THE MYOSITIS ASSOCIATION

THE OUTLOOK

SUMMER 2008 For the inflammatory myopathies

Can we chat?

If you're not a frequent visitor to TMA's website, you may be missing the new and improved "chat with the expert" sessions that TMA has been sponsoring all year. The conventional chat format has been changed, so the discussion is orderly and very informative.

The live discussions are held every month except September, when TMA breaks for the Annual Conference. They are a benefit included in TMA membership. You are invited to submit questions in advance, or ask them spontaneously as the flow of the discussion suggests other topics.

In these issues of *The OutLook* and *JM Companion* we've included excerpts from two discussions: one on topics in juvenile myositis and one on side effects of myositis medications.

In October, Dr. Chet Oddis will discuss interstitial lung disease (ILD), a common and potentially serious complication of myositis and myositis drugs. Take the time to pose questions for Dr. Oddis in advance of the discussion October 15 at 4 pm EDT by following the instructions in the "live discussion" page found under "Community" at www.myositis.org. While you're there, browse through the transcripts of previous discussions about cancer, statins, juvenile myositis, side effects of drugs, and dysphagia.

Please feel free to suggest topics of interest to you for future live discussions.

Myositis drugs: side effects, formulations and comparative costs

It's confusing for myositis patients to understand why they take drugs and drug combinations that are different from patient to patient, and why some are presented in different forms and with different, often widely varying, costs.

A new government study of rheumatoid arthritis drugs may help clear up some of the confusion. The review, published by the Agency for Healthcare Research and Quality, looked at medicines prescribed for people with rheumatoid arthritis, many of which are also prescribed for myositis. This guide will help you understand the benefits, the risks and the costs of some commonly-prescribed myositis drugs. For more information, the entire review is available online at effectivehealthcare.ahrq.gov.

Medicines that control pain are not included in the guide below. Keep in mind that medications are not the only route to feeling better with chronic disease. Other measures, like exercise, rest, positive relationships and healthy food also help people with chronic disease remain independent and have more energy.

Learn some basics before starting any drug

If one myositis drug isn't working well enough, you have other options. Switching to a different drug or adding another kind of drug can help.

Steroids are often used in treating myositis. They help with pain and swelling, but using them for a long time can cause side effects.

Some drugs can increase the chance of infections and other side effects. Regular checkups and blood tests can catch these problems early.

Protect your bones with a diet high in calcium and vitamin D, and discuss supplements with your doctor.

Steroids and disease-modifying anti-rheumatic drugs

Steroids help with pain and inflammation, but it is not known if they can slow down the disease. Prednisone is the steroid often used for myositis.

Some of the drugs prescribed for myositis are called disease-modifying anti-rheumatic drugs (DMARDS). These medicines don't just relieve pain. They slow or stop the changes in your muscles. DMARDs come in two groups. Some are pills, and the others are given by shot or other type of injection into your veins. Both sup-

See **Myositis Drugs**, *page 4.*

Published by: TMA, Inc.
THE MYOSITIS ASSOCIATION
1233 20th Street, NW, Suite 402
Washington, DC 20036
P: 202-887-0088
P: 800-821-7356
F: 202-466-8940
Email: tma@myositis.org
Web: www.myositis.org

Executive Director: Bob Goldberg
Editor: Theresa Reynolds Curry

Use of exercise and dietary modification for IBM: an update

Researchers at the University of Kentucky are studying mice who have given up most carbohydrates and run five times a day on a device called a rotarod. The mice, genetically altered to have a form of mouse IBM, are part of a TMA-funded study to examine whether the special diet and exercise program will reduce the levels of amyloid beta in their brains and muscles.

Amyloid beta is of great interest to researchers studying both IBM and Alzheimer's disease because a much greater accumulation than normal of this protein is seen in the brains of Alzheimer's disease patients and the muscles of IBM patients. Scattered studies have suggested that the diet, a ketogenic diet, decreases the levels of amyloid beta in the brain and muscles. Exercise has also been shown to diminish the protein as well as slowing the loss of strength of IBM patients.

Other mice were fed a mouse version of a typical western diet, so researchers could test the differences in levels of amyloid beta to compare the two groups.

In the first year of the two-year study, researchers Christa Studzinski and M. Paul Murphy adjusted both the diet and exercise programs for the most meaningful results. Early findings indicate that the ketogenic diet does lower the levels of amyloid beta in the brains of the altered mice. Drs. Studzinski and Murphy are waiting for further studies to show if the same is true in the muscle.

Fish oil controls pain in rheumatoid arthritis

Myositis patients who take a lot of non-steroidal anti-inflammatory drugs (NSAIDS) to control pain may want to ask their physicians about cod liver oil. According to a nine-month study of about 100 rheumatoid arthritis patients reported in the March Rheumatology Journal, adding 10 grams of cod liver oil per day reduced the need for NSAIDS by 30 percent.

Patients took either the cod liver oil or a placebo and were monitored for the duration of the study, and reduced their NSAIDs by 30 percent. At the end of 36 weeks, the patients did not experience any increase or worsening of their disease from the decrease in NSAIDs. The fatty acids in cod liver and other fish oils are believed to have anti-inflammatory properties.

Researchers are always interested in an alternative to NSAIDs, because heavy use can cause gastrointestinal and cardiovascular risks.

Learn how to prevent falls, preserve independence

Drug companies are still searching for the perfect bone protection drug, but public health officials are also approaching the issue of injuries and fractures in the elderly from another angle. Their advice: Don't fall. Everyone knows senior relatives or friends whose broken hip or fractured wrist led to a long period of disability and a greatly-diminished quality of life.

This advice is of special interest to myositis patients, whatever their age. People with dermatomyositis and polymyositis, often on regular doses of prednisone and other bone-weakening medications, are more likely to have osteoporosis and are at greater risk when they do fall. And everyone with IBM knows what it's like to have your knees give way at the same time your upper body tilts backwards.

According to the Centers for Disease Control and Prevention, five percent of all people older than 65 either consulted a healthcare provider or restricted their own activity during a three- month period because of a fall. That's almost 6 million people in a recent quarter-year. If we counted falls in those who are very elderly and patients with muscle weakness and other chronic diseases, the percentage would be even higher. Many people have repeated falls.

Falls break fragile bones, but they can also cause brain, muscle and nerve damage, all of which rob myositis patients of independence and comfort.

The CDC tells us that falls can be prevented, and it offers several guidelines for reducing the chance of falling, both for individual people and for communities of seniors and chronic-disease patients. To find out what kind of programs work, researchers examined strategies from all over the world, and found some that were particularly effective:

- Strengthening and balance exercises like Tai Chi and yoga, help followers keep their balance, particularly in Asian communities where Tai Chi is a lifetime discipline practiced by all ages. Some form of these ancient arts can be practiced by people, regardless of their age and ability, and senior centers in this country are now offering them.

- General good health and obesity prevention make people much less likely to fall and, when they do fall, reduce the extent of injury. The more weight on bones and tendons that are stressed by a fall, the more likely they are to tear and break . Myositis patients, even older ones, can significantly improve their health by losing excess weight. TMA medical advisory board member Michael Harris-Love, a physical therapist, speaks about one study of two men with IBM. The difference, he said, between one man continuing to walk and one man spending all his time in a wheelchair was the difference in their respective weights.

- Prudent home organization eliminates obstacles that cause trips. "Less is more" is true when taking stock of the furniture and clutter around your house. Now might be a good time to give away some of the extra furniture that makes it hard to get around. It's also a good idea to avoid setting things on stairways, even as a reminder to take them up or down stairs. Find a nearby table for that purpose.

- Adequate home lighting is sometimes a dilemma for those of us wanting to conserve energy. Make sure that stairways, entrances and commonly-used areas are well-lit, and leave energy-conserving nightlights on near bathrooms and in hallways.

- Avoiding risky situations is an important step in fall prevention. Even if you've always gotten up on your roof or used an extension ladder to clean your gutters, you may want to ask a friend or relative for help. Try to realistically assess your ability to do certain chores. Sometimes, improved equipment will allow you to continue to do maintenance tasks that require strength, coordination and balance. Investigate these aids to see which may be useful for you.

- Education is a key to fall prevention. If you care for a myositis patient, encourage him or her to follow some of the steps above. Detailed resources for communities and families can be found online at www.cdc.gov/ncipc/preventingfalls.

- IBM and acupuncture. Jay Levitan, a Minnesota furniture restorer, told his story in the Dec. 2007 OutLook. Levitan, an IBM patient, said the physician who diagnosed him did not give him any tools. "He offered me nothing," said Levitan. "It was 'you have IBM and sorry, Charlie.'" Shortly thereafter, Levitan joined TMA and got information on exercise and its importance for IBM patients. "That was one thing," Levitan said. "The next thing was when I got tired of hitting the floor backwards." He tried acupuncture and has been almost free of falls. "We've done some tinkering with the needles and the positioning," he said. "But basically, I am not falling anymore." After his story ran in *The OutLook*, Levitan heard from IBM patients all over the country and from as far away as Israel.

Read Levitan's whole story in *The OutLook* or go to his mini-session at the TMA Conference in Denver, Sept. 18-21. He is also willing to talk to any patients who wish to call him, at 952-935-3349.

Myositis Drugs, *from cover.*

press the immune system, slowing down the body's attack on itself.

These medications are given in pill form:

- Hydroxychloroquine (brand name Plaquenil)
- Methotrexate (brand name Rheumatrex, Trexall)

These medications are given in shots under the skin:

- Etanercept (brand name Enbrel)

These medications are given by intravenous injection (IV):

- Infliximab (brand name Remicade). Find information on remicade and myositis by going to "Research" at www.myositis.org and clicking on "Current Trials."
- Rituximab (brand name Rituxan). Find information about rituximab and myositis by going to "Research" at www.myositis.org and clicking on "Current Trials."

Know the risks of myositis drugs

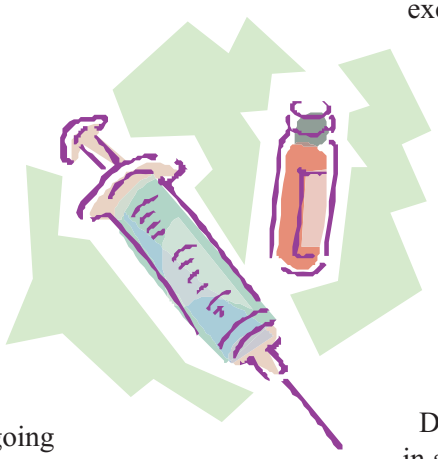
Although drugs are put through rigorous testing, all drugs include a measure of risk. Educate yourself about the risks associated with the drugs you take so you can be alert for side effects:

Many drugs weaken the body's defenses. This means that serious infections, like pneumonia, are more likely with these drugs. A serious infection must usually be treated in a hospital.

Methotrexate (Rheumatrex, Trexall) can cause liver and kidney problems. Methotrexate can also cause low red blood cell counts and painful mouth sores.

Steroids like prednisone can weaken bones, raise blood sugar, and cause weight gain. That is why steroids are often prescribed in low doses and for a short time.

TMA presented a comprehensive discussion of the side effects of myositis drugs last spring. Find the chat with Dr. Robert Wortmann on TMA's web site, www.myositis.org under "Community." See excerpts from Dr. Wortmann's discussion at "Ask the Doctor," on opposite page.



Drugs injected by needles can cause superficial symptoms

Drugs that are given in shots can cause redness, itching, rash, and pain at the spot where the shot is given.

Drugs given to people intravenously cause a reaction in about half of them. People get chills or become dizzy or sick to the stomach. But only about 2 out of 100 people stop their medicine because of reactions. Reactions often disappear when the patient becomes accustomed to the IV.

It's rare, but medications given by IV can also cause a serious reaction, like a seizure.

Drugs to avoid while pregnant

Methotrexate (Rheumatrex, Trexall) can cause serious birth defects. Other drugs less commonly prescribed for myositis can also cause birth defects. Be sure to discuss this with your physician and your pharmacist.

Both men and women taking these pills should talk with their doctor or nurse before planning a pregnancy, and should use two forms of birth control while taking these pills.

How to reduce risks of side effects or reactions from myositis drugs:

- See your doctor or nurse for regular checkups and blood tests.
- Checkups and blood tests will help catch infections and other problems early.
- Stay away from people who are sick.
- Call your doctor or nurse right away if you have signs of infection, like fever or cough.
- Make sure your flu shot and pneumonia shot are up to date. Check with your doctor or nurse before getting any other vaccines.
- Be sure to get enough calcium and vitamin D.

Reducing the cost of your myositis drugs

Often, the price of drugs varies according to whether you are using generic or brand-name medications. The following chart, courtesy of the Agency for Healthcare and Quality, will help you compare the prices of some of the drugs you take.

Newer myositis drugs, like etanercept, rituximab and infliximab, do not have a generic form as yet, but prices are listed to help you see what the expense will be if your insurance does not pay.

If you need help paying for myositis drugs, there may be a program for you. The Partnership for Prescription Assistance can tell you about these programs. Find the Partnership's website at www.pparx.org. Phone: 1-888-477-2669. Another way to pay for these drugs is to enroll in a drug trial that furnishes the drugs as part of the trial.

Note: Doses vary, and these are

just samples. The following drug regimens and costs are based on a 154-pound person per month.

Hydroxychloroquine (Plaquenil)
400 mg. once a day
Generic: $70
Brand name: $135

Methotrexate (Rheumatrex, Trexall)
15 mg. once a week
Generic: $80
Brand name: $90

Etanercept (Enbrel)
50 mg. once a week
Generic: NA
Brand name: $1,585

Infliximab (Remicade)
210 mg. every 8 weeks
Generic: NA
Brand name: $1,465

Rituximab (Rituxan)
1000 mg. (2 doses)
Generic: NA
Brand name: $1,015

Prednisolone (liquid)
10 mg. 2 x a day
Generic: $30
Brand name: $55

Prednisone (pills)
10 mg. once a day
Generic: $3
Brand name: $6

Sources: The information above comes from a detailed review of 156 research reports. The review is called *Comparative Effectiveness of Drug Therapy for Rheumatoid Arthritis and Psoriatic Arthritis in Adults* (2007) and was written by the RTI-University of North Carolina Evidence-based Practice Center.

For free print copies call, the AHRQ Publications Clearinghouse toll-free:

(800) 358-9295, and ask for AHRQ Publication Number 08-EHC004-2A.

Ask the doctor

Myositis patients ask about side effects of methotrexate, prednisone, cyclosporine and lithium.

Dr. Robert Wortmann is Professor of Medicine at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire, and the chairman of TMA's Medical Advisory Board. This is an edited excerpt of Dr. Wortmann's live discussion on the side effects of drugs used to treat myositis. Find the entire transcript of his discussion with TMA members about the side effects of myositis medications at www.myositis.org.

Question: Is it safe to take methotrexate for polymyositis when the patient also has interstitial lung disease (ILD)?

Dr. Wortmann: The short answer is yes. Methotrexate is actually one of the medications used to treat ILD. Although methotrexate can cause lung problems, these complications are rare. If a patient with ILD is taking methotrexate and develops a cough, shortness of breath or unexplained fever, he should stop the medicine immediately and contact his physician.

Question: I have been on methotrexate, imuran and prednisone. I was taken off of methotrexate and azathioprine (Imuran) because of liver inflammation. Which of these three medications can cause liver problems?

Dr. Wortmann: Both methotrexate and Imuran can cause liver problems. I assume your "liver inflammation" was diagnosed because of abnormal liver function tests. It is important to determine if the elevations are due to the medication or the result of the myositis. CPK is the enzyme we most commonly associate with muscle disease, but the AST (SGOT), ALT (SGPT), commonly considered liver function tests, are also abnormal in muscle diseases. Prednisone does not affect the liver.

Question: I have polymyositis and mixed connective tissue disease. I currently take prednisone, azathioprine and methotrexate. I have constant peeling of skin in my mouth, which is driving me crazy. Is there anything that I can take, like a vitamin, to combat this? I currently take 1600 mcgs of folic acid daily.

Dr. Wortmann: Both methotrexate and azathioprine can cause mouth sores (stomatitis.) If it is the methotrexate, then increasing the folic acid to 5000 mcgs a day might help. If this does not work, your physician could prescribe leukovorin as a trial. I don't know of a therapy that treats the stomatitis caused by taking azathioprine other than reducing the dosage or discontinuing the medication. Prednisone does not affect the liver.

Question: What are the side effects of methotrexate?

Dr. Wortmann: The side effects of methotrexate include hair loss, mouth ulcers, diarrhea, rash and fatigue. These can usually be treated quite readily with folic acid supplementation. Very rarely this drug can cause a cough and pneumonitis. We are also concerned about potential effects on the liver and blood cell counts. The serious liver problems caused by methotrexate do not occur in people who do not consume alcohol. The side effects of methotrexate are the same at higher doses as with lower doses. Actually, early reports detailing the use of methotrexate for myositis used doses as high as 75 mg IV a week.

See **Ask the doctor**, *page 7.*

Consider rail travel for comfort and safety

With the price of gasoline and airline fares soaring, many people are considering train travel as an alternative. There are obvious advantages for people with physical challenges:

- If you're in a wheelchair, you don't have to transfer to a seat,
- You know that any devices you need at your destination are onboard with you,
- Scheduled stops mean you can get up and move around safely.

Most Amtrak stations in major and many middle-sized cities are accessible to passengers with disabilities. By 2010 Amtrak expects every station in America to be in full compliance with the Americans with Disabilities Act.

Make sure you have the most up-to-date information regarding accessibility of the stations on your itinerary by calling 1-800-USA-RAIL (1-800-872-7245). This is also the number you'll use for finding routes, checking ticket prices, making reservations and buying a ticket. There is a website at www.amtrak.com, but Amtrak recommends talking by phone with a customer service agent for information about what you'll need to make your trip comfortable and safe for you.

When you call, the call will be answered by "Julie," a computerized agent, and you'll have several options to make reservations and buy a ticket. Amtrak recommends that people with special needs bypass Julie and ask for a live agent. If you need assistance with hearing, call 1-800-523-6590. Agents are available at this number from 5 am to 1 am ET, seven days a week.

Ticket agents at staffed stations can sell tickets during regular ticket office hours. Again, call 1-800-USA-RAIL (1-800-872-7245) for details.

Amtrak offers a rail fare discount to passengers with disabilities. To receive the discount, you must book your reservation by telephone or at a ticket counter. You must also provide written documentation of disability at the ticket counter and when boarding the train, in one of these ways:

- Transit system ID card
- Membership card from a disabilities organization
- Letter from a physician

Getting your tickets

If you've purchased your tickets at least a week before your departure, Amtrak will mail your ticket to you. If you are departing from a station with a staffed and open ticket office, you may pick up your ticket when you arrive at the station. To find out if your departure station has a ticket office that is staffed and open at the time of your departure, you can find the station at the 'Stations' section of the web site at www.amtrak.com, or call 1-800-USA-RAIL (1-800-872-7245).

To make sure you get the space and accommodations you need, make a reservation for any of the following, according to your needs:

- Wheelchair space
- Transfer seats (for when you travel in a seat and store your wheelchair)
- Accessible sleeper accommodations

When you reserve your accessible sleeper, it becomes your daytime room as well, so you won't need both a sleeper and wheelchair space or a transfer seat in coach class. Make reservations for such accommodations on all trains, including on "unreserved trains" (trains on which reservations for ordinary seats are not required).

Accessible space is limited, so make your reservation as far in advance of travel as possible. Up until 14 days before the departure of each train, accessible bedrooms are reserved for passengers who have reduced mobility. After that, as other accommodations fill up, accessible bedrooms are made available to all passengers according to who calls first.

At the station

The best way to make sure that you receive the assistance you require at a station is to specifically request it when you make your reservation. Arrive at the station at least one hour before the train departure time. There may be a wait if there are a large number of passengers who need assistance, or if staff is limited.

Amtrak staff will help you get to and from the restroom or up and down stairs. Courtesy wheelchairs and wheelchair lifts are available at most staffed stations, and larger stations have a customer service office.

All aboard

Amtrak offers assistance to people in wheelchairs for:

- High platforms. Amtrak staff assists you across the gap between the platform and the train by using a bridge plate.
- Low-level platforms. Staff provides level boarding for you using station-board lifts.
- Bi-level trains. Amtrak provides a wheelchair ramp to help you board the lower level of the train.

Taking a seat

If you use a common wheelchair, including a battery-operated chair, you may remain in your wheelchair for the whole trip. When wheelchair lockdowns are not available, you'll be asked to apply your wheelchair brakes. Many first class and business class cars also have accessible seating. If you choose to transfer to an accessible seat, you may store your wheelchair nearby.

Amtrak trains accommodate most wheelchairs in use today, provided they meet the ADA definition of a "common" wheelchair. Some guidelines:

- The chair should not be larger than 30 inches wide and 48 inches long. It should have two inches of ground clearance.
- The weight limit for an occupied wheelchair is 600 pounds, whether manual or battery-powered.

Getting to and from meals

On all trains with meal service, Amtrak serves customers with disabilities. You may order from the menu and have your meal brought to you, either in your room if you have a sleeper or at your seat, if you're traveling by coach. When possible, Amtrak will also serve you in the lounge car. On some long-distance trains, passengers in wheelchairs may transfer to and from the lounge car at appropriate station stops. Please ask your onboard service attendant to make the necessary arrangements.

If you are traveling in a sleeping accommodation, you are a first-class passenger, and your meals are provided without extra charge.

Ask the doctor, *from page 5.*

Question: Cyclosporine seems to be the medication that works for me. I stopped taking it because of a "flushing" side effect that at times felt debilitating. I would get very warm about 30 minutes after taking it. I would then get a little light headed or spacey. I had to recently go back on cyclosporine because my CPK levels have started going up again. I have tried hydroxyzine and aspirin to help with the side effects, but they did not help. Do you know of anything else that might help?

Dr. Wortmann: Flushing is a recognized side effect of cyclosporine. This may be a more common side effect in people who also drink grapefruit juice or take a medication that affects cyclosporine's elimination from the body, such as a statin for lowering cholesterol. I don't know of anything that is guaranteed. You might try taking aspirin or an anti-inflammatory drug like ibuprofen or Aleve. If this does not work, you might ask your pharmacist if there is another preparation of cyclosporine you might try, to see if that makes a difference.

Question: What are the dangers of long-term prednisone use and what is a "safe" dose of prednisone?

Dr. Wortmann: Long-term prednisone can cause obesity, hypertension, diabetes, osteoporosis, osteonecrosis, thin skin, abnormal hair growth, stretch marks, poor wound healing, edema, increased risk of infection, adrenal gland suppression and cataracts. Our bodies normally make the equivalent of 7.5 mg of prednisone a day, so doses less than that are generally considered safe.

Weight gain is a common side effect of high-dose steroid use and one of most difficult side effects to avoid. Weight gain primarily occurs because of the increase in appetite, but the drug may also promote fluid retention in some individuals. If you carefully watch what you eat you should not gain weight, but you must be super diligent. If you develop swelling in your feet and ankles, a diuretic may be needed.

Prednisone, as well as the diseases it is commonly used for, may be associated with premature atherosclerosis. Monitoring blood pressure, blood sugars and cholesterol levels is important for people having used long-term prednisone. If there are problems in these areas, they should be managed carefully.

Question: With the recent news that lithium chloride may slow the progression of IBM, what are the side effects of this medication? Is the dosage similar to that given to patients for bi-polar disorder?

Dr. Wortmann: Lithium is a potentially dangerous drug and can cause a variety of cardiovascular, nervous system and kidney side effects and toxicities. It also has many interactions with other drugs. When prescribed, its use should be monitored and supervised very closely. Doses are usually determined by monitoring blood levels.

Attend live discussions online, a benefit of TMA membership. Submit questions and read the complete transcripts of past discussions at http://www.myositis.org/expert_chat/discussion_list.cfm

Upcoming discussion:

Wednesday, Oct 15, 4:00-5:00 PM ET

Interstitial Lung Disease (ILD)

Chet Oddis, M.D., answers questions on interstitial lung disease

Bridging the gap: Importance of KIT groups

By Quineesa Smith, TMA Member Services Manager

As Member Services Manager, I speak to people every day, for different reasons. However, one particular conversation that has cropped up over the last few months is with individuals who have been members of TMA for many years, but never joined their KIT group.

I asked myself, "Why wouldn't they want to be a member of a support group that discusses issues relevant and important to them, and helps them cope with the stresses and challenges of myositis?"

After a few discussions, I calculated the top three answers. I've found that some just didn't want to be a part of the KIT—initially. Some never knew about the KIT support groups. A few actually thought they were members of their support group, only to find out they weren't enrolled in their local group. I'd come to realize there has been a communication gap.

First, KIT (Keep In Touch) groups are available to all TMA members. There's no fee, no application, no enrollment process. If you'd like to be a part of your KIT group, you're more than welcome to join.

KIT groups are active in many parts of the country and most meet on a very regular basis. A challenge KIT groups often face is geography. Because myositis is so rare, there may only be 10-20 people in a state the size of Montana in the KIT group. So, understand that if you elect to join your KIT group, some travel may be involved, although KIT leaders try different methods of communicating with members to overcome this obstacle. Some use conference calls; some send emails and cards and notes through the mail; some have bi-monthly meetings—and most use a combination of these three methods. KIT groups operate under the banner that if there is a will, there is a way.

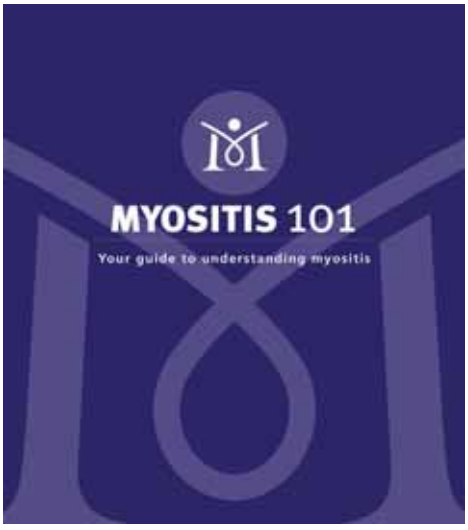
KIT groups provide members with the opportunity to sit and talk to those who understand exactly what you're going through as a myositis patient. Most meetings are centered around an activity or meal, and may even include a speaker. They are an excellent source of information sharing, support, and networking. And if you don't want to talk, no one will force you, and you can just listen. It's truly your time and you can experience it however you decide.

If you're not a member of your local KIT but would like to be, you can join your KIT online at My TMA, or call the TMA office at 1-800-821-7356 ext. 502, and ask to be added to your local group. Signing up is a simple process and takes less than a minute. You may wish you'd done it long ago!

TMA Announcements

MYOSITIS 101 NOW AVAILABLE!

Myositis 101, a comprehensive 44-page booklet for those recently diagnosed with myositis, is now available. This publication, produced by The Myositis Association, can be viewed on TMA's website at http://www.myositis.org/pdf/resources/Myositis101.pdf. Hard copies are available free of charge to physicians and TMA members.



BIGGEST GOLF TOURNAMENT YET!

We are pleased to report that the 6th Annual Myositis Benefit Golf Tournament Sponsored by SOLTEX in Kingwood, TX this summer raised over $60,000 for the fight against myositis. Thank you to all who made it so successful!