

## Minor adjustments aid recovery

Children grow up with praise for each step in their journey towards independence, so it's especially hard for children with juvenile myositis to find themselves temporarily unable to do some of the simple daily tasks they did before.

Parents often report their four and five year old children crawling from place to place after they have been walking for years, a situation that's painful to watch and distressing for the child.

In "Myositis and You" Kristi Whitney-Mahoney, Dorothy P.I. Ho and Susan Maillard describe some of the adjustments a family can make to help a child whose mobility is suddenly limited by the onset of JM, or who is in a flare.

In the chapter, "Adapting to Physical Limitations," the authors suggest that parents explain to their ill children that they will feel stronger again and will be able to climb stairs, dress themselves and eventually participate in family activities. It's also important that parents recognize the difference between what they should expect of children with active disease who are feeling very weak and sick, and what to expect when children are recovering, but have muscles weakened by the double whammy of disease and the weakness that follows lack of physical activity.

When the disease is active, the authors say, children need rest, accompanied by passive exercise and careful monitoring of activity. When recovering, parents will want to gen-

tly encourage their children to increase exercise in small increments, gently pushing a little further each day.

### When there's a flare

Children who have difficulty walking more than a few steps may be able to use the stroller they had when they were younger.

If your child can sit up in a wagon, new lightweight wagons with backrests and seatbelts allow toddlers and school-age children to sit in comfort on walks and trips, especially if they're propped up with pillows and blankets. This will allow a child in a flare to enjoy outings with the rest of the family. The Arthritis Foundation suggests that, on family trips, you may want to plan two different agendas in the early morning, with the child with JM getting ready for the day and the other children going on the day's most strenuous outing. Later, the family can come together for activities that every member is able to do.

If your child is able to crawl up and down stairs, it's okay for him or her to crawl from floor to floor. If your child cannot climb stairs safely, put him or her on a floor with a bathroom, even if you have to set up a temporary bed or crib.

It's also important to have the child near you or another caregiver during the day, especially if the child spends most of the day in bed. Change the child's position often, and move him or her to a chair for part of

the day. It's very important that the child does not rest for long in one position, both for comfort and health. Children who remain in one position for too long are at risk for skin problems as well as muscle and joint pain.

Ask your doctor about passive exercise if your child cannot exercise on his or her own. Consistent exercise appropriate to your child's level of disability will allow him or her to avoid stiffness and painful muscle contractures and to resume daily chores like dressing and using the bathroom more quickly once the flare has passed.

**Range-of-motion exercises** keep muscles stretched and joints flexible. These are especially important for children whose muscles have become contracted from reduced activity. Children who are too weak to stretch their joints and muscles need help from their parents under the supervision of a rehabilitation specialist (a physical therapist or occupational therapist or an OT or PT aid). In passive range of motion exercises, each joint is moved through its fullest possible range. These exercises are "passive" rather than "active" because you are moving the child's joints for him or her. The Children's Clinics of Minnesota have some tips for parents as they work with their children to preserve range of motion:

- Use only under the guidance of an occupational or physical therapist.
- Move one joint at a time, supporting with one hand just above and the other hand below the joint.

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## THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600

Alexandria, VA 22314

P: 703.299.4850

P: 800.821.7356

F: 703.535.6752

Email: [tma@myositis.org](mailto:tma@myositis.org)

Web: [www.myositis.org](http://www.myositis.org)

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Editor: Theresa Reynolds Curry

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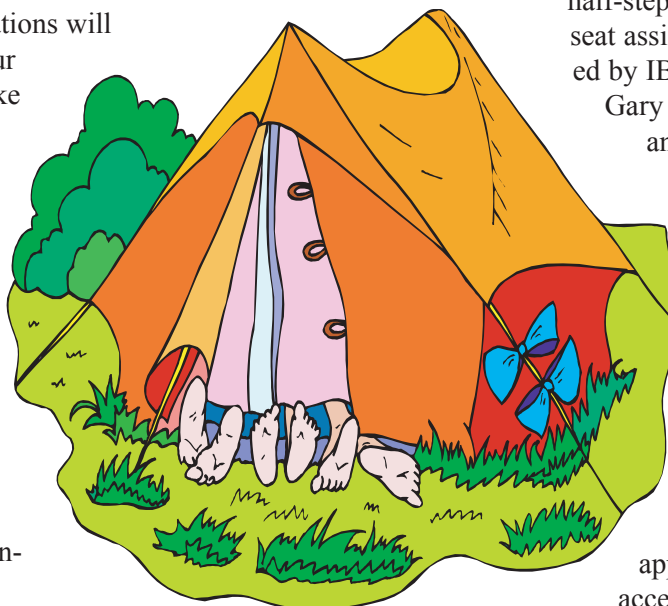
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### From the editor:

Register now (it's free!) for TMA's Juvenile Myositis Conference, July 17, 2010, a family-friendly gathering at the Mayo Clinic in Rochester, MN. Dr. Ann Reed, a pediatric rheumatologist at Mayo, and other experts will discuss the disease course, symptoms and treatment for JM. Other presentations will help your teens take control of their care, give insights into family dynamics, and explore the mind-body connection.



A young adult who has been through the trials and tribulations of JM will speak of her personal experience with the disease and how she's doing now.

The Conference is free to members of TMA and their parents, and you are encouraged to stay at the nearby Springhill Suites, where TMA has a group rate of \$89 per night. The hotel offers a free shuttle to the Mayo Clinic where the sessions will be held.

Visit the TMA website and check out the "News and Announcements" section, where TMA posts timely items of interest to myositis patients and families. Many of the announcements are notifications regarding research that has been posted on TMA's website, including extensive reports by Drs. Lisa Rider, Lucy Wedderburn and Adam Huber. Visit TMA's site often to keep up with current thinking on JM treatment.

Some of you have asked why we send both the adult and juvenile newsletters to all subscribers. Take a look at the "OutLook" – TMA's adult newsletter – and you may find some items of interest, including some time-honored advice from myositis patients on helpful items. Your kids and teens may be interested in the

half-step and the uplift seat assist recommended by IBM patient

Gary Wooldridge; and the kitchen

gadgets and bath items that Anda Cochran has found to make her life easier.

And by all means, check out the iPhone

app that locates accessible bathrooms and eateries in local malls.

The Summer "Companion" will have more on the JM Conference, an exploration of what makes some children resilient, and the results of JM clinical trials. Email [TMA@myositis.org](mailto:TMA@myositis.org) with your suggestions. Please let us know what else you'd like to see in these pages.



## Minor adjustments

*Continued from cover*

- Move slowly and steadily, avoiding rapid or abrupt motions.
- Move in a straight line from starting position to ending position.
- Move only to the point of resistance. Do not force the movement, as this can cause injury.
- Do the exercises when your child is relaxed, such as during or after a bath.
- Having a routine will comfort your child and increase acceptance. Do the exercises at the same time and in the same place every day.
- Use calming music in the background.
- Make it fun! Sing with your child. Make up stories.
- If your child is older, the therapist will show your child how to use hot baths, hot packs, hot wax or cold treatments before exercise to make the therapy easier.

## Getting stronger

In “Adapting to Physical Limitations” the authors suggest you encourage a child who is recovering from a flare to walk as long as he or she can, prolonging the time walking unassisted a few minutes after he or she first feels tired. A few more steps each day will build up stamina and strengthen muscles.

Your physical therapist will ask about your child’s level of activity. Much of children’s muscle-building and strengthening activity comes from their daily routine: swimming, sports, running and regular play. If your child has difficulty resuming these activities gradually, you may want to ask your doctor about seeing a physical therapist for strengthening exercises.

**Strengthening exercises** build muscle, strength and endurance. Stronger muscles help support muscles that are weak. Doing these exercises on a regular basis is challenging, and your child will need a lot of family support as he or she prepares to resume his normal recreational outlets.

The goal is always to have your child get most physical activity in natural ways. Whenever possible, have your child resume traditional recreational activities. These activities exercise joints and muscles, develop



important social skills and make exercise fun for your child.

Some children do better than others at getting back into team sports and organized recreation. Older children may be embarrassed that they’re weaker or slower than the other children. Some may be open about their disease; others may be very secretive. Still others, especially those who have been outstanding athletes, will push themselves to the point of pain or injury. Whatever your child’s particular case, suggestions from other JM parents may help:

- If your child is not able to keep up with a group, encourage activities like bike-riding or swimming, activities that limit stress on muscles and can be done with other children but don’t necessarily include competition.

■ One JM family works with their doctor to support their child, an outstanding athlete. “We know he’s doing too much,” they said, “but it’s in his personality to push like this and we monitor him. His doctor agrees that there’s a risk but also agrees that, so far, it has been worth it.”

■ Humor works wonders: “Sarah is always at dance practice, whether she can dance or not,” says Sarah’s mother. “If she falls or does something clumsy, she laughs at herself and goes on. When the other dancers laugh, it’s clearly with affection.”

■ “We saw Josh retreating into video games and television,” said one father. “He didn’t want to be laughed at, so he just kind of gave up.” It was a painful process, but Josh’s parents limited his sedentary time and came up with all kinds of ways to keep their son active, including horseback riding, a flag football team that brought him into contact with a new group of friends, tennis and surfing. Eventually, Josh was able to return to his soccer and softball teams, but he kept some of his new interests, too.

■ Allison was a runner and her parents feared the long distances would damage her weakened muscles. She checked with her doctor, and used elastic bandages, ice packs and lots of recovery time to keep up with the sport she loved.

## Loosen up

Some children feel especially weak or stiff when they get up in the morning or after a nap. Taking a hot bath or shower, using a sleeping bag, sleeping on a heated water bed, doing range-of-motion exercises first thing in the morning, and using a hot or cold pack helps relieve stiffness. After exercise, muscle soreness sometimes responds to cooling. Use a plastic bag of ice, or even a bag of frozen peas to help relieve the pain.

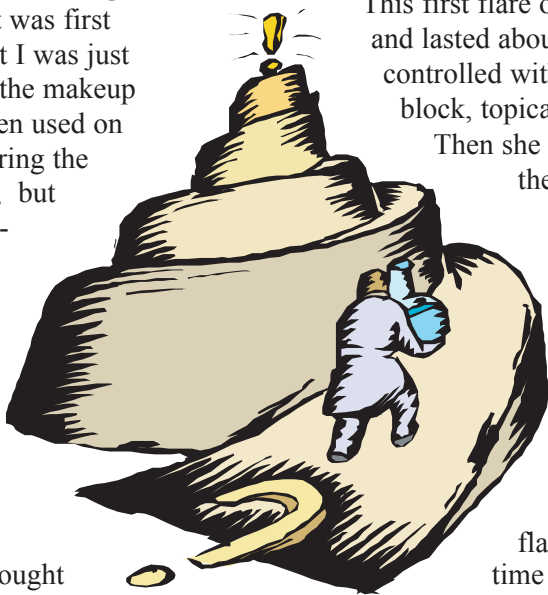


# WHAT DID YOU NOTICE FIRST?

## JM parents and patients talk about early symptoms and signs

**My daughter's first symptoms were really vague.** She was cranky and extremely fatigued. I thought it was from getting adjusted to a new schedule for first grade and longer days. That was in the fall of 2003. Right after the holidays, the rash appeared on her eyelids, chest and back. To make a very long story short, after repeated visits to the pediatrician (with me whining and worried) we were sent to Children's Memorial in Chicago. By the time my daughter was admitted, she could not hold her head up, sit up, or swallow. She was diagnosed in March of 2004 on her 7th birthday. Right now she's fantastic! We just tapered her off Cellcept. Her only medication left is Plaquenil. We're still extra cautious about germs and sun protection, always will be, but I think she's pretty much reached remission!

**Well, the first sign for me was the rash.** It was first thought that I was just reacting to the makeup that had been used on my face during the Nutcracker, but when it didn't go away after a month, my mom started to get worried. I was taken to a dermatologist who thought I had eczema. After I didn't respond to treatment, he told me I just looked like that. Then I started to get muscle weakness which made my doc run blood tests, thus discovering the myositis! It took over six months to diagnose.



**Our daughter was diagnosed when she was 4.** She is now 9, and has never been in remission. She has been on prednisone, IV Solumedrol, Plaquenil, methotrexate (both oral and sub q), cyclosporine, Cellcept and IVIG. About 6 months before she was diagnosed with a muscle biopsy, she had a cold and flu that we thought triggered the JDM. We had also moved into a new house about 18 months prior to diagnosis.

**In 1995 my daughter got strep throat.** It took a few rounds of antibiotics before she got better. After that, we noticed a red spot on the bridge of her nose. It looked like a bruise and we thought that she'd just bumped herself, however it got bigger instead of going away. We took her back to the doctor and were told that a rash commonly follows strep throat and that it would go away. It didn't, but continued to get worse. We went to several doctors and were given a variety of diagnoses before we found a doctor who properly diagnosed her. This first flare only involved her skin and lasted about four years. It was controlled with sun avoidance, sun block, topical meds and Plaquenil.

Then she was able to come off the Plaquenil for the next four years. She maintained with just sun avoidance and sun block. She still had a little rash but it was considered by the doctor to be "controlled."

In 2003, she flared again, and this time it came back with a vengeance. The rash practically covered her and she was having difficulty walking, standing etc. I can't tell you how many times we had to pick her up and carry her because she would give out. The problem was that the lab tests being used at that time

were coming back normal so the doctors were not aggressive with treatment.

In 2004, I contacted Dr. Lisa Rider and my daughter was accepted into one of her studies. The plan of care was implemented when we returned and finally she started showing signs of improvement. Approximately 6 months later we went back to the NIH for a week to complete the second half of the study. As some meds were tapered, her doctor added Cellcept to her cocktail of meds. She continued to show improvement, and by January 2009 she was off all meds and received her last dose of IVIG.

## Recommend a doctor

We often get questions about where to find doctors experienced with JM. Do you have a doctor you'd care to recommend? Please let us know so we can add them to our list of JM doctors. We'd also like to make our brochures, newsletters and other materials available to doctors seeing myositis patients, so let us know how to reach your favorite doctor. Email [TMA@myositis.org](mailto:TMA@myositis.org).



# JUVENILE MYOSITIS RESEARCH

## Currently of interest

### Rituximab in life-threatening juvenile polymyositis

Belgian researchers report the case of a patient with severe interstitial pneumonitis, mild polyarthritis and polymyositis, accompanied by the presence of anti-Jo-1 antibodies diagnosed as anti-synthetase syndrome. The concurrence of anti-Jo-1 with anti-Ro/SSA antibodies leads to a more severe form of interstitial lung disease. This patient was referred to the Belgian hospital because of life threatening respiratory failure. He did not respond to prednisone and cyclophosphamide, but was successfully treated with two infusions of rituximab.

The child's clinical condition improved very rapidly. His response to treatment was well correlated with the fall of levels of serum soluble IL2-receptor. The doctors confirmed the decrease in lung disease activity using PET-scans before and after the two rituximab infusions.

### MRI for JM

We've often heard pediatric rheumatologists say, "Treat the child, not the blood tests." The use of MRIs may be one way to do this. The distinction between active muscle inflammation and disease damage can be difficult, especially when a child is undergoing treatment for active disease and the blood tests don't seem to match the functional muscle scores. The gap between the clinical appearance and

symptoms of a patient and the blood-test results is a gap that continues to cause confusion in treatment.

A Swiss report demonstrates the benefit of whole-body magnetic resonance imaging (MRI) as a diagnostic tool for detecting and managing disease in JM. The report

follows one patient with JDM who was monitored using clinical examination, muscle enzyme tests, muscle scores and whole-body MRI.

During treatment, the patient was seen several times when there was no clear connection between the clinical picture, muscle enzyme tests and muscle scores. The authors reported that whole-body

MRI was reliable in assessing the true state of the disease, providing important information for treatment. The authors say this has promising implications for preventing further damage in children with active disease that's not clearly indicated by the laboratory reports.

MRI has also been used to examine changes below the skin of juvenile dermatomyositis, especially the swelling that's present in as many as 85 percent of patients. Researchers used weighted relaxation time measurements to monitor intramuscular swelling after a physical therapist led an exercise program in children with active and inactive JM.

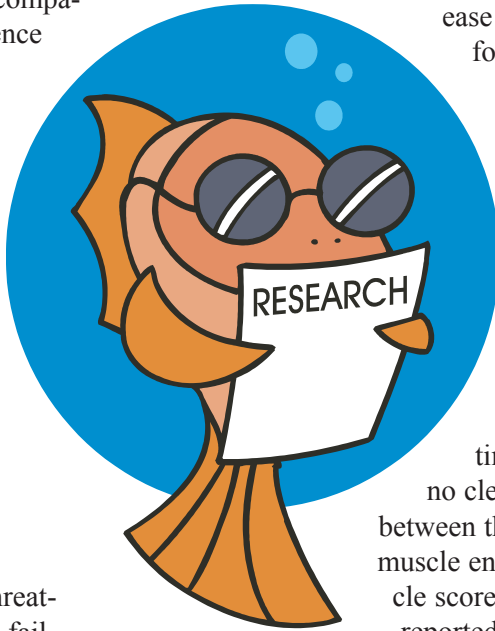
The MRI was able to confirm that the appropriate exercise did not increase swelling, an important step for adding to present knowledge about JM. No changes in the degree of inflammation were detected within the muscles immediately after the exer-

cise as compared with before it. MRI was therefore helpful in adding to other evidence indicating that moderate exercise is safe.

The researchers were also able to detect the development of calcinosis before it was felt or seen. MRI is useful in detecting milk of calcium as fluid collections, with the results varying with the amount of calcium.

MRI has also been used for scans of the thigh muscles of children with active and inactive juvenile dermatomyositis, finding that relaxation times were significantly increased in active juvenile dermatomyositis compared with inactive juvenile dermatomyositis, and relaxation times in healthy children.

There were also good correlations between the MRI scores and the clinical measures of muscle strength and function when the clinical measures did not correlate with the muscle enzymes.



## Volunteer this summer

If you are a JM family member, or have recovered from JM and are strong enough to help someone else with a muscle disease, you'll find it rewarding to volunteer at one of the many camps for children with chronic disease. Camps look for teenagers who have experience with handicapped aids, medication and muscle weakness; and for those with understanding and compassion for children who struggle with weakness. As someone with experience with JM, you are uniquely qualified to work with young patients.

No camps nearby? You can still make a difference with your special skills and knowledge. Volunteer with a disabled children's program at a local school, handicapped sports league, park, YMCA, Parks and Recreation Department, Boys and Girls Club or children's hospital. Remember that you are especially well-suited for this kind of work because you understand what these kids are going through. Your experience may be exactly what a child needs for encouragement and hope.

If you're not strong enough yet to help a child with outdoor activities, consider another kind of volunteer work that doesn't require a lot of muscle power. Libraries, children's rehab centers, school summer programs and all of the groups mentioned above also need tutors, craft aids, story tellers and drama coaches. When you call, mention that you have experience with muscle disease and would like to help a child with a disability. Be pre-

pared to furnish references, a short resume, and a transcript from your school.



## Take a look at TMA

If you are now taking a part in your own medical care, you may be keeping track of questions to ask your doctor. It's important to do this because he or she is the one who knows your own particular case.

But for everyday, general questions about JM, you may find answers on TMA's website at [www.myositis.org](http://www.myositis.org). You will find information about JM in several different places. You'll want to look at the reports on JM under "Research." You may also want to look at the DM studies and trials reported on the "Polymyositis and Dermatomyositis" sections of the "Research" page.

You'll find detailed information on the disease-specific pages of the website at "Types of Myositis." Be sure to check out "Juvenile Myositis" and "Dermatomyositis." You'll find a great deal about treatment, medications, complications and side effects. You can also learn about autoimmunity on these pages.

For more specific information on teens and young adults with JM, go to the "Teens" page under "Children and Families." These pages highlight unique issues faced by teenagers and young adults living with myositis. Find these pages under the "Patients, Families and Caregivers" tab at the top of the home page. Here's what you'll find:

**Disease information**, with description by other teens about how myositis feels for them. You'll also find information on tests and treatment.

**Personal stories** written by other young people about their battle with myositis. You can add your story and photo, too.

**How you can solve problems** such as what to eat, what to wear, and other topics.

**How to get involved** to help people understand juvenile myositis, and to raise funds to help researchers find a cure for JM.



## Go to the vault

TMA has published many hundreds of pages aimed at teens with JM in the "JM Companion," including articles about continuing education, pregnancy, STDs, special training, joining the work force and being an advocate for your own health. Most of the past issues are available to TMA members online. Go to "Community" and select "My TMA" to view past issues. If you need help finding information on any topic, email [TMA@myositis.org](mailto:TMA@myositis.org).



## Have questions? Find the answers at TMA

Whenever you have a new question about myositis, the place to go is TMA's website at [www.myositis.org](http://www.myositis.org). Here's what you'll find.

**Answers about JM**, including how it will make you feel, and what you can expect when you go to the doctor.

**Other children with JM**, including their photos and their stories about how they found out they had JM, how they live with it, and how they feel now. You'll also have a chance to send your photo and tell your story online.

**Kidstuff**, with tons of things you can learn:

■ **How to be safe** in the sun and why it's important to wear sunscreen all the time.

■ **Why pets do more** than just eat and play. Did you know that animals can help people feel calmer and happier?

■ **Why art can help you**, especially when you can't be as active as before. Coloring, painting or creating any type of art can relax you and make you feel better.

■ **What kind of doctors**, nurses and other people will take care of you. Learn who's on your health teams and how you can help.

■ **How to keep moving**. If you can't exercise yet, here are a few ideas to keep you active.

■ **What's for dinner?** What you eat can make you feel better or worse.

■ **How you can help**. Everyone can make a difference by teaching people about JM or raising money to help find a cure.

■ **How to get in touch** with the TMA staff, with questions, complaints, suggestions or other ideas.

■ **Have fun!** You can send a postcard or e-card, find an e-pal, look up a recipe or color a picture, all online.



## Go to camp!

Find a camp near you that is okay for someone with JM and go to it. TMA will pay the camp \$100 of the camp's cost. Email [TMA@myositis.org](mailto:TMA@myositis.org) to find out the details. See more details at [www.myositis.org](http://www.myositis.org).



## WORD PUZZLE: Finish the sentence with the words listed below.

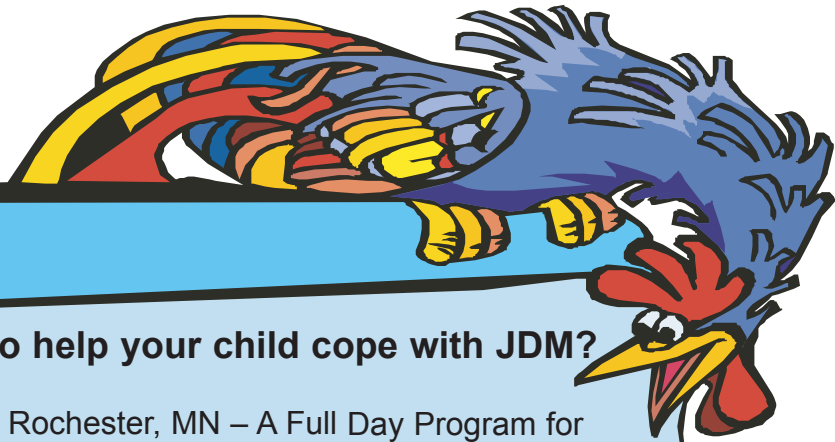
1. I am scared of \_\_\_ s.
2. Let's tell scary stories around the \_\_\_ m \_\_\_ r \_\_\_.
3. We are going to catch some \_\_\_ s \_\_\_ down at the lake.
4. I love eating grilled \_\_\_ d \_\_\_.
5. We can roast some \_\_\_ h \_\_\_ l \_\_\_ over the campfire.
6. The \_\_\_ y is so clear today.
7. The relay \_\_\_ c \_\_\_ will start in 5 minutes.
8. There is not a cloud in the sky. The \_\_\_ u \_\_\_ is shining so bright.
9. Please make sure your \_\_\_ k \_\_\_ are tied before the race.
10. Let's take a \_\_\_ m in the lake.

**BUGS, CAMPFIRE, FISH, HOTDOGS, MARSHMALLOWS, RACE, SKY, SNEAKERS, SUN & SWIM**



THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600  
Alexandria, VA 22314



### Want to learn more to help your child cope with JDM?

July 17th at Mayo Clinic, Rochester, MN – A Full Day Program for  
Parent and Child

- Disease Pathogenesis – Ann M. Reed, MD, Chair, Pediatric Rheumatology
  - Staying Strong – Leslie Antiel, Pediatric Physical Therapy
  - My Experiences with JM – Peyton Hutchins, Young Adult
- Mind Body Connection – Stephanie Yerhot, Mind Body Instructor
  - Coping With Illness – Dr. Daniel Hilliker, Pediatric Psychologist
- Teens Taking Charge – Fran Anderson, RN, Pediatric Rheumatology and Paul Freitag, Social Work

Registration is free. Lodging provided by the SpringHill Suites for only \$89.99.  
For more information or to register for the Conference, email [Quineesa@myositis.org](mailto:Quineesa@myositis.org)  
or call 1-800-821-7356, extension 3.

We hope that you will attend this special day set aside for you and your family.

# JM COMPANION