

Meet Monica

Monica Anne Pedano is one of the newest members of TMA's Board of Directors, bringing a wealth of enthusiasm, energy and passion.

She is a sports enthusiast, especially enjoying golf. Monica has held three successful annual golf tournaments to benefit The Myositis Association. The tournaments have created a greater understanding of myositis in her community and produced much-needed funds for research and programs.

Monica's commitment stems from her son's diagnosis with juvenile dermatomyositis when he was just 18 months old. He couldn't walk, had a sunburn-like skin rash, and looked as if he was an old man trying to pick up things. When he lost all movement in his upper body, she knew something was terribly wrong. Still, it took doctors six months to find the right diagnosis. All it took was a blood test, but the first doctors weren't familiar enough with JDM to recognize the symptoms and find the right answers.

Now 7, Joseph still struggles with JDM, recently coming out of remission. "This is unbelievably frustrating," Monica says. "But I draw strength from him on a daily basis." Joseph and brother Michael are her priorities, and her ultimate goal is to make sure both boys are the best they can be. That includes making sure Joseph gets better.

"This is an awful disease," she says. "We need to find a cure for it or at least some type of relief for them."



Large JM study sheds new light

How will juvenile myositis (JM) affect my child in the future? That's a question asked by many parents. Answers have been scarce, so TMA-funded researcher Angelo Ravelli, MD, along with his colleagues, sought to determine the long-term outcomes of juvenile myositis and identify early predictors of organ and system damage.



To date, the researchers have assessed almost 500 patients whose disease onset was two or more years prior to the study. The majority of them are diagnosed with juvenile dermatomyositis (JDM). The researchers look at patients' histories for potential predictors, disease course and drug therapies used. Different measures are compared in determining disease activity (i.e. Manual Muscle Testing, Disease Activity Score), patient-reported quality of life (i.e. Child Health Questionnaire for Children) and accumulated disease damage (i.e. Myositis Damage Index).

Their preliminary findings:

- 60 percent have normal muscle strength
- 50 percent have normal functional ability
- About 50 percent show signs of disease activity, especially in skin and muscles

- Almost 70 percent have damage in at least one organ or system, most often cutaneous (skin)
- Impairment was seen more often in terms of physical aspects than psychosocial areas as compared to healthy children
- Overall mortality rate is less than 5 percent

Based on this, their early conclusions are:

- two years or more after diagnosis, active disease remains and cumulative organ damage is found in a substantial percentage of children with JM; and
- the results highlight a critical need for better treatments and strategies to effectively control the disease activity and reduce the occurrence of organ damage.

These findings are important to the JM community as they draw attention to the importance of further collaborative research and standardized measures.

READ MORE

Ravelli A, Ruperto N, Trail L, Felici E, Sala E, Martini A. Clinical assessment in juvenile dermatomyositis. *Autoimmunity*. 2006 May;39(3):197-203.

Also find out more in *Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers*, available for purchase at www.myositis.org or by calling 1-800-821-7356.

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Kathryn Spooner with sons (left to right) Caden, Rhys, and Calum.

Dear Families:

With great pleasure and excitement, I'd like to let you know that *Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers* is now available from TMA.

This book brings together the knowledge and understanding of some of the world's leading doctors, nurses, and other professionals in the field of juvenile myositis. In fact, more than 75 health professionals from around the globe had a hand in seeing that the concept of this book became a reality. We are indebted to them for devoting their time and careful attention to this important resource.

I know you will appreciate the range of topics covered in the book—the basics of JM, treatment options for different stages of the illness, management of the illness both practically and emotionally, related issues and complications, and helpful resources for everyone. In the *JM Companion*, we will examine several of these topics throughout the year.

I hope you will all take advantage of this invaluable resource. It truly was a labor of love for the editors, contributors, and all who worked on it.

Warmly,
Kathryn

Come together with other families, friends

Most families don't know another person dealing with juvenile myositis, at least in the beginning. And as many of you have probably experienced, your child's doctors may only treat a handful of JM cases, if any.

The Myositis Association has held family events around the country since 2005, and we're happy to help organize one near you. These can be structured meetings with a keynote speaker and presenters on related topics; or they can be informal, allowing more time to talk with other families.

These family events are often held in hospital conference rooms. If possible, it's helpful to find someone at your child's hospital who could help

with arrangements like speakers and reserving a meeting room. Many pediatric departments have a social worker or nurse practitioner who can handle these types of requests. We'll be happy to work with you and the hospital staff on specific arrangements.

These events have helped families learn from healthcare professionals as well as from one another. It also provides the children with an opportunity to meet other children experiencing the same challenges as they are.

Contact TMA at 1-800-821-7356 or kathryn@myositis.org to start planning a meeting in your area.



Look ahead to summer fun

Children look forward to summer with great anticipation, and many school-aged children eagerly await summer camp. Images of roasting marshmallows by the campfire and whizzing down the zip line add to their excitement.

Parents of children with juvenile myositis (JM) may not be as keen on the idea of sending their children away. Will the camp understand and meet your child's specific needs? Will she be able to participate in the activities offered? Will he fit in and make friends?

Treatment plans for JM increasingly include recommendations that take into account children's emotional and social well-being. Attending summer camp provides therapeutic benefits for many children with JM, increasing confidence and independence through their experiences. The activities in general provide a break from the monotony of summer days and foster interactions with other children.

*Myositis and You** (see back cover) includes a chapter focused entirely on summer camps. The authors write that children with myositis often feel isolated and misunderstood. "The right camp is a way to bridge these difficulties," they say, "by allowing children to participate, compete, develop skills and friendships."

Some camps cater to special needs, while other camps ably handle special needs but are not limited to this population. What camp you choose depends on your child's current disease activity and what he or she will need while away, like taking or injecting medicines. Other considerations:

■ **Cost.** Decide what you can put toward summer camp, and look into possible scholarships. The Myositis Association offers up to \$100 per child to attend summer camps. (Visit

www.myositis.org for more information, or call TMA at 1-800-821-7356.)

■ **Location.** How far is the camp from your home? From the nearest hospital or medical center in case of an emergency?

■ **Type of camp.** Is your child prepared to stay at an overnight camp, or is a day camp more appropriate? How well the illness is controlled helps determine whether day or overnight camp is the better choice.

■ **Staff.** What is the staff-to-camper ratio? Are staff members knowledgeable of JM and the medicines your child is taking?

■ **Accessibility.** How is the camp laid out? Are distances from different locations too far for your child to walk? If so, are there other options?

■ **Activities.** If there are activities in which your child cannot participate, will other activities be available? Are rest periods factored into the schedule?

■ **Special needs.** Can the camp accommodate any specialized diet your child requires? Will a staff member be available to apply sunscreen when needed? Can the staff handle any emotional swings the medicines might cause?

It's important to research the camp carefully and interview the camp director to make sure he or she understands your child's needs and can meet them to your satisfaction. You and your child can then *both* have a positive camp experience.

* *Ann S. Christiano, MS, ARNP; Dana Driesman-Klover, BSc OT, OT Reg. Ont.; Megan Perron, RN, BScN; Joyce L. Sundberg, RN; and Ilona S. Szer, MD, contributed to the "Summer Camps" chapter in Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers.*

WE'LL HELP

■ **Pick a camp** that is appropriate for your child. Check with your doctors, local hospitals, patient groups, and other organizations. Web sites like www.acacamps.org (American Camping Association) and www.kidscamps.com (KidsCamps.com) list camps using different categories.

■ **Be a TMA member.** Camperships are only available to members of TMA, and your family can join for as little as \$15 per year.

■ **Complete the camp application** and have the camp director or administrator sign it and return it to TMA. Find the application on the web site www.myositis.org or by calling the TMA office.

DON'T JUST TAKE OUR WORD FOR IT

"I had a really wonderful time at camp. There are a lot of things you can do, like wall climbing, swimming and archery. There are so many people to be friends with. The nurses are so much fun to be with. They are always laughing and they make you smile."

Tecia (9)

"She has met some wonderful friends that she continues to email. The first year she missed home for a few days; the second year she only missed home for one day. This past year she cried because she had to LEAVE camp. It's great. Thank you for helping let this be an important part of her life."

Joy, mother of Marlea (13)



Complicating the problem of JM

The word “complications” seems a bit redundant when you’re dealing with an already complicated disease. Like with many other diseases, children who have juvenile myositis (JM) sometimes deal with conditions beyond the characteristic muscle weakness and skin rashes. These include problems with digestion and swallowing, calcium deposits, growth issues, and more.

Myositis and You addresses many of the complications JM children experience, from the perspective of some of the most experienced and knowledgeable doctors, nurses and health professionals. Throughout the year, the *JM Companion* will explore different possible complications in more detail. In this issue, we discuss digestion, specifically stomach problems.

More than just a tummy ache?

Digestion is the process of swallowing food or liquid, its breakdown in the stomach, absorption of nutrients through the small intestine, and finally passage through the large intestine and out of the body. When muscles used throughout this process are weakened due to inflammation, the process is thrown off. The most common digestive complaints children have are trouble with swallowing and stomach pain.

Barbara Sonies, PhD, CCC-SLP, Margaret Marcon, MD, FRCPC, and Lisa Imundo, MD, discuss *Swallowing and Other Digestive Problems in Myositis and You*. Swallowing problems can be fairly easy to notice—your child coughs repeatedly when eating or has the feeling of food “going down the wrong way.”

Problems occurring later in the digestive process might be harder to distinguish.

Coughing is a protective reflex when food or liquid enters the airway,

as it does with nasal reflux. This coughing reflex isn't always triggered. In silent aspiration, foods or liquids enter the airway basically unobserved. Be aware if your child has a gurgly or wet sounding voice after swallowing, write the authors, as this is a common sign of aspiration.

Belly pain, constipation and weight loss are all signs of potential problems in the esophagus and stomach, the authors say. A few potential causes for these problems:

- Medicines used to treat JM can sometimes be hard on the lining of the digestive tract.
- Acid from the stomach enters the esophagus (acid reflux) if the contents of the stomach empty too slowly or the sphincter of the lower esophagus does not work properly to keep the acidic contents in the stomach.
- The intestines might be hampered by slowed or uncoordinated movements, not allowing for the proper absorption of nutrients into the system.
- Vasculitis, or swelling of the blood vessels, can occur in the digestive tract, contributing to pain and poor nutrition.

The medicines your child takes for the myositis itself often treat these stomach complications as well. However, there are medicines that specifically target the digestive tract to decrease stomach acid (i.e. Zantac) or help the stomach empty properly (i.e. Motilium).

Even simple changes to diet can help. For children whose stomachs empty slowly, try smaller, more frequent meals and snacks, suggest Carol Henderson PhD, RD, and Barbara Ostrov, MD. Foods lower in fat are better choices as they require less time to digest. With acid reflux or GERD (gastroesophageal reflux disease), they recommend making sure your child eats sitting upright and

remains upright one to two hours after eating.

It is especially important that your child sees a doctor if stomach pain becomes severe. Vasculitis in the digestive tract can lead to ulcers, causing pain and sometimes bleeding. Dark or blood-tinged stools might point to ulcers. Doctors can order tests to determine the root of the problem.

WHAT TO LOOK FOR

- Coughing or gagging
- Seeming distracted during meals
- Complaining of stomach aches
- Pointing to or near the chest after eating
- Frustration and irritability when eating
- Leaking or spitting foods or liquids
- Tensing their bodies while eating
- Losing weight
- Changes in your child's voice (hoarseness, gurgly sounds)
- Vomiting
- Fever after eating

A La Orange Julius

From *The Dysphagia Cookbook* by Elayne Achilles, this recipe makes a refreshing summertime drink.

- 3 oz. frozen orange juice concentrate
 - ½ cup milk or half-and-half
 - 2 cups ice
 - ¼ cup vanilla-flavored Torani syrup
 - 1 pasteurized egg (optional)
 - 1 ripe banana, peeled
- Blend all of the ingredients in the blender for 30 seconds. Serves 2 to 3.

Don't forget the sunscreen!

Many parents find themselves shouting this as their children head out the door. It's an important reminder, especially for those with sensitive skin. But how do you convince your kids that sunscreen really is that important? It might help to explain exactly what some of the terms mean:

The sun's rays emit **ultraviolet** radiation (UVA, UVB and UVC). UVC is mostly absorbed by the earth's atmosphere, but UVA and UVB rays have the potential to cause sunburn, cataracts, wrinkles, and cancer. **Broad-spectrum** sunscreens and sun blocks protect against both UVA and UVB radiation. The **sun protection factor** (SPF) measures how much of these rays a given sunscreen blocks. An SPF of 15 means that 92 percent of the sun's damaging rays are blocked; an SPF of 30, 96 percent.

Weather reporters incorporate the **UV index** into their daily forecasts. This index measures how much radiation from the sun reaches the earth's surface at a given time, ranging from 1 (minimal) to 11+ (very high). With a mild UV index, it takes the average person about 60 minutes to sunburn; with a high to very high index, only 10 to 15 minutes. With already sensitive skin, children with JM should cover up at all times. The UV index simply helps reinforce the idea that protection is a must.

Even if your children will only be out for short a time, protecting their skin is essential. "Repeated mini exposures to UV radiation may account for 80% of total exposure over a lifetime," says Richard Sontheimer, MD. "Thus, daily use of sunscreens throughout the year is advisable."

Children may not fully realize the negative effects the sun can have on their skin, with or without JM. Understanding the terms helps, but so does understanding the consequences—a painful sunburn, worsen-

ing of symptoms like weakness and skin rash, or a flare after a period of remission.

Tips for remembering

Once they understand the whys, figure out the hows:

Make applying sunscreen or sun block a part of the daily routine, just like eating breakfast and brushing their teeth.

Be a role model. By practicing sun safety yourself, you model the behavior you want your children to follow. Since avoidance of these harmful rays is a healthy choice for everyone, have the whole family adopt this as a part of their normal routines.

Find what everyone likes—lotion, cream, spray, or stick—so you're all more likely to keep sunscreen use a part of your normal day. Some companies sell a cooling mist spray; several manufacturers offer a stick that is easier when covering your face. Some sunscreens have tints or glitter. Find one your children will use regularly.

Keep a bottle, stick or tube of sunscreen everywhere—at home, in the car, in your handbag, in your kids' bookbags, and anywhere else that will keep it readily accessible. This makes it handy when you need to reapply. Amy, a teenager with JM, suggests choosing a bright, colorful bottle that's easy to find or a bottle with a clip on it to hook to your bag, belt loops, or keys.



GENERAL SUN SAFETY

The standard guidelines for staying safe in the sun haven't changed much over the years:

- Use broad-spectrum, waterproof sunscreen with an SPF (sun protection factor) of 15 or higher. [Remember that nothing is truly waterproof but instead protects the skin in water for a certain amount of time (40 minutes for water-resistant, 80 minutes for waterproof).] Find PABA-free formulas for sensitive skin.
- Avoid the sun as much as possible between 10 am and 4 pm. When you must be outside, find shade. Shady spots don't eliminate the need for sunscreen—the sun's rays can reach you through leaves and by reflecting off sidewalks, water, and other surfaces.
- Wear clothing with tightly-woven fabrics and long sleeves. Find resources for sun-protective clothing at www.myositis.org.
- Reapply sunscreen or sun block every two hours—more if you have been active.
- Put on a wide-brimmed hat that shades the face and neck.
- Remember sun glasses with UV protection to safeguard your eyes from these rays.

SUNSCREEN OR SUN BLOCK?

Sunscreens and sun blocks are different, but they are both effective in protecting your skin. Sunscreens absorb the sun's harmful rays while sun block does what the name suggests—blocks these rays. Sun blocks contain ingredients like titanium dioxide, zinc oxide and avobenzone.

New products seem to pop up on the stores' shelves endlessly, so read the ingredients carefully. Some suggestions from TMA members include Neutrogena 50 SPF cooling mist, Mary Kay #30, L'Oreal Ombrelle 45 with mexoryl, Blue Lizard Australian Sun Cream, and Bullfrog Sun Block.

Balancing JM and life as a teenager

Teenagers are learning to juggle many activities: homework assignments, after-school events, and social engagements. Teenagers with juvenile myositis juggle even more: taking their medicines, keeping doctor's appointments, and maintaining recommended exercise or nutrition programs.

How can you make it easier?

People who have JM, along with their families and friends, often share with us how they look at things. Here are just a few general suggestions given from many TMA members:

Know the facts.

Learn as much as you can about JM, the medicines you take, and possible side effects or complications. If you have questions, don't hesitate to ask the doctor or your parents to explain things more clearly.

Take care of yourself. There are many ways you can help yourself. Remember your medicines and any supplements the doctors recommend. Use sunscreen regularly (see page 5). Pay special attention to what you eat, making sure to stick to a healthy, balanced diet. Stay as active as you can, but know when you need to rest.

Feel your feelings. As Amy points out (see *Feelings and emotions*), it's okay—and healthy—to experience your emotions. Just don't let them

take over. Sometimes, talking to other people helps. Read on...

Talk about it or keep it quiet?

Deciding whether to let other people know about your JM or keep it private is a personal choice. Will it help to open up to friends? Or is it better to just let it go? Here are two teenagers' views:

"You shouldn't feel ashamed or embarrassed about having juvenile dermatomyositis," says Amy (JDM). "Lots of people have medical problems. Think about the kids you know with asthma, allergies, or even diabetes.

Some kids have glasses, some kids have braces. The point is no one is perfect. A lot of times those kids don't hide their medical problems so you shouldn't have to hide yours!"

One girl with juvenile diabetes

writes: "At first I was really quiet about having diabetes. I refused to tell anyone in school. Then, when my friends began asking me why I had to go to the nurse's office all the time, I decided to tell them. It turned out to be a good choice. Everyone was interested. When I had low blood sugar at school, my friends noticed it immediately and were able to help me." [Visit www.kidshealth.org/teen for more stories from teenagers.]



Feelings and emotions

By Amy M., teenager with JM

Between doctor visits, medication, and not feeling so good, JDM may really bring you down. You may feel sad at times. Maybe you feel like JDM is ruining your life. Maybe you feel like nobody has the slightest clue about what you're going through. Don't keep all these feelings inside. Talk.

You may want to join a support group. The people there will know exactly what you're going through. If there aren't any support groups for JDM in your area, see if there is one for arthritis. These two diseases are closely related when it comes to side effects and medication so these people will have some understanding of what's happening. Your doctor may be able to help you locate one.

Sometimes just talking to your parents, close friends or family will help. Even if they don't 100 percent understand what's happening, they are always there for you and they care about you. If it's okay with your parents or guardian, you may be able to get a pen pal to talk to.

Sometimes the best way to make you feel better is to help other people. Consider volunteering to help raise money to find a cure for JDM.

Also, try doing something that cheers you up. Watch a funny movie or play that video game that you are really good at. Whatever it is that turns that frown upside down!

Remember, it's okay to feel sad or angry about having JDM but you don't always have to feel this way!





JUST FOR ME

Fun facts and news for children affected by JM

Just being me

People might ask you a lot of questions about juvenile myositis. Some children don't mind explaining JM; other children don't like to talk about it. You need to decide for yourself, but here's what a couple of other people have done:

One day while running up the hill, Ricky's backpack pulled him over. He simply said to his friends, "I have dermatomyositis—it makes me get tired easily." His friends simply said, "Oh," and they went on.

Alison told her friends about having JM: "My friend Rebecca used to help me do things," she says, "like if I was sitting on the ground, she would help me get up."

Christine tells her friends that she used to be sick (she is in remission) without saying much more. If they ask, she'll tell them more. "Reactions to my disease aren't usually a big deal," she says. "Some people ask,

some people don't, and those who do ask I tell, then they usually say okay and we move on."

How can you make it easier?

Learn as much as you can. Learn what you can about juvenile myositis, your medicines, and how your medicines might make you feel. If you have questions, ask your doctor or your parents to explain things to you.

Take care of yourself. Remember to take your medicines, use sunscreen every day, and eat foods that are good for you. Keep doing what you can, but know when you need to rest.

Let yourself feel however you feel. It's okay to feel sad or mad, but it's important not to feel this way all the time. Sometimes talking to other people helps you feel better, or maybe listening to music makes you feel good. Find something that cheers you up.

Keeping a journal

Have you ever thought about writing down your thoughts and feelings? Sometimes it's hard to tell family or friends just how you feel. Putting it on paper has helped a lot of people. So grab a journal and get going.

Write down how you feel about JM, school, friends, and other parts of your life. Put what makes you smile, feel sad, get frustrated, or laugh.

You don't have to worry about making things sound just right—like a homework assignment. Simply write down anything that comes to your mind. You might have fun reading what you've written later on!



Springtime snack

Fruit-n-cheese kabobs



What you'll need:

- Pineapples, cut into chunks
- Cheese, cut into cubes
- Toothpicks

What to do:

Slide a chunk of pineapple on a toothpick, followed by a cube of cheese and then another pineapple. Put as many on as will fit on the toothpick (between 4 and 5 for a regular toothpick). Serve and enjoy!



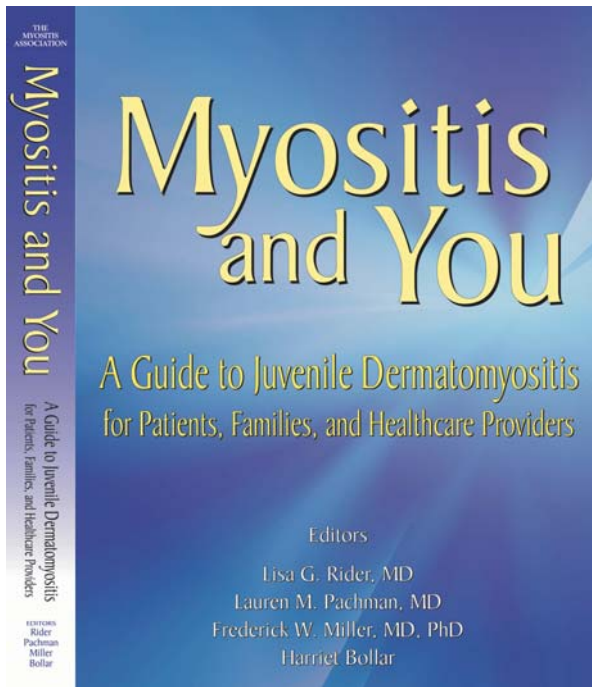
Wiggly Word Fun

This isn't your usual word search. These words are found winding up, down and around. All of the letters in each phrase are connected, but you won't find them in a straight line. Have fun!

- Fun in the sun
- Wear a hat
- Use sunscreen
- Find shade
- Cover up
- Be sun smart

[Answers will appear in the next issue.]

A	U	T	P	C	E	K	M	B	S	F
S	E	S	U	S	O	W	U	N	I	H
U	I	M	O	B	V	F	P	L	N	C
S	N	C	H	V	K	U	B	S	T	A
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S	F	I	R	U	N	S	P	U	A	U
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