

SPRING 2006

Plan your Florida vacation

There are plenty of family-oriented activities in the popular family destination city of Orlando, this year's host for The Myositis Association's Annual Conference.

Join us from August 31–September 3, 2006, for what's sure to be a great experience for everyone. There will be opportunities to learn from the expert medical panellists speaking on the different forms of myositis, breakout sessions for small group discussions, and plenty of time to meet with others who have similar experiences and concerns.

There will be ample time to meet informally with other JM families and children in a relaxed and fun atmosphere. TMA will help coordinate these times with you so that everyone knows when and where to meet.

Attractions close to the Conference hotel are Pleasure Island, House of Blues, Planet Hollywood, Disney Quest, Cirque de Soleil, and Downtown Disney Marketplace. If you'd rather not leave the hotel, there are several restaurants and cafes, an outdoor swimming pool, a video arcade, and health club.

So plan your vacation now and join us in Orlando for a great conference and learning experience. Watch for details on TMA's web site, in future issues of the *Companion*, and by TMA email.

We look forward to seeing you there!



Making connections

Anger, relief, sadness, anxiety, frustration, encouragement, stress, hope. This is just a short list of the emotions parents and children feel when confronted with the diagnosis of juvenile myositis (JM). Dealing with this rollercoaster of emotions may be one of the biggest challenges you encounter.

As a caregiver, you play an important role in your child's life with JM, but it's equally important that you take care of yourself—by eating healthy food, relaxing, exercising, and taking time for yourself. You readily support your child throughout his or her struggle with JM, but finding support for yourself isn't always so easy. Your parents, siblings and friends offer compassion and encouragement, but they don't live with the daily unpredictability of this strange disease.

Connect with someone who lives day to day with the same raw emotions you experience, without having to explain or rationalize them. This may be the boost you need. This relationship gives you a way to candidly exchange ideas, strategies and successes.

Embrace support

Each child with JM is different—and each family has its own distinct personality—but families confronted with chronic disease have a great deal in common. Take advantage of this. You'll find a sense of relief at finally finding someone who identifies with your new realities.

Accepting help or advice from someone else is not always easy.

But when you sit down and think about all of the changes and obstacles introduced one right after the other, it's a bit overwhelming.

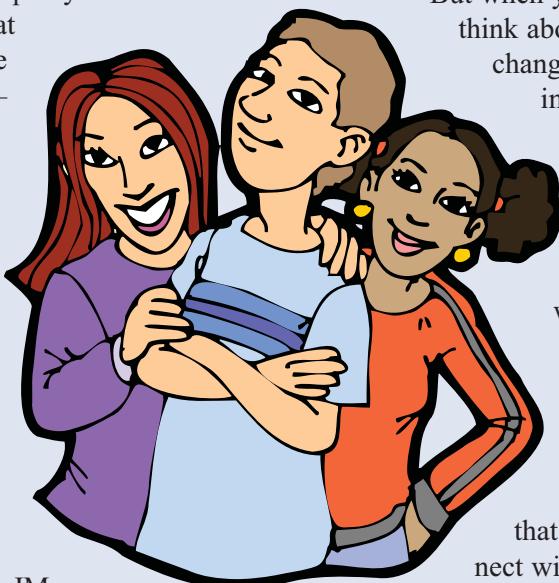
Talking things out may be just what you need to be able to take a deep breath and relax, even if just for a short while.

Keep in mind that whoever you connect with is gaining a lot themselves. They're fulfilling the natural desire to help other people and benefiting from you sharing how you've learned to manage the obstacles in your own life.

Establish your connection

The Myositis Association can help. There are many families who have expressed their willingness to phone or email anyone who needs someone to lean on. Children happily take part in this, too.

See Connections on page 2



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

Dear Families and Friends:

As The Myositis Association continues to grow, there are inevitable changes made. The most noticeable change for the *JM Companion* is the fact that it is now a part of *The OutLook*. Why? Although the *Companion* remains distinctly separate from *OutLook*, it is now in one publication so that all TMA members can read more about the exceptional and inspiring children and families that make up the JM community.

Another change starting with this issue of the *Companion* is a page dedicated solely to teenagers and young adults with juvenile myositis (see *Transitions*, page 6). Thanks to Sarah, a teenager with JM, who emailed to suggest that we focus one section on the specific needs of the teen community. If you are a teenager or young adult—or soon to be one—please send your ideas for this page, as well as for the teens' pages of the web site. What has helped or not helped you? What would you like to read more about? What concerns do you have now or for the future? We're very interested in your thoughts.

We hope to pack these pages with as much helpful material as possible, and, as always, appreciate your suggestions.

Warmly,
Kathryn

Connections,

continued from cover

Carly (13 years old) was diagnosed with JM almost five years ago, so she has wrestled with the many ups and downs of the disease. She didn't know other children going through the same changes she was at the time, and that—along with her natural willingness to help everyone—drives her to be there for other people now. Recently, she contacted another young girl newly diagnosed with JM. "This is an amazing experience for me to just be able to see someone who is going through the same problems as I was and being able to help her cope with them," she said. Her mother was there, too, to answer any questions the parents might have about their situation and feelings.

Several families have taken it further by meeting for a weekend. The Adelmans and Stephens met in San Antonio, scheduling Go-Kart racing

and a Mexican dinner for a more festive and casual atmosphere. The children enjoyed getting to know one another while the parents had time to bond as well. Kacie and Sarah, two teenagers with JM, hooked up by email through TMA, and then their families met for a weekend of skiing. Even though one lives in Virginia and the other in Tennessee, they made the effort and forged a relationship.

Creating a strong bond with someone can be complicated under the best of circumstances. Shared challenges, like those that accompany JM, serve to reinforce connections with other parents and children once you establish the relationship. Those people who have shared their experiences with us delight in having someone there to trust with their innermost thoughts.

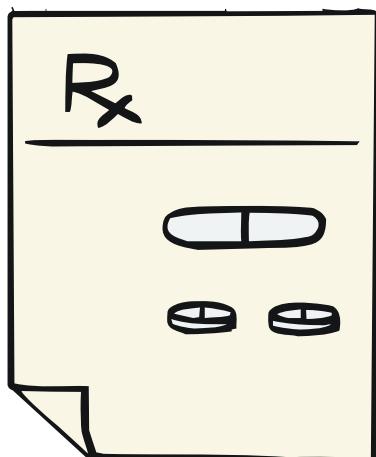


A closer look at diagnostics

The criteria used when diagnosing juvenile dermatomyositis (JDM) have been around for decades. Researchers are constantly trying to refine these criteria to make them as useful and accurate as possible in practice.

A survey of pediatric rheumatologists worldwide produced the following list of criteria which were most helpful in diagnosing JDM:

- observations of proximal (toward the center of the body) muscle weakness
- characteristic skin rashes (i.e. heliotrope rash, or reddish-purple discoloration around the eyes, often with swelling; Gottron's papules, or raised bumps over the knuckles, elbows and knees)
- elevated muscle enzymes (increased levels of these proteins found in the blood indicate muscle damage, though not specific to JM; tests include creatine kinase and aldolase)
- muscle biopsy findings (study of a small piece of muscle under the microscope to note any damage to muscle tissue or blood vessels)
- magnetic resonance imaging (MRI) findings (test using magnets to create images of muscles to find inflammation)
- changes on the electromyogram (EMG) (test of the electrical activity of muscles by inserting small needles into the muscles)
- nailfold capillaroscopy (study of the small blood vessels at the base



of the fingernails—dilated, uneven capillaries are related to how severe the weakness and rash are)

- neopterin (part of the immune system that, when elevated in the blood, indicates persistent muscle damage)
- factor VIII-related antigen (protein on blood vessels that is released when the vessels are inflamed)

The first two criteria are essential; items 3 through 6 are considered to be important; and the last three criteria are used by about one-third of those surveyed.

Researchers did a survey intended to rank these criteria in terms of importance and usefulness in actual practice. Proximal muscle weakness, skin rashes, and elevated muscle enzymes remained at the top of the list, followed by MRI and muscle biopsy changes.

These surveys identified nine criteria considered most helpful in diagnosing JDM, but researchers noted these need to be further studied for an international agreement on a standard set of diagnostic criteria.

From Brown VE, Pilkington CA, Feldman BM, Davidson JE. An international consensus survey of the diagnostic criteria for juvenile dermatomyositis (JDM). *Rheumatology (Oxford)*. 2006 Feb 8; [Epub ahead of print].

Web alert: Read the abstract of this study online at www.myositis.org on the Juvenile Myositis pages. Visit the Parents' pages for this and other research abstracts and articles.

FOCUS ON RESEARCH

Although there are some research studies and case reports looking at animal-assisted therapy, most of these call for further, more detailed studies on using animals as an interventional tool for people in certain situations, including extended hospital visits.

One Chilean study noted that animals helped people adapt to their new environment and lessened feelings of anxiety, pain, blood pressure, and stress.

A Canadian group reported: "It appears that dog-assisted therapy may contribute to alleviate psychological distress in children and parents, facilitate their adaptation to the therapeutic process, and promote their well-being while hospitalized."

A staff nurse at the UCLA Medical Center implemented an animal-assisted therapy program for critically ill patients in the cardiac care unit: "Patients report feelings of increased happiness, calmness, more feelings of love, and less loneliness."

Barbara A. McClaskey, PhD, RNC, at Pittsburg State University in Kansas, presented her findings that the presence of a pet is a positive factor in a child's self-concept, showing that companion animals can be important in the lives of chronically ill children.

These reports lend credibility to the idea of using animal-assisted therapy as a formal therapy program and may lead to studies using larger populations.



Read more about the benefits of animal therapy throughout this issue.

Healing with the help of animals

Like many people fresh out of graduate school, Patty Malo has a business plan. She's a self-described "animal collector" and an occupational therapist. She plans to someday combine these two facets of her life to initiate an animal-facilitated therapy practice.

This may not happen for five years, or possibly ten, but she's focused on this dream and continues to advance her own belief that animals have a major effect on the lives of people, especially those with a special need.

She has worked in animal-assisted settings before: at a center for handicapped horseback riding near her hometown and at a program near her graduate school. "When you see it in action," she said, "it's just great." She grew up a horse fanatic herself, so when polymyositis prevented her from riding a horse in the customary way, she stopped altogether. She soon realized that modifications are a great—and acceptable—way to get back to what you really want to do.

PATTY'S STORY

The symptoms of adult-onset PM came on quickly and noticeably while Patty was serving in the Peace Corps in Thailand. Unable to stand from a seated position on the floor, she realized something was wrong. She was diagnosed in Bangkok and sent home despite her pleas to stay and continue her mission. It took months to get her disease under control, which gave her time to think about her future. She loved working with people and working with animals, so she devised a plan to do both. She hopes to eventually

use rescued or homeless animals in therapy sessions with children and adults dealing with chronic illnesses like myositis.

A career in occupational therapy seemed a natural progression. She spends her days exploring how a person's condition affects every part of his or her life. Patty currently works with students in a rural school system. She isn't able to introduce animals into her therapy sessions yet, but she continues to consider how they could help.

Sometimes children are unable to put their problems into words, she said; animals make discussions easier through their calming influence. Other children have physical limitations, and working with animals in a variety of ways, including grooming and walking them, provides therapeutic benefits in a more fun and relaxed environment.

COULD ANIMAL-ASSISTED THERAPY WORK FOR JM?

Although there are few accredited programs available for animal-assisted therapy, Patty supports the principles behind it. Animal therapy programs promote the natural bond that exists between people and animals. The presence of animals creates an atmosphere of safety, love, acceptance, and calm.

Patty has never worked with a child who has juvenile myositis (JM), but she believes animals could be used successfully in therapy, depending on the children's own limitations and with the approval of their doctors and therapists.

One child with JM may have vastly different needs from another child with JM. Some children need more emotional support; others lack range of motion or muscle strength.

Animals can help in both of these sit-

uations. A central component of animal-assisted therapy, Patty said, is the motivation the animals give the children to participate, whether physically or emotionally.

Physical advantages

Animals can become a part of rehabilitation without the children even knowing it. Therapists manipulate the scenario for the children's individual needs—using larger dogs to require children to reach up higher to brush them, or playing games with the dogs (or other animals) to work on balance and coordination.

Patty often shares her thoughts on animal-assisted therapy with her students' parents, giving practical examples of how their own pets might help. A few of her preschool-aged students were encouraged to crawl using pets as motivators. For other children, animals allowed them to concentrate and increase hand-eye coordination.

Emotional benefits

Beyond the physical advantages of animal-assisted therapy, the emotional aspects are perhaps more rewarding. Animals allow children to feel safe and comfortable when confronted with unfamiliar or scary situations. Anecdotal reports suggest that interactions between animals and people provide satisfaction on many levels, helping people feel better and connect with others more readily. Scientific research studies, though limited in their scope, show measurable decreases in blood pressure, heart rates and stress with the introduction of animals in therapeutic or hospital settings.

Linda Spence PhD, RN, and Lana Kaiser RN, MD, DVM, of the Michigan State University College of Nursing, studied the role of companion animals in helping chronically ill children adapt. "Early intervention to enhance the quality of life for these children could lessen later psychological problems and promote long-term adaptation," the authors stated. They noted that companion animals often



serve as friends and confidants to the children and remain nonjudgmental during stressful times. Since many children may already have pets, they may already be taking advantage of the health benefits of companion animals.

More applicable to the larger group of children with JM, who do not have access to the few available animal-assisted therapy programs, is the fact that animals change the focus from the day-to-day routine of medicine schedules, doctor's visits and exercise regimens. This departure from the routine, even if just for a minute, is a great benefit to caregivers, too, Patty said: "It's a quality-of-life enhancer. If you have a chronic condition, it occupies all your time and thought. If you have an animal to care for, that gives you another focus." Working with animals also takes the spotlight off their limitations and instead allows children to focus on what they can do.

Children who have trouble socializing with others may be more willing to talk when an animal is present. They may talk directly to the animal, or simply feel more comfortable speaking to other people when they do not feel as though they are the center of attention.

Animals tend to exhibit unconditional love and acceptance, and children are quick to recognize this. "Animals are always there," Patty said. "They don't talk back. They don't make fun." This acceptance helps children feel safer and more self-confident.

There are countless ways animals can help in a therapeutic setting. "Your imagination is your limit," Patty said. "There are such bonds between animals and the people who need them. It seems the most natural thing in the world to care for animals."



A REAL-WORLD EXAMPLE

It's an all-too-familiar story: When playing kickball or tag during recess, 11-year-old Kelli Bassett noticed she couldn't keep up with her friends anymore. She tired easily doing her normal, everyday activities. Like so many, she assumed it was the flu or a virus that was going around. But the feelings of exhaustion just didn't go away. That's when she went to the doctor and learned a new term that would mean many things to her over the next few years—juvenile dermatomyositis.

"At first," she said, "I didn't really know what to think." Her doctor explained things to her, but she admits it went in one ear and out the other as her own thoughts spun around. Prednisone caused facial swelling and stomachaches but didn't ease her symptoms. Adding methotrexate made the difference. She continues to have methotrexate injections and take folic acid tablets. Now almost 14, she's feeling better but isn't back yet to where she started. Her energy is drained at times when she walks longer distances, and she can't participate in athletics with her friends. "I'd be content with just being able to run at home for an extended amount of time," she said, "or playing basketball and not getting tired. Even though I'd love to do these things, I'm still limited to very little."

Finding comfort in a friend

Medicines are obviously important to fight JM, but emotional support is also vital to fight loneliness, sadness and worry. It can be tough to find emotional support outside of the family. "Nobody really understands," Kelli said. "Besides my family and closest friends, no one at school really wanted to know or understood why I looked swelled, or why I wasn't at school for months at a time." Except for a few friends with JM who live further away, Kelli recognizes that it's hard for people to relate to her situation. "Sometimes it's hard to cope emotionally even after three years of dealing with this disease," she said.

Kelli has the constant support of her family but found another source of comfort when her wish for a horse was granted by the Make-A-Wish Foundation. "Scout—and my dogs—have greatly helped me through JDMS," she said. "My horse helps me to get stronger because every time I ride him, I have to groom him before and after I ride, which does exercise me. It may seem very little, but it's the perfect amount of physical activity I need and can handle." Scout gives her something to look forward to—an exercise program that's fun to do.

It may sound like a cliché that people discover good things under bad circumstances, but that's the case with many children dealing with JM. For Kelli, Scout has been a tremendous help. "I don't know where I'd be if I had never gotten him," she said. She also feels lucky to have met so many great people: "The doctors I've met, the other children I've met at special camps, they're just great people to know."

HORSEBACK RIDING AS A THERAPEUTIC TOOL

In therapeutic horseback riding, the focus is on a person's *emotional* well-being. A person may be learning how to ride to help with developmental and social skills, Patty Malo said. Riders may face obstacles along the way but are encouraged when they overcome them.

Hippotherapy is a type of *physical* rehabilitation using horseback riding in addition to traditional exercise programs. The way a horse moves has a physical impact on the rider, Patty said. Depending on what the rider needs, animal-assisted therapists develop a riding program to work on balance, coordination or strength, for example. The horse is acting on the rider to aid the rider physically.

It's important to know the animals well, she said. Use the animals' strengths to pair them up with the right people for this type of therapy.





TRANSITIONS

For teenagers and young adults living with JM

What's this?

Thanks to Sarah, a teenager with juvenile myositis (JM), who suggested that teenagers and young adults have their own section of the *JM Companion*. There are many topics that are relevant to everyone with JM, no matter what your age, but there are special issues for teenagers and young adults. Becoming an adult is a challenge under the best of circumstances. Add a chronic condition and there are even more obstacles to overcome.

That's where this section and TMA's web pages come in. Share your ideas with us! We rely on you to let us know what you'd like to see on these pages in the future. We want to highlight what has helped you in the past, how you've worked through tough times, and what questions you may have for the future.

Thank you for your valuable contributions!

Contact Kathryn at kathryn@myositis.org or 800-821-7356 x 601.

Finding friends

Email from a teenager with JM:

"I would love a contact my own age or somewhere close to it. My doctor is encouraging it, but she doesn't know many kids with JM because it's such a rare disease. I am in need of somebody to talk to who can really understand what I'm going through. My parents have been great, but let's admit it, they aren't the one getting needles every week and dealing with the side effects of steroids. I need to find people who can understand me and my language."

If this sounds like something you could have written, you're not alone. There are children, teenagers and young adults who feel the same way, wanting to talk to people who understand the ins and outs of dealing with JM day after day. Parents, brothers, sisters, and friends are central members of your support team, but without firsthand knowledge of JM and how it

actually feels, they just can't see the whole picture, no matter how hard they want to and how hard they try.

By the same token, parents and siblings may need to make a connection—someone who realizes the frustrations of not being able to take away their child's, brother's or sister's illness.

Your doctor doesn't treat another person with JM. No one at your school has ever heard of it. So what do you do? If you want to connect with someone, contact TMA and we can help. Sarah and Kacie "met" by email and then decided to get together in person for a weekend with their families. These relationships can become even more important as you arrive at unexpected hurdles along the way.

Carly (13) noted that when she was approached by someone newly diagnosed with JM, she gained so much by seeing how much this girl appreciated her responses and being able to help her cope.

Special help for college

The School for New Learning at DePaul University in Chicago, IL, developed the Inside Track Program, an innovative Chronic Illness Initiative to help students with chronic disease relapses and flares make the move from high school to college.

For some students with juvenile myositis (JM), a program like the Chronic Illness Initiative may be a useful stepping stone to a more traditional college experience.

The program is designed to help students 18-23 years old with a chronic condition like JM obtain a college degree or simply decide if they can manage the college experience on their own.

To find out more, call 866-765-3678, email lroyster@depaul.edu, or visit www.snl.depaul.edu/current/chronic.asp.



Summer safety

The American Academy of Dermatology (AAD) recently sent out a reminder that the sun's harmful ultraviolet rays don't just reach you outside—they come through windows, automobile glass and sunglasses. The AAD offers practical solutions for avoiding these rays:

- Sit away from direct sunlight.
- Use blinds or shades during peak sun hours.
- Wear sunscreen and protective clothing, indoors and out.

Read more about sun safety in the next JM Companion and on the Teens' Pages of www.myositis.org.





JUST FOR ME

SPRING 2006

Fun facts and news for children affected by JM

Pets and people

If you have pets at home, you know how great it is to have them sit next to you when you're feeling lonely or sad. Animals just seem to know how you're feeling. They'll also listen to you—and you can trust they won't tell anyone else what you've said!

Did you know that people study how animals help people? These people have found that animals helped people feel calmer when they were worried about something they were about to do. For people who had to stay in the hospital for several days at a time, animals helped them feel happier and not as lonely. Your own pets can do the very same thing for you!

If you have trouble moving your arms up and down, either because you don't feel strong enough or it's hard to stretch that far, bathing or brushing your dog can help you. Walking your dog or playing games with your pets can give you some exercise, too.

So whether you like to take your dog for a walk or tell your secrets to your cat, keep it up. You're helping yourself!



Baby names

Match the type of animal with the name of their babies:

Animals

Zebra

Camel

Alligator

Bat

Goat

Kangaroo

Deer

Monkey

Babies

Pup

Hatchling

Calf

Infant

Colt

Fawn

Kid

Joey



Infant
Kangaroo = Joey; Deer = Fawn; Monkey =
Zebra = Colt; Camel = Calf; Alligator =
Hatchling; Bat = Pup; Goat = Kid;
Answers to Baby names

Sudoku challenge

In the puzzle below, use the letters A-B-C-D but only once in each row (across), once in each column (up and down), and once in each 2 x 2 square box (box with darker lines around it).

A	C		D
	A	D	B
B		C	

B	D	C	A
C	A	D	B
D	B	A	C
A	C	B	D

SWIMMING WITH MYAH

Even animals you couldn't keep as pets can pick you up when you're feeling down. Lauren Adelman (now 14) was diagnosed with juvenile myositis when she was in fifth grade. She's feeling better now and enjoys a lot of activities. One summer, she had the chance to swim with a dolphin named Myah.

"Riding Myah made me feel like I could do anything. Even though I just met her, I trusted her to carry me safely through the deep water. It was so neat to feel her heartbeat," Lauren said.



7

Akeelah and the Bee

Wouldn't it be exciting to know that your name was the very same name of a movie character? Akeelah Anderson thinks so.

Akeelah is 6 years old and has juvenile myositis (JM). Her family found out that her name was also the name of the main character in the movie "Akeelah and the Bee."

The movie isn't about JM. It's about an 11-year-old girl who is good at spelling words, but her family doesn't encourage her much. Like children with JM, she works hard to deal with her problems and wins a spot at the national spelling bee.

Akeelah was invited to meet the stars of the movie, and her family was thrilled to share with them more about JM and what it's like to live with it every day.

Parents: Read more about Akeelah on page 8.

The Real Akeelah

Akeelah Anderson is like many children diagnosed with juvenile dermatomyositis (JM). She and her family are discovering what it means to live with a rare, chronic disease. Unlike most children, though, Akeelah recently had the thrill of a lifetime meeting movie stars Angela Bassett, Laurence Fishburne and newcomer Keke Palmer at the April 20

Hollywood premiere of the movie "Akeelah and the Bee."

What's the connection? In "Akeelah and the Bee," actress Keke Palmer plays a fictional Akeelah Anderson, an 11-year-old with a knack for spelling but lack of encour-



agement to pursue her gift. Even though the character does not suffer from JM—in fact, JM is not a part of the movie at all—she must overcome obstacles to compete in spelling bees, eventually winning a spot in the prestigious national spelling bee in Washington DC. Through her courage and success, she unites her neighborhood.

Learning about the movie by way of its pre-release publicity, 6-year-old

Akeelah Anderson discovered that her name was the same as the main character in the movie. This brought a smile to the face of this young girl who had recently learned she has JM. After her family contacted Lions Gate Films and explained the special

meaning of the movie to their daughter, Lions Gate extended a special invitation for Akeelah to attend the film's premiere.

Sponsored by TMA, Akeelah and her mother flew to Los Angeles to take part in the red-carpet premiere and spread the word about juvenile myositis. They shared TMA materials with the cast and production team of the film. Akeelah also met the one and only Fabio, who will be helping TMA make others aware of all forms of myositis. As you can see in the photo, Akeelah was overjoyed to be in the arms of the famous model.

Upon returning home to Minnesota, Akeelah's mom, Chamise, said, "The sound of giggles now flows throughout my home again, and I can't help but smile and hold back tears every time I hear them."

Read more about Akeelah and Fabio, the Italian-born actor and model, in The OutLook, attached.



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JM COMPANION

For children, families and friends affected by juvenile myositis