

Myositis in the news

Gene therapy

Drs. Jerry Mendell and Brian Kaspar were featured in national newspapers as well as on National Public Radio in early November for their research regarding the use of gene therapy to increase muscle mass and strength in leg muscles of non-human primates. The research by their team at The Research Institute at Nationwide Children's Hospital is funded by The Myositis Association, and will move to human trials of IBM patients next summer. To hear the NPR spot on "All Things Considered," go to <http://www.npr.org/search/index.php?searchinput=kaspar+gene+therapy>. Drs. Mendell and Kaspar also hosted a live discussion on TMA's website. To see the edited transcript, go to www.myositis.org.

"Myositis Miracle"

While we wait for the true Myositis Miracle, TMA at least has the race-horse, Myositis Miracle, now running and drawing attention to this disease. Myositis Miracle has run three times so far and has drawn media attention with his name. Soon, the other "myositis horse," Stop Myositis, will be racing. Good luck to the myositis horses!



Myositis and heart disease

Patients who suffer from polymyositis and dermatomyositis are at increased risk of developing cardiovascular disease, say several recent studies. Dr. Christian A. Pineau and his team at the Research Institute of the McGill University Health Centre published a study linking muscle inflammation to increased cardiovascular risk last September. The results of the research were published in *The Journal of Rheumatology*, and are available online at www.myositis.org under "Research."

Besides the inflammation causing muscle weakness, reduced mobility and skin rashes, inflammation also can affect muscles of the heart and lungs, Dr. Pineau said.

The heart-myositis connection is something myositis researchers have known previously. Manchester rheumatologist

Robert Cooper plans a 2010 study of this connection. Dr. Cooper, a member of TMA's medical advisory board, explains the way the heart is affected by chronic disease. "In other autoimmune diseases, such as rheumatoid arthritis and SLE (lupus), the systemic or 'whole body' inflammatory processes somehow cause impaired function of the inner layers of blood vessels, and this makes them much more liable to thrombosis events or blockages, causing excess numbers of heart

attacks, and strokes," he said.

Myositis differs in some ways, Dr. Cooper said, by not always affecting the whole body. This makes it a good candidate for study apart from other autoimmune diseases that are more correctly called systemic.

Several general-population studies have provided ample evidence that inflammation from any source plays a role in heart disease. The way inflammation impairs the blood vessels is by causing a build-up of fatty deposits called plaque within coronary arteries, and causing blood clots and blockage of blood vessels within the heart, said Dr. Pineau. Any of these events place

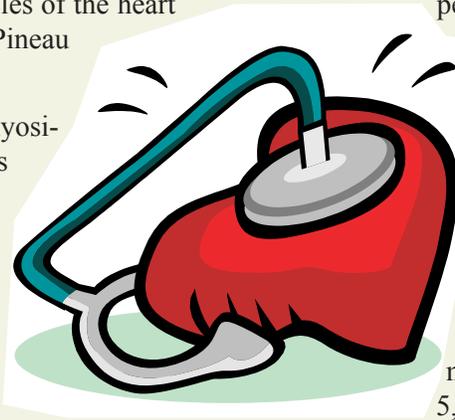
people at increased risk for heart attack.

Because of this, inflammation is now recognized as a risk factor - along with hypertension and cholesterol problems - for arterial diseases.

The Pineau study estimates that nearly one in 5,000 people suffer from

PM or DM, including 7,000 in Canada and 75,000 in the United States combined. Dr. Pineau became interested in the possible connection between inflammatory muscle disease and heart disease partly because he had seen a very large incidence in SLE (lupus) patients at the University Health Care Centre in Montreal.

Dr. Pineau said the study done at McGill made use of databases



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Myositis

Continued from cover

throughout the Quebec province. To verify the diagnoses of PM and DM, his review looked at the tests performed by family doctors, specialists and university centers. They then looked at the numbers of correctly-diagnosed PM and DM patients who later had heart problems. To make sure the results were accurate, the researchers ruled out people who had heart trouble previous to their myositis diagnosis, even though – given the length of time involved in many myositis diagnoses – these also could have been related, Dr. Pineau said.

Most of those studied (84 percent) had been treated with prednisone, 26 percent received methotrexate, 21 percent had been treated with azathioprine, 14 percent had taken anti-malarial drugs like Plaquenil, and 6 percent had been treated with cyclophosphamide. Almost 30 percent had a history of taking aspirin for pain, and 6 percent had taken blood thinners.

In the years spanned by the study, there were 124 arterial events in 80 subjects during an average of three years after being identified. Comparing the myositis patients with a group of Canadians without myositis, the researchers found the expectation would be roughly 17 arterial events.

To make sure the results weren't skewed by the gender and ages of the myositis patients, researchers compared the results to a similar sample in regards to age and gender in the general population. The average age of study participants was 62, and three quarters of them were women. Because diabetes and high blood pressure can be caused by prednisone and are predictors of heart trouble, the researchers also ruled out myositis patients who had these two chronic health conditions, whether caused by prednisone or not.

With these adjustments, the results indicated that the risk of heart attack is twice as high in these people as in the general population, said Dr. Sasha Bernatsky, a study co-author. "Each year, one out of every 200 people with muscle inflammation, or myositis, succumbs to a stroke and one out of 75 to a heart attack."

The researchers also noted that the immunosuppressive therapies currently used to treat PM and DM may have a preventive effect against heart attacks. "This is an extremely interesting finding for patients who are suffering from PM and DM but who may be hesitant to undergo this type of treatment," adds Dr. Pineau, noting that some patients are concerned about the possible side effects of immunosuppressive therapies, such as reduced immunity to infection.

"Sometimes patients do not want to undergo immunosuppressive treatment, which can last for years," adds Dr. Bernatsky. "Knowing that it has additional preventive effects may help some people decide to opt for the treatment."

Cardiovascular diseases are the world's leading cause of death, and the researchers hope that their results will provide a clearer picture of the possible benefits and possibilities of immunosuppressive treatment. As a result, Dr. Pineau and his team are now turning their attention to possible benefits of immunosuppressive therapy on other health risks associated with inflammatory diseases.

The question of therapy with corticosteroids (prednisone) and its possible role in heart disease is a complicated one, says Dr. Cooper: "Steroids represent a specific additional risk in SLE (lupus) and rheumatoid arthritis, as they also adversely alter lipid profiles, but whether steroids represent a specific separate risk in myositis is also unknown. "A poor lipid profile is indicative of possible heart disease and one of the factors physicians con-

sider when deciding whether to begin treatment.

What about IBM? Nothing so far indicates that IBM patients have a higher risk of heart disease than the general population, although it's worth noting that those at the highest risk for IBM (men older than 50) are also in the highest risk group for heart disease, so ongoing monitoring is the best course for all patients.

Here's how Dr. Pineau monitors his PM and DM patients for heart disease: "First, I make sure we look carefully at blood pressure and cholesterol levels," he said. "Obviously, when the disease is active that's our first concern." Pineau counsels patients to quit smoking, keep their weight under control, exercise as it becomes possible, and observe a heart-healthy diet. "Once the disease begins to be controlled, we might introduce cholesterol-lowering medications if cholesterol levels seem to require this." Pineau said this must be done very cautiously because of possible effects of statins on muscles. He monitors the inflammation level in the muscles very carefully. "If the disease worsens, we withdraw the statins," he said.

Read the entire article and others about heart disease and myositis under "Research" on TMA's website: www.myositis.org.



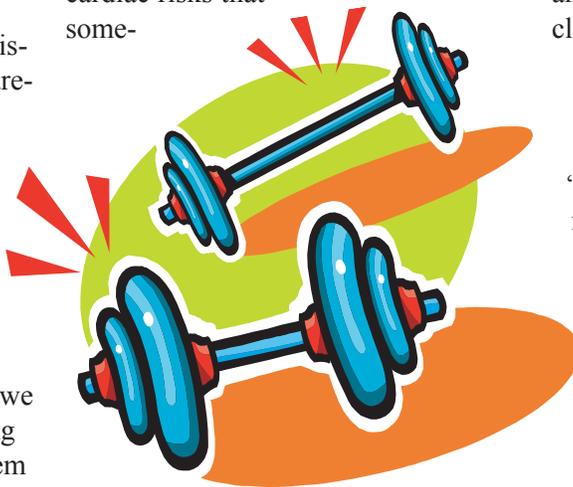
Exercise: land and water

Kerry Duffy began her discussion on exercise at TMA's Annual Conference with a paraphrase of Hamlet's famous line. "To do or not to do, that is the question," she said. By the end of the presentation, though, it was clear that Duffy, a certified physical therapist and aquatherapist, has no doubt at all that some type of exercise is appropriate for all people with myositis.

Many of the benefits of exercise are readily apparent. An exercise program promotes flexibility and

strength, Duffy said. Other benefits are more subtle. Exercise is important for maintaining optimism, conserving memory and allowing the digestive system to function properly.

Exercise is also helpful for avoiding weight gain (an important factor for those who find themselves more sedentary than before) and in controlling pain. Duffy notes that exercise can be important in controlling the cardiac risks that some-



times accompany inflammatory disease (see page 1). The same risks should be discussed with your physician to determine a suitable program for your particular case. Those with active disease should also discuss the possible inflammatory effects of exercise, Duffy said, but even those with active disease can benefit from range-of-motion exercise, the gentle stretching of each muscle to avoid stiffness and contracture. You can do range-of-motion exercises with help if you're confined to a bed or chair, or you can do them unassisted if your disease level permits.

Recent research touches on a role for exercise beyond alleviating the disease symptoms. Duffy quotes research that indicates it may have an effect on the disease process. According to Dr. Ingrid Lundberg, a Swedish rheumatologist, in *Molecular effect of exercise in patients with inflammatory rheumatic disease*, "exercise training can reduce systemic

inflammation by its effect on molecular processes, and can promote tissue repair.

Three different types of exercise help you achieve different goals. Range-of-motion exercises (or stretching your muscles to their full range) promote flexibility, aerobic exercise helps you achieve healthy lungs and heart and prevents weight gain, and strengthening exercises protect bones and help those with weakened muscles get stronger.

Those with muscle disease should proceed slowly with the strengthening exercises, Duffy said. "Start with light resistance only, no more than 5 to 10 pounds. If one repetition is easy, go ahead and add several pounds. Rest between repetitions and give yourself a break between sessions."

Myositis patients often use exercise aids like bands and balls, and Duffy recommends them. She also demonstrated several strategies for strengthening hand grip, an exercise that's particularly important for IBM patients, she said.

Know when you've had enough

There are signs you should take as serious warnings that you should stop your exercise session, says Duffy. Dark urine, muscle cramping, or noticeable increase in weakness in the exercised muscles mean you need a break. Your heart will give you some warning, too: shortness of breath beyond what's typical for exercise, chest pain, spikes in your heart rate, unaccustomed weakness, nausea, excessive sweating and a gurgling sound in your lungs should signal an immediate stop and a call to your doctor.

Avoid these major "stop" signals by keeping your exercise submaximal, she said, keeping your heart rate at 65 percent or less of its maximum. How do you know what's submaximal? You can use a chart to figure out your

appropriate exercise heart rate, or you can use an easier measure. “If you can’t talk, you are doing too much,” Duffy said.

Take it to the water

Exercising in the water is the most often-recommended form of exercise for people with neuromuscular disorders, Duffy said. There are several ways that water makes for a safer and more effective workout.

As in all worthwhile exercise programs, aquatherapy allows the instructor to tailor the exercise program to your individual needs. Besides providing support for weak muscles, water exercise is especially helpful when there is pain, decreased bone density and diabetes, and in patients with high blood pressure.

Aquatic therapy is unique because of properties of water that differ from conditions on land. These qualities are explained in more detail in Duffy’s presentation on TMA’s website at www.myositis.org. Briefly, water counteracts gravity and supports the weight of the patient in a controlled fashion, helping improve balance and strength. For those with muscle weakness, the buoyancy of water permits a greater range of positions due to the virtual elimination of gravitational forces, particularly for exercises that require lifting the legs, the heaviest limb of the body. Exercises such as range of motion stretches for hip flexors and abductors are generally much easier to try out first in water because the leg is supported somewhat as the individual learns the right positioning. Buoyancy when doing water therapy exercises can be increased with the use of floats.

The viscosity of the water provides resistance with gentle friction, while

reducing the risk of further injury due to loss of balance. There are powerful effects produced by hydrostatic pressure that improve heart and lung function, making aquatic exercise a very useful way to maintain and strengthen these functions. This pressure effect also aids in improving muscle blood flow.

Together, all these properties promote exercise that minimizes the weight placed on the spine and risk of injury due to unintended movements during exercises. Duffy pointed out that water is a safer medium for exercise, not only for the patient but also for the trainer, since loss of balance and control do not result in dangerous falls for either.

Getting started

Demonstrating from the pool, Duffy explained that water exercise can satisfy the need to increase the heart rate for cardiovascular conditioning (aerobic) or can be anaerobic and strengthening, providing light resistance for toning muscles. Some beginning tips and simple exercises:

- All exercises are done while standing on the floor of the pool. Wear pool shoes or aqua socks to protect your feet.
- Begin with stretching. To make sure you include every muscle, do it systematically, starting at the head and progressing down to the toes.
- Walk in the water swinging your arms to get your heart rate up. The faster you go, the harder it is.
- Try some wrist twirls. With your arms in front or out to the side, twirl your wrists.
- To strengthen legs, hold on to the side of the pool with one hand and

swing one leg back and forth several times. Switch sides.

- Use “shutter” paddles that you can open and close to increase or decrease resistance
- Hold the paddle against the inside of your forearm (one end of it is in your hand) and do curls, bending your elbow and bringing your hands to your shoulders.
- For back and shoulders, hold the paddles in the middle (one in each hand under the water), shoulder height and perpendicular to your arms. Spread your arms in the water out to the sides and then bring them together in front of you. Repeat several times.
- Do bicep curls with foam dumbbells. You can work triceps with these, too.

■ To strengthen the core (abdomen and back), use a board, hold it parallel to your body with your hands on either side of the board with arms straight. Pull the board to and from your abdomen several times. Hold the board flat, floating on the water, and squat so you pull the board down with you.

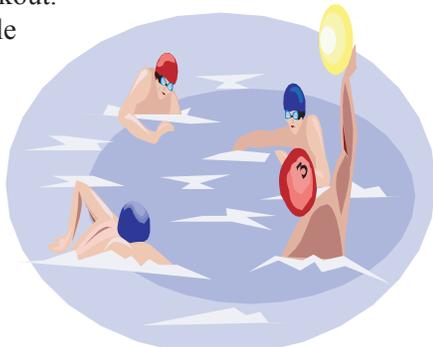
■ A weighted belt is another good aquatherapy aid.

■ In the water, do “cross country skiing.” Swing your arms as well as your legs.

Since not everyone has convenient, year-round access to a good place for water exercise, Duffy recommends combining it with land-based exercise. The typical exercise pattern, she said, is two sessions in the water to one on land if you exercise three times a week. If you exercise four times a week, try two sessions in the water and two on land.

Adele Greenfield, IBM caregiver, contributed to this article.

Read Kerry Duffy’s full presentation on TMA’s website at www.myositis.org.



Possible PM misdiagnosis

Be aware that some types of muscular dystrophy can mimic inflammatory myopathies, leading to misdiagnosis and ineffective treatments in some patients, but there are new tools that can help with an accurate diagnosis.

Recent research notes that some patients diagnosed with inflammatory myopathies may actually have a muscular dystrophy. Some types of limb-girdle muscular dystrophy as well as facioscapulohumeral muscular dystrophy are identified as autoimmune diseases because their clinical and laboratory presentations are similar. If you have been diagnosed with PM and are not responding to treatment, ask your physician for a follow up visit and express your concerns.

Of the various muscular dystrophies, dysferlin protein deficiency, caused by mutations in the dysferlin gene, is particularly prone to misdiagnosis as polymyositis. Because the inheritance pattern is recessive, you may have this even if it's not present in your immediate family. Researchers found recently that, of 40 French patients with dysferlin deficiency, 25 percent had previously been misdiagnosed with polymyositis.

It's important to pursue the correct diagnosis to avoid the possible side effects of ineffective treatment. There are now very specific tests used to diagnose different types of muscular dystrophy.

If you or your physician have questions regarding a possible misdiagnosis of an inflammatory myopathy, the Jain Foundation may be able to help determine whether the cause of the muscle weakness may instead result from a muscular dystrophy. The Jain Foundation ([\[foundation.org\]\(http://www.jain-foundation.org\)\), a non-profit organization dedicated to helping people determine the underlying cause of their muscle weakness, is privately funded. The Jain Foundation focuses mainly on identifying patients with dysferlin deficiency and funding research into various treatment options for this disease. You can register directly with the Jain Foundation at <https://www.jain-foundation.org/patients.php> and someone will contact you. Additionally, you can contact Esther Hwang, Director of Patient Relations at the Jain Foundation, by email \(\[ehwang@jain-foundation.org\]\(mailto:ehwang@jain-foundation.org\)\) or phone \(425-882-1440\).](http://www.jain-</p></div><div data-bbox=)



News from myositis support groups

Throughout the last quarter of 2009, KIT support groups around the country were active with meetings, community outreach and fundraisers. The southwest Florida group held its first Carrabba's Luncheon, Silent Auction and Raffle to commemorate Myositis Awareness Day. Across the state, the Northeast Florida KIT held its first swimming, tennis and raffle event at the Jacksonville Golf and Country Club. The group had swimmers swimming laps, promoted "pay to play" tennis matches, and sought items from local establishments for a gift basket valued at \$1,000, which was raffled. Both events were great successes!

The Massachusetts KIT group had the wonderful opportunity of supporting a KIT member with a walkathon organized on her behalf by the local Masonic lodge. The day's events were recorded and edited into a short video of everyone who showed

up to support her at http://www.youtube.com/watch?v=5S5j5LS_RpI.

The New Jersey KIT group has an ongoing campaign of raising \$1,000. The Illinois KIT group participated in a Bloomingdale's Shopping Event in the Fall to not only help folks save a little at the register, but to raise money for TMA at the same time.

New support groups have organized around the country: Suffolk County/Long Island NY; Ohio Western; and Missouri/Southern Illinois (in the St. Louis area, home of the 2010 TMA Annual Patient Conference). Other groups are currently forming and will announce their first meetings in early 2010.

If you are not currently part of a support group, and would like to be, let us know by emailing Quineesa at Quineesa@myositis.org. If you are in an area that doesn't have a group leader and would like to get a group started, let us know as well. The time commitment of being a support group leader is small compared to the tremendous impact.

TMA truly appreciates the support of our volunteer KIT leaders, as well as the members who support those leaders in any way they can.

---Quineesa Smith, TMA member services manager.



Take charge of your health care

When it comes to your health or the health of your child, who is the best advocate? It's you, says Dr. Lawrence Phillips, so it pays to understand the best ways to remain involved and informed about your health and that of your family members.

Dr. Phillips is a professor of neurology at the University of Virginia School of Medicine and a TMA medical advisory board member. He spoke to patients at TMA's Annual Conference about how to improve communication between themselves and their doctors.

Communication, communication, communication

No, this doesn't mean calling your doctor every day or sending email after email. It means being thorough during your doctor's visits. Dr. Phillips recommends being totally upfront and honest about your medical condition, symptoms, concerns, the medications you are currently taking (including over-the-counter medications, vitamins and supplements), allergies you may have, family medical history, diet and alcohol or illegal drug consumption. All of these things influence what may be causing a current flare, how to navigate the next six months of your care, and what medications you should and should not be taking. Something as simple as a type of eye drops or anti-itch cream could interfere or react with your medications.

Understand the flow of information

As a patient with a chronic rare disease, you probably see several doctors for different reasons. All of these doctors should be in touch with one another and have correct contact information, in case one doctor has a question for another.

You are the conduit for everyone involved in your care. Be certain each of your doctor's offices has information for every doctor you see. Offices are busy and generally do not have time to either call you or search a phone book to find your other doctors.

Avoid errors

There are as many as 98,000 hospital deaths annually from medical errors. What can you do to prevent errors in



your case? Dr. Phillips says the single most important way you can prevent errors is to be an active member of your health care team. It's not that you should be telling the doctor what to do, but be a part of every decision that concerns you. Keep current copies of your medical records and share them with all your doctors. Don't feel embarrassed or "a burden" if you need to add more information to your medical record at your doctor's office, or if you request a copy of your file for the 50th time.

Know your medications

Unless you are a doctor, you probably don't understand the jargon for medication you are taking, so ask your doctor to help you understand. Get it in writing if needed. Ask about the side effects. Are the side effects something you are willing to tolerate, even if the medication controls your symptoms?

Some questions you should ask about your medications:

- What is this medication for?
- How am I supposed to take it, and for how long?
- What side effects are likely? What do I do if they occur?
- Is this medicine safe to take with other medications or supplements I'm taking?
- What food, drink or activities should I avoid while taking this medication?

Once you've been informed of the pros and cons of a procedure or medication, make an educated decision as to what is best for you.

For information on drug interactions, visit the website www.drugs.com/drug_interactions.html. Work with your doctor to understand the decision-making process, what lies in the future, and what kind of results you want. Often, the doctor-patient team makes different decisions based on a patient's willingness to endure side effects, work very hard at rehabilitation, or avoid certain drugs.

Bring a family member or friend

This is highly recommended. You may be too confused or distracted during your doctor's visit and may forget some key questions to ask while you're there. Bringing another set of ears is a great idea. Your companion can provide comfort and support for you, and remain focused on what the doctor says, help remember instructions given to you, and ask rel-

evant questions you may not think to ask.

Also remember to ask about...

■ **Exercise.** Do it, or not? Helpful or hurtful? How aggressive?

■ **Diet.** Do you recommend an anti-inflammatory diet? Examples?

■ **Clinical Trials.** How can I become involved in a clinical trial?

■ **Second opinion.** “Dr. Smith, I’d like a second opinion on this. Can you recommend anyone?”

■ **Familiarity with myositis.** How many myositis patients have you seen or are currently seeing?

■ **Effects of other or overlapping diseases.** How can I keep myself healthy, while managing my other conditions?

■ **Immunizations.** Are they recommended for me in my current condition? If I get better, do I still need to get immunized? Will it cause a flare?

-Quineesa Smith, TMA member services manager

Understand your medications

By Adele Greenfield

People with myositis are normally treated by either rheumatologists or neurologists, and each tends to have familiarity with different drugs. They’re finally getting together and meeting in the same room to learn more about myositis, said Dr. Bob Wortmann at TMA’s Annual Conference. “There’s a difference in philosophy.” Dr. Wortmann, professor of medicine at Dartmouth Hitchcock Medical Center, spoke at TMA’s Annual Conference in Charlotte.

Whatever the approach, diagnosis is tricky, Dr. Wortmann said. For example, IBM was not known until 1979, and under the microscope, alcoholic myopathy looks like IBM with the same inclusions in the muscle. Obviously, the doctor needs to know if this is an issue before diagnosing and treating.

Case reports (not peer-reviewed, carefully designed trials) claim certain agents help certain people with myositis. These are strictly individual reports where clinicians share what’s worked for their patients. Because of the lack of larger trials, Wortmann said, there’s just not enough science to know exactly what to do. The physicians will use the medication they’re most comfortable with and have the most experience with. Dr. Wortmann’s presentation on medicines commonly prescribed for myositis is available on TMA’s website at www.myositis.org.

Dr. Wortmann also talked about over-the-counter medications and supplements:

Boost your energy

Sleep, exercise, vitamins, and various supplements can give you a boost, Dr. Wortmann said. He suggested:

■ Vitamin C

■ Omega 3 fish oils for a mild effect on energy

■ Vitamin D - 800 to 1000 IU day offsets Vitamin D deficiency, which is common

■ COQ10 - 100 mg. in a gel cap, not a powder

■ L-Carnitine, an amino acid found in all our cells. It’s made by the liver and is in dairy products and meat.

■ Creatine (which comes in gel pack, pill or powder form) can help if you exercise. Creatine is controversial, so it’s best to check with your physician about using it in your particular case.

Managing pain

Although there are effective pain-relieving drugs, none is completely without side effects, Dr. Wortmann said. There are some non-medicinal ways to reduce pain:

■ Cognitive behavioral therapy (CBT) looks at how you characterize and react to your situation and

includes meditation and stress reduction. It can be helpful to reduce pain and alter your perception of pain.

■ Total body exercise like walking or yoga helps. Exercise damages and breaks protein in muscles and when they repair, muscles can make more protein. Exercise also reduces stress and helps pain by producing endorphins.

■ Each pound you lose decreases the pressure in your knees by four pounds. If there’s pain in a joint, the stronger the muscles are around the joint, the less pain.

■ Studies in Sweden show that exercise improves strength in IBM. Yoga, Pilates, and stretching are good. You shouldn’t hurt (see page 3 of this issue and Dr. Wortmann’s Conference presentation on TMA’s website at www.myositis.org.)

Pain management is a science of its own. Dr. Wortmann recommends starting with low doses of aspirin or Tylenol and moving up to Ultram or Ultracet (Tylenol plus Ultram). If that isn’t effective, your physician may move you up to Tremadol. Neurontin and Lyrica can be useful for neuropathic pain. All pain medications have side effects like gastrointestinal problems and kidney failure.

Work around any physical problems

Dr. Wortmann disagrees with some old theories that exercise weakens muscles in IBM and suggests starting slowly and building up. He suggests a little work with weights to make the muscles that aren’t involved stronger. One of his patients exercises three hours a day and it is helping to make the “other” (non-affected) muscles stronger. Aston Pilates is less strenuous than the traditional type and the program can be modified.

Be sensible when exercising. Cool down properly or muscles may shake.



The Myositis Association
2010 Annual Patient Conference

September 23-25
St. Louis, MO



September 23-25, 2010

To register or learn more, go to www.myositis.org

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