very hard," he said. "I've found my patients who are willing to follow a fanatical diet of no more than 2,000 calories and two grams of sodium are able to do it." He also recommended a single morning dose of prednisone for those who have trouble sleeping at night; and a dose every other day for those experiencing troubling side effects. "Less effective, but better tolerated," he said.

■ **How do I taper if I'm on multiple drugs?** Again, something to be done with your doctor's help. "Taper one at a time, based on his or her recommendations. Monitor changes very carefully."

Basic science presently holds key to progress in inclusion-body myositis

Advances in the field of muscular dystrophies have changed definitions of inclusion-body myositis in the last couple of years, Dr. Anthony Amato said, and many people who formerly believed they had familial inclusion-body myositis now understand they have a form of muscular dystrophy where inclusion bodies are found. He recommends further testing for those with what seems to be a familial history of IBM.

■ **What about exercise? If it leads to higher creatine kinase in your blood, doesn't that mean it's actually leading to degeneration?** "Don't assume that exercise affects your disease in a negative way because your CKs go up," Dr. Amato said. "That just happens when anyone exercises." Dr. Amato advises his patients to exercise as much as they can, for mobility, for heart protection and for mental health.

■ **What would you do if you had unlimited funds?** That wouldn't change what he's doing, but would speed results along, Dr. Amato said. "For instance, I'm looking at genes; I'm looking at proteins. If I do a gene study, it's \$1,000 a pop; for proteins, \$3,000 a pop. Obviously, we could move forward a lot faster if we had a lot of money, and I could also pay for my colleagues to send blood and tissue for study."

■ **Could IBM come from exposure to toxins?** One questioner mentioned an exposure to Agent Orange. "It is my opinion that some kind of exposure, when encountered by people with the genetic predisposition, will cause IBM," he said. "But my opinion is that it's probably a virus rather than exposure to a toxin."



Patients learn tools for independence

Anyone who faces temporary or long-term disability naturally worries about losing independence, said Sandra Hubbard, PhD, OTR/L, ATP, University of Florida. Dr. Hubbard and her team of occupational therapists from the University of Florida—Roxanna Bendixen and Megan Witte—presented some of the ways occupational therapists work with patients to find ways to accomplish the daily work of everyday life by suggesting tools, mobility aids and home modifications.

The examination of the different pieces of the independence puzzle by trained experts often allows people to maintain or develop the skills necessary to remain living at home, Dr. Hubbard said.

There's no question that remaining independent in their own homes greatly adds to the quality of life for people who are disabled.

Much of the therapist's focus is on the activities of daily living (called ADLs). It's no secret that the simple things we do each day, like bathing, dressing, grooming, toileting, eating, and transferring in and out of bed or a chair, involve a certain amount of mobility. Other necessary activities as we go about the business of living are household chores like cleaning the house and mowing the lawn, shopping and other errands, paying bills, using the telephone, preparing meals and getting to appointments.

Occupational therapists are able to recommend, find and sometimes even design equipment or products that allow people with disabilities to function better. Some are extremely simple, Dr. Hubbard said, like improving lighting around doorways, putting nightlights in dark hallways or the bathroom to reduce tripping, or

putting in higher-watt light bulbs. Other simple and inexpensive ideas for people with weakness, whether from muscle disease or age:

- Raise furniture 3" to 4" to so you can slip in and out
- Use electric seat cushions that give you a little push
- Use electric chairs that lift you out
- Replace faucet knobs with levers
- Replace doorknobs with levers
- Buy large-button telephones

Other very simple adaptations can be made in the bedroom and bathroom:

- Non-skid strips in the bathtub or shower make bathing less slippery
- Grab bars make it possible to pull up from bath or shower
- A bath bench allows for more comfortable seating in the tub or shower
- Placing water temperature controls where

they can be seen reduces the chance of an accident

- A hand-held shower allows you to direct the spray
- A long-handled sponge and foot brushes mean that your back and feet will get clean
- Soap dispensers banish the slippery sliver
- Urinals make it easier for men in the bathroom

Keeping an eye on your energy

One of the most difficult parts of chronic illness is simply adjusting to a reduced or fluctuating energy level. Hubbard advises patients to plan their day's activities keeping in mind the energy each one will take, and include a little time for rest when you know your day includes a high-energy task. Another strategy Hubbard recommends for overall endurance is

taking short rest breaks of 5 to 10 minutes during any daily activities. She also suggested some simple strategies and tools for those with weak muscles and low energy reserves:

- Avoid bending and stooping to clean by using long-handled tools and flexible-handled dust mops
- Avoid long periods of standing by using a stool while cooking or ironing
- Avoid extra trips by using a cart
- Take some short cuts in your home-making—allow dishes to air dry and take advantage of pre-packaged foods

Once you've adopted these energy-conserving tips, Hubbard suggests taking a look at the overall environment:

- Adjust work heights for comfort—elbows should be at 90 degrees, with shoulders relaxed
- Arrange work areas so needed tools, equipment, and supplies are nearby
- Use turntables and step-shelving for easier access

For those inclined to pull everything out of the closets before sorting through unwanted clothing or set out on a long walk, Hubbard cautions to never begin an activity that can't be stopped immediately if it becomes too taxing.

Take a look at your home

There are three main problem areas in your home to consider, said Hubbard: getting in and out of your home; getting up and down stairs; and managing in the bathroom. Any mismatch between the environment and a person who has declining ability makes it very difficult to carry out the activities required for daily living and increases the risk of accidents, such as falls. For a home safety checklist, go to Dr. Hubbard's presentation at www.myositis.org.



Energy Conserving Tip:
Never begin an activity that can't be stopped immediately if it becomes too taxing.

Helping children adapt to their occupation: Being a kid

Occupational therapy is based on helping people perform or actively participate in the meaningful activities of day-to-day life despite possible limitations. The word “occupation” means whatever it is we do that engages most our time, said Dr. Hubbard. For children, this entails getting themselves ready for school in the morning, completing tasks at school, and enjoying play activities or sports—just “being a kid.” Sometimes it takes a small tweak, sometimes a larger adaptation to help children return to their daily activities.

Dr. Hubbard highlights different goals used by occupational therapists working with children who have JM:

- Restore a skill that has been hampered
- Maintain the skills the children are capable of doing
- Modify activities to support independence
- Prevent further barriers to accomplishing tasks

Therapists assess children individually to decide what types of adjustments are needed to make life easier, and most agree that using the least restrictive device is the best way to

help your children remain as independent as possible. For children having trouble with their grip strength, therapists might suggest using extra padding on pencils to aid in writing and on cutlery to help with eating. “The job of eating can be made easier with positioning,” Dr. Hubbard said. “For example, if the table is at shoulder level rather than waist level, children will not have to work so hard to lift their arms.”

Some children have aspirations of returning to the soccer field or dance floor. Children often stay on task better when there’s an end goal and when it’s an activity they enjoy—dancing in the recital, riding bikes with friends, or swimming in a competitive meet. Occupational and physical therapists can design programs to work toward these goals.

“Strength and endurance can be a double-edged sword,” Dr. Hubbard said. “Too much activity can over-fatigue muscles while not enough does not challenge the muscles optimally. Physical therapists are especially trained to identify peak muscle performance.” Occupational therapists use a more activity-based



approach and would look at the extent to which the child’s participation can be increased or needs to be decreased. In other words, she said, the occupational therapist can help monitor the activity, suggesting modifications as needed.

How children respond to occupational therapy depends partly on their age. Just like with other aspects of therapy, such as avoiding fats and salt at mealtime, the whole family can participate in certain parts of occupational therapy to make it easier to accept. Pad all of your children’s cutlery instead of singling out the child with JM. Buy them all rolling backpacks for school. Give them each a long-handled sponge for bathing and reachers for grabbing objects.

Through all of this, be careful not to set unrealistic goals, said Karen, parent of a child with JM, as that might only lead to further disappointment. Working with your child’s therapist will help design the program that’s just right for your child.

RESOURCES FOR ADAPTIVE EQUIPMENT

Dynamic Living @ www.dynamic-living.com
1-888-940-0605

Independent Living Aids @ www.independentliving.com/home.asp
1-800-537-2118

MaxiAids @ www.maxiaids.com
1-800-522-6294

Sammons Preston Rolyan @ www.sammonspreston.com
1-800-323-5547

The Wright Stuff @ www.thewright-stuff.com
1-877-750-0376



Pain, perception, peace and hope

Where to start when your life seems diminished

“Just as ‘my pain’ belongs in a unique way only to me, so I am utterly alone with it. I cannot share it. I have no doubt about the reality of the pain experience, but I cannot tell anybody what I experience. I surmise that others have ‘their’ pain, even though I cannot perceive what they mean when they tell me about them. I am certain about the existence of their pain only in the sense that I am certain of my compassion for them. And yet, the deeper my compassion, the deeper is my certitude about the other person’s utter loneliness in relation to his experience.”

Ivan Illich (1976)

Pain, illness, uncertainty, the elements that fill the lives of people with myositis and their families, are entwined tightly with individual perceptions. “Perception is everything,” said Barbara Cloues, PhD, private practice Licensed Clinical Psychologist. She helped her audience find ways to examine their own perceptions about chronic illness, and to find approaches that allow for hope and productivity.

One way to define stress, said Cloues, is as a force that produces change. Chronic illness—a major stressor experienced by 100 million people in our country—requires many lifestyle changes and presents serious challenges. Once the shock has worn off a little, people with chronic illness can learn as much as they can about the illness and its implications for their lives; appreciate and pursue its treatment; and somehow incorporate the illness into a their stable sense of themselves. The self-image can be terribly hard, especially when people face threats to their independence, their body image and their feeling of having one foot in the world of the well and the other in the world of the sick.

Sooner or later, people with chronic illness will need to adjust their behavior. They’ll delegate some of their per-

sonal and professional responsibilities, find a balance somewhere between rest and activity, keep connecting with family and friends, and develop new relationships that come from chronic illness: support groups, health providers, social workers and others in the health care system.

After considering their new challenges and altering their behavior, patients face their emotional work, said Cloues. They struggle with accepting their physical condition and accepting their grief. “Chronic illness is a loss of health, and can lead to a loss of dreams,” she said. “These losses must be grieved.” It’s not the grief we want to avoid—we must grieve in order to heal—but the pain of the loss, she said. The steps of grief are the same as for any loss: denial, anger, bargaining, depression and, finally, acceptance. Cloues notes that all these stages resurface when the illness changes, and that you may repeat certain stages again and again.

Perhaps because the losses associated with chronic illness are ever-present, the risk for depression is much higher in this population than for the rest of the population experiencing other kinds of losses: a third of patients with serious medical conditions experience symptoms of depression and, often, they’re overlooked because we believe it’s “normal” to be depressed if you have a chronic illness. *For the signs of serious depression, see the presentation by Dr. Cloues at www.myositis.org; or send for TMA’s “coping” fact sheet at tma@myositis.org or 800-721-8356.*

How perception affects pain

Almost everyone knows that pain extending over a long period of time has an important impact on all areas of a person’s life, but we don’t always understand how our personality affects our response to pain. Consider

the athlete who goes back in the game after a serious injury; the person who is distracted from a terrible headache while having a conversation; or the way pain seems worse when you’re already grouchy or tired.

As the Illich quote at the beginning illustrates, we all operate in isolation from the pain of others. We learn by observing the way people respond to pain: by crying, limping, guarding the sore place, resting, or talking compulsively about their pain or their health. Sometimes this kind of display allows people to get more attention or to avoid responsibility. When this happens—or if people respond in an overly attentive manner—sometimes people maintain the response after the initial cause of pain is gone.

Studies have found that pain behavior increases in the presence of those who are overly attentive, Cloues said, but this doesn’t mean that all pain response is “wrong” or a “problem.” It’s only a problem when it becomes out of proportion to the physical condition or the severity of the disorder.

Since we can’t really experience anyone else’s pain, people evaluate their pain based on their prior experiences of pain. Here again, perception is everything: everyone’s pain is influenced by the meaning they give their pain, and by how other important people in their lives responded to pain.

In the end, our potential for peace, growth and hope depends on how great a threat we perceive our illness and pain to be. Certainly, there’s a great deal of justification for perceiving chronic illness as a threat of catastrophic proportions, Cloues said. But if everything depends on our ability to diminish this threat, how do we do it? This is the purpose of cognitive-behavioral therapy.

Learning to cope

Cognitive-behavioral therapy (CBT) is used to treat a variety of disorders such as depression, anxiety, panic, and pain. Some of the techniques therapists use are cognitive restructuring, relaxation, modifying pain behavior, and problem solving. Studies have generally found that CBT appears to be at least as effective, if not more effective, as medications in the treatment of depression, and that there is a lower rate of relapse with CBT, or CBT plus medication, than with medication alone. Therapy teaches coping skills to help deal with future mood problems. There are three principles:

- Your moods are created by your thoughts.
- When you are feeling depressed, your thoughts are dominated by a pervasive negativity.
- The negative thoughts that cause negative moods almost always contain gross distortions.

First you must recognize the distortions in your negative thinking and eliminate them by changing those thoughts to more rational ones. When you start to think more objectively, you begin to feel better. This takes a great deal of persistent effort, Cloues said, but it is effective. A study of children with sickle cell disease found that higher levels of negative thinking were associated with higher levels of self-reported distress, and a study of children with chronic or recurrent pain found that their magnifying the significance of pain was substantially related to pain severity and disability.

Are your negative thoughts automatic? To become aware of your automatic negative thoughts, identify your negative internal dialogue and write it down. Talk back to the negative thoughts with more rational thoughts and write them down. Ask yourself, “What is the evidence for my automatic negative thoughts? What is the evidence against them?” Cloues calls this the “two column technique.”

Relaxation exercises are an important defense against negative thinking because they allow your body and mind to achieve a state of calmness, decreasing stress, tension, and pain perception. Cloues recommends four effective relaxation exercises: abdominal breathing, progressive muscle relaxation, visualization, and meditation, discussed in more detail in the following notes.

For those wanting to help a chronically ill patient modify the way pain prompts his or her actions, Cloues suggests identifying what might be reinforcing someone’s behavior, like getting out of doing chores or increased attention. Instead of giving increased attention and relieving them of responsibilities, encourage the person to actively cope with their symptoms by becoming absorbed in something else or practicing relaxation techniques. Another way to move a chronically ill person from concentrating on the negative is to help them develop good problem-solving skills. There are five steps, Cloues said:

- Define the problem
- Think of as many solutions as possible
- Compare the different solutions and choose the one you think will work best
- Implement the solution
- Evaluate how well the solution worked and repeat the process if needed

Moving from despair to hope

Face the changes and challenges associated with living with a chronic illness.

See that our perceptions of the illness and its effects can have a profound influence on our experience.

View our illness as a challenge, rather than as a threat or a loss, and resolve to live with hope rather than fear or depression.

Practice positive coping techniques, to develop more control over our illness and have more confidence in our ability to deal with it.

Insights from informal group discussions

It’s traditional for people at the Conference to meet informally in groups arranged according to their disease before the formal program begins. In the groups, facilitated by myositis veterans, everyone has the opportunity to share stories and offer support. Some insights from this year’s groups:

IBM – Harris Teller discussed the five stages of grieving as identified by Elizabeth Kubler-Ross, one of the founders of the hospice movement. Denial, anger, bargaining, depression and acceptance are parts of the process that lead us to learning to live with our loss, said Teller; and this is true of IBM patients who have lost their former state of health. It’s not a linear process, he said; or a neat package. As conditions worsen, patients may go through some of the steps again.

Polymyositis – Sister Peggy Mahoney said her group was especially interested in the medications and other types of treatment fellow polymyositis patients experienced. One thing that added some depth to their understanding of each other, Mahoney said, was to say something about themselves that was apart from their disease. This way, group members learned about each other’s families, work and hobbies.

Dermatomyositis – Ken and Terri Johnson report that their DM “Get-Acquainted” group was very interested in the relationship between cancer and DM that couldn’t be controlled by medication. The Johnsons were pleased to note that many of their group members were patients whose treatment had been successful and found themselves fairly stable and able to resume normal activities.



What happens to a family when one child is ill?

Change happens all the time in families—children grow and assert their independence, parents change jobs or responsibilities. These changes always affect the family, but chronic illness has a greater impact than most. “It disrupts normal interactions between family members,” said Dr. Barbara Cloues, PhD, private practice Licensed Clinical Psychologist. This disruption is more intense if the change is sudden and overwhelming.

Although families can’t change the reality, how they react is extremely important. They may react in ways that make things worse, Cloues said, becoming overprotective or denying the illness. There are other, more productive ways:

Learn about the illness and how it might affect your child’s life. Understand the treatments—why they’re important, what risks they carry. This gives you more control in situations that seem out of control, said Cloues.

Fit your child’s treatment plan into your daily activities as much as you can. As it is, she said, many parents act as full-time chauffeurs for their kids’ activities. This is one more “activity” to add to the schedule.

Encourage active contribution in the family. You may need to reassign tasks for each child, but don’t take away all responsibility from the child with JM. “Give your child a task so that he or she feels a part of the group,” she said. Keep routines as normal as you can in a “not normal” situation.

Watch for your child’s symptoms, but do this without creating extra worry or invading your child’s privacy. Be vigilant for signs of depression. “Symptoms of depression may be overlooked because they are ‘normal’ in someone struggling with chronic illness,” Cloues said. There is a real need to acknowledge and address this. Is your child not sleep-

ing because of the pain or because her thoughts are racing? Is this irritability due to the disease or a normal stage in growing up?

Understand and help your child deal with personal challenges. JM often hits as children are beginning to become more independent. It’s not always easy asking for help—it feels like they’re taking a step backwards rather than moving forward, Cloues said.

Help your child maintain relationships with siblings and friends. This can become a negative cycle: it’s not easy for them to keep contact, so they feel more isolated. The more isolated they feel, the less likely they are to put forth the effort to re-connect. Sometimes it takes a bit of encouragement, even an ice-breaker to get everyone together, and there are still hurdles to overcome. “It’s nice when friends don’t make a big deal about the disease,” said Sarah, a teenager with JM. “They accept it and move on.”

Relate with your child on an emotional level. “Let them know it’s okay to feel their feelings,” Cloues said. Find out what’s on their minds. Parents also need to come to terms with their own feelings, whether they be grief, guilt, blame, worry, or fear.

Keep other relationships in mind

Relationships among siblings are the longest lasting in the family, and children learn how to socialize and deal with conflict through these relationships. Parents often need to focus on their sick child, especially in the beginning, and brothers and sisters have reported changes in the time their parents spend with them and in the support they give, Cloues said. They, too, are scrambling to understand this disease and why it happened to someone in their family.

Some siblings might feel jealous,

resentful, fearful, or left out; some may seek attention. How siblings react depends on their own age at the time of the change. Preschoolers may feel responsible for the disease or become scared that they might “catch” it. Elementary aged children might withdraw from family and friends. Adolescents are more able to reason through the process but may become moody or resentful.

Even though behavior problems are possible, families often report more positive outcomes. Children who live with a brother or sister who has a chronic illness often feel closer to their family and have more compassion in general. They relate well with other children and with their families as a whole. Parents and children might find that they develop stronger and more meaningful relationships with other people due to their own experiences.

Marital relationships go through changes as well. If already strained, Cloues said, chronic illness may simply intensify the problem. Most couples find, though, that sharing the responsibilities of caring for their child improves the relationship. “Don’t become so fixed in your own role or responsibilities that isolation occurs,” she said. Make sure there is interaction.

From the families

It’s very telling to hear what children, parents, and siblings have to say about their own situations. Here are some concerns and comments from the families who participated in this year’s Annual Conference:

■ Sometimes your child is physically not able to do things, but other times she might be playing it up to get out of her responsibilities. A big challenge, said one mom, is when the parents don’t agree on what the appropriate behavior really is—one parent pushes hard while the other tries to

see things more objectively. When are parents expecting their children to do too much, and when should they push? Is she defying you because she's a "normal teen," or can she really not complete the task? Take the illness into account, Cloues said, but treat the child normally. This will be different for each family and even for the same child in the different stages of the disease.

■ Chronic illness affects so many facets of life, said one teenager. People could be dealing with this disease while also living with a single parent, growing up as an only child, or experiencing life changes like moving on to college. People don't always have a true understanding of what the medicines do, she said. She lost her freedom to drive due to her medicines' side effects, and she is now at home rather than off at school like many of her friends.

■ All of the families strongly opposed giving in to the disease, but most of them agreed that it's also important to reassess your goals. Sometimes you need to change your focus, even if just for a little while. "You don't want to set yourself up for failure," one mom said. Don't set unrealistic goals that will lead to disappointment. Sarah struggled with losing her ability to dance while she was on bed rest. She's now dancing again: "It doesn't stop you from doing things—you just do them differently. I may not be dancing as well as I used to, but I'm not on the floor."

■ Take something from the disease. How you look at JM and define things is so important, Cloues said. Sarah has learned a lot from her JM and maintains a positive outlook on life: "JM is like a gift in a really freaky box," she said. "You have to get over the box first then get inside and use it right."



Finding support and encouragement

Research shows that people who receive support from a social network cope better, feel more in control, and have better outcomes than those who remain isolated. TMA provides different means of support through its *Keep In Touch* support groups and its online message boards.

Support groups take on different roles for different people—with regular meetings among friends, phone calls from people who understand, or simple emails to bolster your spirits. No matter how support group members connect, the main elements people are seeking are understanding, encouragement, and compassion.

TMA members often speak about family members and friends not understanding their conditions because they don't "look different." In fact, many who suffer from myositis don't have the telltale signs like wheelchairs or rashes that show that everything isn't as it should be.

Members of a support group are living with similar symptoms, frustrations, concerns, and obstacles. These groups give you a chance to say what's on your mind in a forum where people know exactly what you mean. Members exchange ideas and encouragement with one another, taking away feelings that you are alone in your struggles.

Here is what some TMA members say about support through KIT and

the online boards:

"This site has literally been a 'life saver' for me! I was so deeply depressed before I found it that I never dreamed I'd ever find my way back!" —DeeDee

"I love hearing everyone's advice. It gives me strength to face this DM on many days." —Michelle

"I've never been looking for sympathy; it's understanding we need. It's nice to know that people can appreciate that it takes a lot of effort for me to do things that some take for granted." —Carla

Be a part of your network

To become a member of your support group, visit "My TMA" online and check that you want to be included on your list of local members. You will have immediate access to the list of members and their contact information. If you are not already a TMA member, simply fill in the membership application online or call 1-800-821-7356.

The online message boards are available at www.myositis.org. Registration is free and allows you to post messages, receive private emails, and subscribe to specific strings of messages.

If you have questions, contact TMA at tma@myositis.org.



WINTER SAFETY TIPS

Winter calls for some extra caution if you or a family member are chronically ill, says Dr. Rafael Bejarano-Narbona, medical director at the Ambulatory Care Network at New York-Presbyterian Hospital. "Before the cold weather arrives, it is important to prepare."

His tips for a healthy and safe winter:

- * Ask your doctor about the vaccine Pneumovax, which protects against pneumonia.
- * Continue your exercise regimen—indoors if possible. However, avoid strenuous exercise like shoveling snow.
- * Drink at least four or five glasses of water every day. This should not change just because it is winter.

Food choices for health and healing

Most civilized nations are facing a nutritional challenge: fast food dominates; jobs are increasingly sedentary; favorite foods are crammed with fats and sugar. At the same time, an aging population has unique nutritional needs. Take these challenges and multiply them and you'll understand the plight of many myositis patients. Made hungrier from drugs and unable to pursue a vigorous exercise regimen, people with chronic muscle disease have an increased challenge as well as more at stake in holding to a nutritious diet and normal weight.

Make food your friend

But food is not the enemy, said Lenore Hodges, PhD, LD, RD, M.D. Anderson Cancer Center. Modern science is rapidly learning how the complicated compounds in food protect us, not only from cancer but from other autoimmune diseases. Dr. Hodges is a dietician who has many years experience with nutritional needs of patients being treated for chronic and acute disease. She presently works at the M.D. Anderson Cancer Center in Orlando and has her own private counseling business. "We've only recently been able to measure some of these things," she said, "and we don't understand exactly what happens, but these discoveries are exciting and move food into a more important position in maintaining health."

Myositis patients don't need huge amounts of supplements or special diets, she said. They need what everyone needs for optimum health. Their disease simply makes it more important for them to make healthy choices. The exciting news is that the beneficial chemicals in foods, called phytochemicals, work hard to help each one of us fight disease. More than 5,000 of them have been identified, Hodges said. They're in blueberries and oats, mushrooms and cherries, oranges and mangoes and tea. Two of

their main roles in our body—reducing inflammation and moderating the effects of aging—are important functions in managing myositis.

Our better understanding of the science of phytochemicals is quite different from the more general categories dieticians formerly used to identify beneficial foods and—for reasons we don't really understand—they can't be separated successfully from the other compounds that make up specific foods. In other words, don't look for them in a pill, although some fruit and vegetable juices contain them in a more concentrated form than is available in the solid plant food.

Look for color

You don't have to understand which foods have phytochemicals and antioxidants in order to benefit from them, said Hodges. The key is variety, and the foods are conveniently packaged in different colors, so by helping yourself to a rainbow of colors, you are also helping yourself to protection on several fronts. Some colors to choose:

Green—broccoli, green peas, kiwi, kale

Yellow and orange—banana, lemon, yellow squash

Red—watermelon, kidney beans, cherries

Blue, red, purple—blueberries, raspberries, raisins, eggplant

White—garlic, onions, scallions, chives

Although the accepted number of servings for fruits and vegetables is six a day, Hodges said many in the scientific community believe the ideal number of servings is nine a day or more. It's not as hard as it seems to do this. One small glass of juice is a serving; a large mixed salad is two; a half-cup or so of any fruit or vegetable is a serving. Hodges also suggests that most of our intake of grains be in the form of whole grains, to get plenty of fiber along with our vitamins, and to avoid the food cravings

triggered by simple carbohydrates and medicines like prednisone.

Fight the fat

Hodges had some quick tips for those wanting to control their weight:

- Choose low fat foods.
- Don't supersize! Watch portion sizes.
- Work some exercise into your day.
- Bake, broil, or stir-fry instead of frying.
- Snack on vegetables and fruits.

And, she said, some healthy substitutions may help you shed a few pounds without even missing your favorite high-fat foods. Instead of conventional potato chips, snack on popcorn or baked chips. Ladle tomato-based sauces rather than cream sauces over your pasta, and toss your salad with vinaigrette rather than a creamy salad dressing. Choose frozen yogurt over ice cream; high fiber cereal instead of corn or rice breakfast cereal; mustard over mayonnaise; lean cuts over heavily marbled steaks; and grilled chicken or veggie burgers over hamburgers.

Weight gain and prednisone

Dr. Richard Barohn observes that a low-sodium, low-carbohydrate, high-protein diet can prevent the excessive weight gain associated with prednisone. He encourages physical therapy and an aerobic exercise program for patients who are able. "This is a very tough diet," he said, "but people who follow it have been successful in combating the weight gain."

For more on food, inflammation, and the future of nutritional science see Dr. Hodges' presentation online. For the TMA fact sheet, "Food Choices for Health and Healing," which includes details about dietary choices and personal stories from myositis patients, email TMA@myositis.org. Additional information on nutrition is also available online in the Spring 2004 *OutLook* in "My TMA."



Dysphagia: better treatments, more choices

Dysphagia is more common in inclusion-body myositis (IBM) patients (reported to be 30-40 %) than in polymyositis (PM) or dermatomyositis (DM) patients, although patients with all forms of the disease experience swallowing problems at times. Dr. Anthony Amato reviewed dysphagia diagnosis and treatment.

A review of the swallowing process and diagnostic testing

You'll be tested before treatments are considered to determine exactly where the problem lies. The swallow is a more complicated process than you might imagine, with many nerves and muscles working together to accomplish what most people take for granted. The entire swallowing process takes from one to three seconds, says Michelle Reuthers, a speech therapist who spoke at a previous Conference. When something—like a muscle disorder—interferes with the timing, the entire process is thrown off. Speech therapists try to find out exactly when and where the process is being interrupted. The most common diagnostic tool is the modified barium swallow, in which the therapist can watch you swallow from start to finish.

Help for swallowing problems

Treatments range from simple modifications to surgery. Especially in IBM, dysphagia is difficult to treat. Like the underlying IBM, dysphagia is not something that typically responds well to medicines. Dysphagia in PM and DM is more responsive to the medicines being used to fight the disease. In fact, Dr. Amato said, if you have been diagnosed with PM and your dysphagia is not responding to your medicines, you should be reassessed for possible IBM. A small percentage of IBM patients might improve with treatments, he said, but in his experience, he has not seen dramatic results and has found no clinical proof of any benefits.

Dr. Amato starts with the simpler solutions—eating smaller bites, tucking your chin down, alternating foods and liquids—to combat this complication. (See *Practical advice*, page 15, for more suggestions.) If these basic maneuvers don't help, there are alternatives:

■ **Medicines:** IVIG has been suggested for dysphagia in IBM patients; however, there are only case reports. There are no clinical studies, Dr. Amato said, and IVIG isn't a one-time thing. The cost is high, and repeated treatments are needed to maintain the benefits. That said, Amato admits this and other medicines are “worth a shot” before trying any of the more invasive procedures. Consider the risks with the benefits, he said. A three-month trial with prednisone or methotrexate, for example, seems logical. You and your doctor can then reassess after that time.

■ **Dilation:** In this procedure, a balloon inserted into your esophagus stretches the opening when it is too narrow. This is typically the first procedural therapy used as it is the least invasive.

■ **Myotomy:** When doctors suspect you have a good deal of scarring but your muscles are still able to contract, myotomy is an option. A surgeon cuts the muscle to increase the size of the opening. You still need working muscles in order to complete your swallow. Since there is no way to measure how much scarring is there and how much muscle remains, there is no guarantee that a myotomy will be successful, he said.

■ **Feeding tube:** A feeding tube is often considered a last resort, but this thought is changing. People with feeding tubes are able to eat, but their main source of nutrition comes through the tube so that they are assured of adequate nutrition. This allows them to eat without having to

take so much time to be sure they are eating enough. One boundary to overcome for many people is the mental picture of a feeding tube as an extreme measure.

Making a decision, like most aspects of myositis, is individual. “We're partners in this,” Dr. Amato said. His approach is to lay out the options, giving the patient enough information to make an informed decision while trying not to bias that decision.

Questions and answers from the Conference

How do you choose a surgeon? You won't find a surgeon who specializes in myositis, Dr. Amato said, but this surgery is not specifically related to your underlying disease. Find a competent surgeon who has experience with myotomies, and be sure the surgeon works with your myositis doctor to understand any possible complications or other conditions you might have.

What are your thoughts on botox as a treatment for dysphagia? “The logic seems counterintuitive to me,” he said. Botulinum is a poison that weakens the muscles—something that is used in dystonia where the nerves in the brain stimulate the muscles to constantly contract. He doesn't see parallel reasoning for its use in IBM and believes it could be dangerous.

Will the throat muscles weaken at the same rate as the other muscles? The progression of muscle weakness is individual, so your legs might weaken faster than your throat muscles, he said.



Do you have dysphagia? See boxes, page 15.

Find the dysphagia fact sheet online at www.myositis.org or call 1-800-821-7356 x503.

Understanding access to care, disability income

ACCESS to answers

Advocating for Chronic Conditions, Entitlements and Social Services, or ACCESS, is a resource offered by Accredo Therapeutics. The ACCESS team is available to help patients in areas of disability and health insurance coverage. Find general information below, and ask your own individual questions in more detail by using the toll-free number below.

At the Annual Conference, Kim Bernstein, Director of ACCESS, noted some situations where ACCESS can help:

When you have a pre-existing health condition, changing jobs—and health insurance coverage—can be a challenge. **COBRA** is an extension of your current coverage available to you for 18 months, at your cost. If your new health plan has an exclusion period for pre-existing conditions, COBRA can extend your current coverage for this condition until the exclusion period runs out. Under HIPAA (Health Insurance Portability and Accountability Act of 1996), you cannot be denied coverage or charged a greater premium than a similar individual based on your medical condition or disability. COBRA allows continued coverage to children for up to 36 months after losing their dependent status. If other options are not available, children may be eligible for guaranteed issue individual health policy. For those eligible for disability, you are allowed to continue COBRA during the two-year waiting period for Medicare.

You can obtain an **individual health plan or HMO contract** under HIPAA rules as long as you have 18 months or more of previous coverage under a group plan; you have had no lapses in coverage longer than 62 days; you are not eligible for coverage under any group plan, Medicare, or Medicaid; you do not have other health coverage; you have exhausted your COBRA coverage; and you had

no previous non-payments of premiums. Some states offer high-risk insurance pools for people who are unable to obtain health coverage and have exhausted their COBRA. Medicaid is also an option, depending on your situation.

Some states offer special health programs for children who are not eligible for other types of coverage. Find out more about the State Children's Health Insurance Program at www.cms.hhs.gov/home/schip.asp.

Contact ACCESS: 1-888-700-7010; www.accredotx.com/access/access.html

More on Social Security

Social Security Disability (SSD) and Supplemental Security Income (SSI) are both options for people with myositis, depending on your personal situation, said Alfredo Brooks, Bilingual Claims Representative for the Orlando Social Security office.

Social Security Disability

The first question to ask when looking into SSD: what does the Social Security Administration (SSA) consider a disability? A disability is based on your inability to work, more specifically that you can't do the work you did before or adjust to other work because of your medical condition. This medical condition needs to have prevented substantial employment for a period of at least 12 months to qualify.

A contracted company (Disability Determination Services) works with the SSA to make the determination that your condition prevents you from working, Brooks said. They take into consideration your past work history, medical records, and physicians' notes. Based on this information, you might be asked to see a contracted doctor for a medical review, he said.

To be eligible for benefits:

■ You must have worked for compa-

nies paying into social security. The amount of your disability payments is dependent on what you've paid into social security.

■ You must have earned enough credits to qualify. The amount you need for one credit changes from year to year (\$970 in 2006). You can earn up to four credits each year, or \$3880 in wages in 2006. Generally you need 40 credits to qualify for social security, with 20 of these credits earned within the last ten years. The actual number you need depends on your age.

■ You must have worked long enough and recently enough to qualify.

Once you apply, the SSA has a list of five questions to determine if you qualify for benefits:

■ *Are you working?* If you've earned more than \$860 per month this year, you are automatically denied.

■ *Is your medical condition severe?* Does your condition interfere with basic work-related activities?

■ *Is your condition in the list of disabling conditions?* If it is, you are automatically considered to be disabled. Not being on the list (like myositis) does not preclude you from being accepted. Instead, the SSA determines if your condition is equally severe when compared to other conditions in the list.

■ *Can you do the work you previously did?* If your condition isn't interfering with your work, you will be denied.

■ *Can you do any other type of work?* SSA considers your medical condition, age, education, past work experience, and any transferable skills when answering this question.

A denial of your application isn't the end of the road. You have the right to appeal, and your application will go to a new reviewer who has not previously read your materials, Brooks said. If you are denied a second time, you can take it to a hearing. Some

TMA members have sought the advice of attorneys, though it is not required to have one present. Keeping complete medical records and journals has helped many TMA members succeed in receiving SSD benefits.

You can receive SSD benefits and work, Brooks said. The SSA will monitor your earnings during a nine-month trial period. If you find you can't perform the tasks required of you, you can stop working and continue your benefits. However, if you continue working beyond the trial period, he said, your benefits will be suspended as long as you make more than \$860 per month. You remain eligible for disability for another 36 months, but after this time, earning more than \$860 per month will terminate your eligibility.

Supplemental Security Income

SSI is designed to help people who are disabled and have limited income and resources by providing cash to meet your basic needs. Your income and resources are taken into account when applying. Adults must be considered unable to engage in substantial gainful activity and their condition expected to last for a continuous period of 12 months or longer.

Children can receive SSI depending on the family's situation. Parents' income and resources are considered in the process, and the children themselves cannot earn more than \$860 per month (this amount changes annually). For children to qualify, their condition must also cause severe functional limitations that considerably hinder their activities and must have lasted or be expected to last for 12 months or more.

If you qualify for SSI, you might also be eligible for other programs like food stamps or Medicaid. Contact your local social services department for more information on these programs. Locate your local office online, www.socialsecurity.gov or call 1-800-772-1213.



DO YOU HAVE DYSPHAGIA?

Continued from page, 13

Signs and symptoms of dysphagia are:

- Pain when swallowing
 - Inability to start the swallowing process
 - Persistent coughing or choking while swallowing
 - Low-grade fevers
 - Sensation of food stuck in the throat or chest
 - Frequent heartburn
 - Lack of interest in eating
 - Coughing overnight
 - Taking longer to eat meals than would be considered normal
- Children show similar signs and symptoms but have unique indicators as well:
- Being distracted during meals
 - Tensing their bodies
 - Taking more than 30 minutes to finish their meal
 - Leaking or spitting foods or liquids
 - Coughing or gagging during meals
 - Losing weight

PRACTICAL ADVICE FROM HEALTHCARE PROFESSIONALS, DYSPHAGIA SUFFERERS

- Tuck your chin down—this shortens the distance for the food or liquid to travel and protects the airway.
- Turn your head to the weak side to shut it off, using the strong side to swallow. Sit upright while eating.
- Find what types of food stimulate a swallow for you. Cold, tart beverages may work for some, while spicy foods work well for other people. Avoid foods that cause the most difficulty.
- Spray your mouth to moisten it before taking a drink of water. Keep your mouth from becoming dry throughout the day by using the spray bottle or sucking on mints.
- Make your own “nosey cup” by cutting a piece out of the top of a Styrofoam cup for your nose to fit while tipping the cup, allowing you to drink without tilting your head back.
- Eat less food more often, especially when eating a meal takes a long time. Try eating six smaller meals each day. Take smaller bites of food and liquid at a time, and make sure your mouth is clear before taking any more.
- Drink small amounts of liquid often enough to keep the hypopharynx (the “pocket” at the base of your tongue near the epiglottis) clear. Alternate foods and liquids during meals.
- Focus on eating—avoid distractions and don't eat when you're overly tired.
- Swallow when you feel the urge to clear your throat. Swallowing is a smoother action than clearing your throat and won't irritate your vocal chords.
- Maintain good oral hygiene—research shows that this helps prevent aspiration pneumonia in individuals with swallowing disorders.
- Add something oily to pills to help them “slide” down your throat.

2007 Annual Conference

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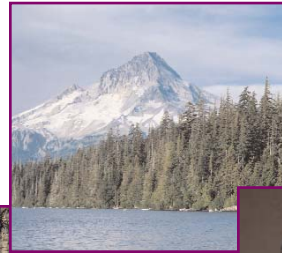
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