

Conference updates

As always, sessions from The Myositis Association's Annual Conference will be summarized in upcoming publications.

Lisa Rider, MD, TMA medical advisor with a special interest in juvenile myositis (JM), focuses on childhood forms of myositis in her Medical Panel presentation and Meet the Experts question-and-answer period. We will highlight her talks in both the Fall JM Companion and the OutLook Extra Treatment Issue.

Other sessions include what you should expect during the course of JM, how to cope with JM together as a family, working with your child's health care team, and complements to your child's therapy, with special presentations on art, music and water therapy.

Calling all artists

TMA wants children with JM, as well as their siblings, to share their masterpieces. We hope to include children's drawings on note cards, e-cards, publications, and other TMA materials to raise awareness of JM. Have your children send in their artwork on white 8 1/2 x 11 paper, and include names, ages and relationship to JM, like self or brother/sister. (We will use only first name, age and relationship when identifying the artist.) Also include your contact information in case we need to reach you. Please send these to TMA and to the attention of Kathryn Spooner.

Email kathryn@myositis.org, call 800-821-7356, or mail to TMA, 1233 20th Street NW, Suite 402, Washington DC 20036.

Encourage activity that's fun and functional

We've covered exercise and juvenile myositis (JM) in past articles, and parents have expressed interest and asked for more. The difficulty in actually recommending an exercise program is that physical therapists and rehabilitation specialists can't be prescriptive in speaking to a general audience, or provide the same step-by-step directions for each JM child. Instead, like the disease itself, the ideal regimen varies widely among the JM population, so only very general guidelines are possible. Ideally, the information in this article will lead to discussion with your doctor about a program specific to your child.

How important is exercise?

Doctors often focus on the medicines that will be most effective for your child. They don't always think in terms of exercise, so they may not recommend a therapist or any home exercise program at all. This trend is shifting in some cases, where physicians recognize the importance of exercise, nutrition, and other complements to your child's treatment plan, but this may be more evident in larger academic centers or research hospitals than in smaller hos-

pitals or private clinics, says Galen O. Joe, MD, staff physiatrist, Rehabilitation Medicine Department at the National Institutes of Health (NIH) Clinical Center. (Physiatrists specialize in physical medicine and rehabilitation, treating individuals with chronic pain and musculoskeletal diseases.)

That's why parents are encouraged to take a proactive role. Parents should be included in any exercise

regimen,

says

Minal

Jain, MS,

PT, PCS, a

pediatric physi-

cal therapist in the

Rehabilitation

Medicine Department,

NIH Clinical Center.

"When children are already

motivated," she says, "we

can give them a range of

exercises to take with

them." Jain suggests

that therapists

identify the

three

most

important

exercise goals

to keep the children

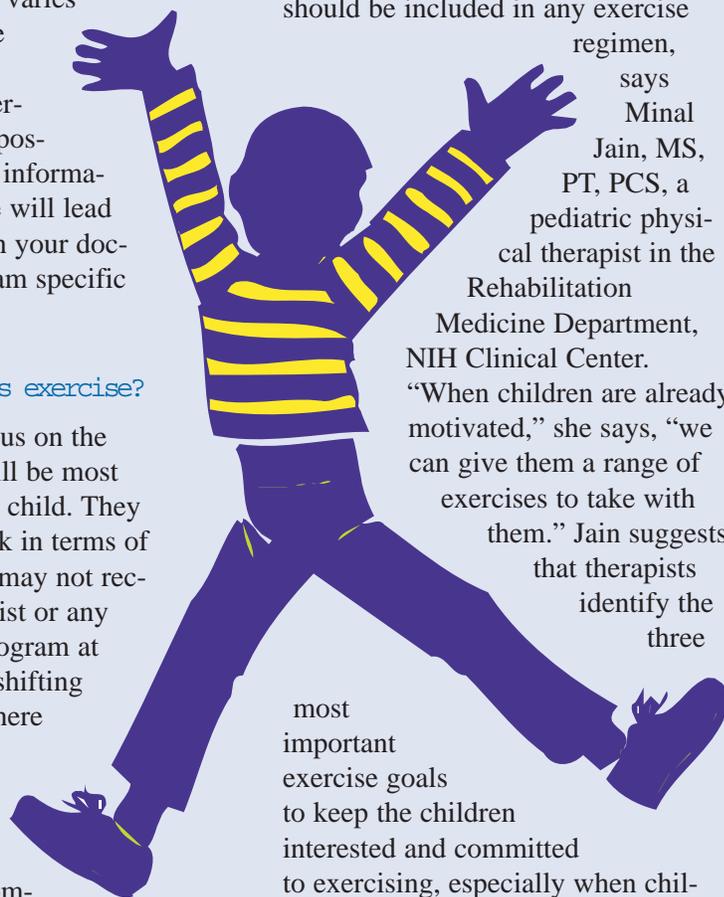
interested and committed

to exercising, especially when chil-

dren were not active before their

diagnosis. When she speaks to parents

of JM children, Lisa Rider, MD,



See Activity on page 3

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Kathryn Spooner and sons Rhys (left) and Caden (right).

Dear Families and Friends:

As a parent welcoming our third son (Calum) in August, I'm constantly amazed when I read your emails and message board posts calmly describing your days balancing carpools, household chores, doctors' appointments, careers, and - most importantly - quiet (?) time with your families.

Parents and children who have "been there" inspire and reassure those family members just beginning their lives with JM, reaching out to them with wisdom born of experience. Online bulletin boards, phone calls, and regional and national events are ways in which you give struggling families a much-needed sense of community and belonging. I've been fortunate to meet many of you in person, and am looking forward to getting to know more of you at the Annual Conference in Cleveland. When we hear your concerns, we better understand your needs and try to meet them. So I hope you'll continue to share your ideas, concerns and suggestions.

Enjoy this issue of the JM Companion, which includes articles on exercise and participating in research studies, as well as a touching poem written by a teenager with juvenile myositis. As always, there are pages dedicated to children - with information, fun facts and activities for all ages.

Thank you for continuing to support TMA and all of the members, friends, and families dealing with JM.

Warmly,
Kathryn

Finding research

Though juvenile myositis is rare, there are many physicians and scientists who have dedicated their research efforts to studying the causes, possible treatments, and potential cures for JM. They also look at ways to prevent or treat side effects from medicines used in JM. TMA members, both children and adults, have participated in research studies to further our knowledge of this rare disease, and two children's experiences are highlighted in this issue of the Companion.

To find out more about JM research, visit PubMed at www.pubmed.com for a listing of journal abstracts. One recent study in New Zealand touches on one concern of many parents - their children's bone health. The researchers look at alendronate (Fosamax®) for children receiving glucocorticoid treatment (like prednisone), with thinning bone

as a possible side effect. The study's authors found that alendronate given once a week is well tolerated in children, suppresses bone resorption, and may improve bone density in certain parts of the body. This treatment did not affect bone growth, however, and the researchers highlight the need to look separately at changes in bone size and in volumetric bone density. Larger controlled studies are needed to determine if alendronate helps reduce fractures or increase bone mass.

Note to parents: Read the abstract of this study, "Effects of once-weekly oral alendronate on bone in children on glucocorticoid treatment," at www.pubmed.com. You'll find other research abstracts - as well as ongoing studies enrolling patients - on TMA's web site in the Juvenile Programs pages.

Activity,

continued from cover

Deputy Chief of the Environmental Autoimmunity Group, NIEHS, NIH, notes that children tend to do better with a structured exercise program. Over time, the therapist can fine-tune the program to fit the child's changing abilities and needs.

Finding and keeping your child's interest

“Let patients know they need to find motivation within themselves,” says Lisa Christopher-Stine, MD, MPH, a rheumatologist and an instructor in the division of rheumatology at Johns Hopkins University in Baltimore. The children need to take on more responsibility themselves, which will in turn keep them motivated to work harder and hopefully garner better results.

“Relate exercising to a functional task,” adds Dr. Joe. Recognizing that sticking to the exercise program will lead them back to what they really want to do – baseball, soccer, dancing, or swimming – inspires many children. As always, though, children need to be careful not to overdo it in the excitement of working their way back. It's important to have goals but also to know it may take time to reach them.

For school-aged children, you may be able to tie in a specific exercise program with the school's physical education class. Therapists are willing to give suggestions to parents, who in turn work with the schools to formulate an appropriate plan, says Jain. But working together at home remains the most important part of exercise rehabilitation. Parents know their children better than anyone, and you recognize what your child is able to do and when they aren't ready for certain activities.

“It's not always a matter of specific exercises,” says Jain, “but doing things to keep moving – going to the park, the mall, etc.” It may take sev-

eral weeks to nail down a program that your child will use for several months, adds Michael Harris-Love, PhD, TMA medical advisor and clinical specialist in the physical therapy section of the Rehabilitation Medicine Department, NIH. Many exercises can be modified in some way, so you can find those activities that your child enjoys and adapt them to fit your child's current abilities.

Remember exercises for bone health, too, especially for children on prednisone who are at a higher risk for osteopenia and osteoporosis. Taking prednisone, or any medicine, has not been shown to be exercise-prohibitive, says Dr. Christopher-Stine. Side effects like fatigue may influence exercise, but the medicines themselves should not deter you from encouraging your child to be as active as possible.

When to move forward, when to hold back

Like most aspects of JM, deciding when to increase the number or level of exercises and when to slow down is individual. “Patients have the common sense to guide themselves,” says Dr. Christopher-Stine. When your child is fatigued or the pain is debilitating, for instance, it's time to pull back. A skin flare, however, is not always tied to muscle involvement, so she encourages people to keep exercising as they feel they are able. When people start to feel better, though, they tend to go overboard. Ease into exercising, she says, and don't be discouraged when there's a bump in the road.

“Always err on the side of caution,” says Dr. Harris-Love.



LET'S GET TO THE POINT

■ Children have different needs, and exercise programs and suggested activities reflect this variance from child to child.

■ Parents need to stay involved, taking an active role in devising and implementing an appropriate exercise plan. Working at home with your child is the mainstay of effective therapy.

■ Find a way to help your children “buy into” exercising so the daily routine doesn't become a hassle but instead a step in a positive direction.

■ Work with your child's school to use physical education classes to your child's advantage.

■ Be aware of how your child is responding to different exercises and what this really means. Children may not express how they're feeling outright, but you know them well enough to interpret their signals.

■ If in doubt, slow down. Though exercise is important, it's better to be safe than sorry in terms of possibly overdoing physical activity.

PLAY A PART IN LEARNING MORE ABOUT JM

Participating in research studies helps your child and others with JM

Twelve appointments with multiple doctors, nurses, technicians, and hospital staff over a few days doesn't sound like fun for anyone, especially children.

But for Kristen* and Kevin, two children with JM, their experiences were great ones – ones they and their families would do all over again.

Detailing every appointment, Kristen's mom Jennifer explained that the staff members were friendly, helpful, energetic, and comforting, making them feel at ease every step of the way.

After learning about the National Institutes of Health (NIH) on The Myositis Association's online bulletin boards, both children's mothers contacted Lisa Rider, MD, Deputy Chief for the Environmental Autoimmunity Group at NIH and TMA medical advisor, to find out more about the research studies currently underway at NIH. Through this contact and with a referral from their doctors, Kristen and Kevin were soon enrolled in NIH studies.

"I was at a loss with our local doctor," explained Jennifer. "I felt that more could be done or tried to help her, but her doctor didn't feel that she could do anymore other than refer her to other doctors." She decided to do something more herself. For Kevin, and his mom, Connie, the decision was just as easy – they have always wanted to find a cure, and research is the key.

More about Kristen and Kevin

Kristen was diagnosed with juvenile dermatomyositis when she was only 2½ years old. Now 11, she continues to take daily prednisone and Plaquenil, weekly methotrexate, and monthly Solumedrol and IVIg infusions. Yet the JM is still active in both her skin and her muscles, and her parents decided to do more.

Kevin is a 12-year-old boy,

with dreams of becoming a professional baseball player. He was diagnosed with JM in 2003 but may have had symptoms as early as 2001. He is currently taking prednisone, IV methotrexate weekly, Solumedrol every two weeks, Plaquenil, and monthly IVIg.

Taking part in the research study

Kristen's first appointment at NIH was with the "home base" nurse, someone who would be with them throughout the study process. After that, the schedule was filled with appointments but still left free time to enjoy the facilities at the Children's Inn (see *All the comforts of home*) and nearby attractions in the afternoons and evenings. Kristen and her mom never waited more than ten

minutes between appointments, which included two magnetic resonance imaging scans (MRIs), a consultation with a dermatologist, a physical exam and medical history questionnaire, manual muscle testing, rehabilitation evaluation, bone age x-rays, isometric dynamometry, ophthalmology exam, muscle ultrasound, photographs, and an endocrinology consult.

The first two doctors were both thorough and informative, giving Kristen and Jennifer greater insight into this disease that had become a major part of their lives almost nine years earlier. "My only regret," said Jennifer of the consulting dermatologist, "is that she is so far away and that we can't have her for our dermatologist here." After visiting with Dr. Rider, she was even more at ease with her decision to bring Kristen to NIH for the many tests that were needed to comply with the research protocol.

One of the next appointments was with Mina Jain, a physical therapist in the Rehabilitation Medicine Department of NIH. (See *Encourage activity*, cover.) "She made the appointment fun for her," said Jennifer, "and provided exercises that would be both beneficial and enjoyable for her." This theme continued



throughout the following visits, with doctors, nurses and staff seemingly going out of their way to make the tests enjoyable while explaining every step along the way.

Kevin's schedule was equally busy but well planned, said Connie. From acceptance into the study through the tests themselves, they ran into no complications.

Why participate?

Would they participate in a research study again? "Without a doubt," said Jennifer. "It helps with the research to provide more information about the disease, and the doctor's there were able to provide more treatment options to our local doctor."

"I recommend this very much to other families with dermatomyositis," added Connie, "because this disease is so rare. We have to stick together and help with research or we will never find a cure. We cannot let this happen to another child."

* "Kristen" requested that her real name not be used.



All the comforts of home

"When you enter The Children's Inn, you walk into a beautiful area that just welcomes you to feel at home and relax," says Jennifer, who went with her daughter Kristen* and family to participate in a research study. "It has a large stone fireplace with a cozy fire, a relaxing loft with a wall of books along with sofas and chairs that beg to be used. It has a play area set up below the stairway that is filled with oversized stuffed animals that the children are encouraged to run, jump, and sit on."

The Children's Inn at the National Institutes of Health (NIH) Clinical Center offers families a place to stay while their children participate in clinical research in any of NIH's institutes or centers. The Inn has 59 sleeping rooms, along with a number of specialty rooms for parents and children to use throughout their stay.

Kristen and her family appreciated having a warm place, not just a standard hotel room, to relax after a long day of tests and questions. They enjoyed a view of the wooded area behind the Inn from their room, but

more memorable than that, Kristen and her younger sister had fun with other children in the indoor playhouse, game room, and playground.

Kevin (12) and his mom Connie also speak highly of the Children's Inn. They joined a family dinner group around the table the night they arrived, meeting other children and parents there for various research protocols. Kevin took advantage of the computer room to email his friends at home, and he and Connie watched DVDs, played bingo, and shot some pool with other families. "It was a very warm and caring place," says Connie.

For more on the Children's Inn, visit www.childrensinn.com or call 800-644-4660. Find clinical research studies currently enrolling children with juvenile myositis at www.myositis.org. Click on Resources and then Clinical Trials, or call TMA at 800-821-7356 for a list of current research studies.

See Other Facilities on page 6 for more information.



RESEARCH STUDIES ENROLLING JM PATIENTS

For more information on these and other studies, including criteria and procedures, visit the NIH site at <http://clinical-studies.info.nih.gov> or TMA's listing of current clinical trials at www.myositis.org/health_professionals/clinical_trials.cfm; or call TMA at 800-821-7356. The list below gives the study name and institute or organization investigating JM.

Twin-Siblings Study: Pathogenic studies in families with twins or siblings discordant for systemic rheumatic disorders; National Institute of Environmental Health Sciences (NIEHS), NIH.

Natural History Study: Studies in the Natural History and Pathogenesis of Childhood Onset and Adult Onset Idiopathic Inflammatory Myopathies; NIEHS, NIH.

Calcinosis Study: Studies on Tissues from Patients with Fibrous Dysplasia of Bone/McCune Albright Syndrome and Other Disorders of Calcified Tissues; NIEHS, NIH.

Total Body Irradiation in Children with Treatment-Resistant Disease: Pilot Study of Total Body Irradiation in Combination With Cyclophosphamide, Anti-thymocyte Globulin, and Autologous CD34-Selected Peripheral Blood Stem Cell Transplantation in Children With Refractory Autoimmune Disorders; Fred Hutchinson Cancer Research Center, Seattle WA.

Rituximab: Rituximab Therapy in Refractory Adult and Juvenile Idiopathic Inflammatory Myopathy (IIM); not yet recruiting patients – check TMA's web site for updates on this study led by TMA Medical Advisors Chester Oddis, MD (University of Pittsburgh) and Ann Reed, MD (Mayo Clinic, Rochester).

Other facilities available to families participating in research

Hosts for Hospitals

www.hostsforhospitals.com

Hosts for Hospitals is a volunteer network of families in the Philadelphia area who invite family members of patients in Philadelphia area hospitals into their homes for a comfortable place to sleep.

Ronald McDonald House

www.rmhc.org

One Kroc Drive

Oak Brook IL 60523

630-623-7048

Described as “a home-away-from-home,” Ronald McDonald Houses across the country and the world provide a place for families to stay when their children are receiving treatment at nearby hospitals. Though a donation of \$5 to \$20 is requested, there is no charge for families to stay.

These are just two of the organizations available to help families in need. For other possibilities, check with your hospital's social work department or call nearby hotels to find out if they offer discounted rates for people whose family members must stay in the hospital overnight or for longer periods of time. It never hurts to ask!

That Girl

By Emily Stephens (13)

She used to play soccer and dance ballet
Her spirit was free and she loved to play

Then during the summer on a day like no other
She got home from camp with her sister and brother

She felt extra tired and wanted to sleep
Little did she know, when she'd wake, she'd weep

Her strength was lost to a terrible disease
Now she couldn't rise if she was on her knees

This girl could no longer play, she couldn't even walk
And as time went on she got worse, she couldn't even talk

Breathing became a difficult task and she worried day and night
She would wake up from a peaceful sleep from such a fright

A couple weeks later, her dad passed away
This girl was in shock and didn't know what to say

Would life go on? Would she make it through?
Things would get better, life no longer blue

She was put on medicines that would make her strong
It's too bad they waited so long

She's almost fully recovered and improves every day
How do I know this? Well let's just say...

I know her very well and I see her all the time
Our names are pretty close, in fact hers is mine

I am that girl who loved to play
I went through a lot and have something to say

Be yourself and be your best
Because if something goes wrong, you'll forget the rest

Focus on the good instead of the bad
Think of all the fun times you've ever had

Life goes on no matter how tough
As long as you give it your all, it will be enough

Editor's Note: Heartfelt thanks to Emily for sending this poem to us. Emily is a teenager who has lived with juvenile myositis since 2001. She wrote this poem for her school and wanted to share it with everyone touched by JM. If you have a poem, story, picture, or anything you'd like to share, please send it to kathryn@myositis.org or mail it to TMA, 1233 20th Street NW, Suite 402, Washington DC 20036.



JUST FOR ME

SUMMER 2005

Fun facts and news for JM patients and friends



Music rocks

What type of music do you like? Which music relaxes you? Gives you energy? Puts a smile on your face?

Music brings out a lot of different feelings in people, and it can remind you of certain people, places or events. Tell us more about how music affects you.

Email kathryn@myositis.org or mail your answers to The Myositis Association, 1233 20th Street NW, Suite 402, Washington DC 20036.

Thanks for letting everyone get to know you better!

Note to parents: We will share some of your children's answers in upcoming issues of the JM Companion and other publications, using only first names and ages for children. If you or your child wishes to remain anonymous, please just let us know. Thank you for allowing them to share this with other children affected by JM!



Picture this

The Myositis Association needs your help. We're sure many of you love to draw, so why not send your drawings to us so we can share them?



The Myositis Association wants to use children's artwork – your artwork – on note cards and e-cards, in

newsletters and brochures to promote JM, on the web site, and more. Your art doesn't have to focus on a certain topic. Draw whatever you'd like, whatever makes you feel good.

Send in your artwork on white 8½ x 11 paper, and make sure you use colors that show up well. Write your name and age on the back of the picture, and send in your address, too. *(Parents: We will only use first name, age and relationship to JM – i.e. self, brother, sister, friend – on any of the pictures. If you have any questions, please feel free to contact Kathryn at kathryn@myositis.org.)*

Thanks for sharing your talents with us!



Fun Fact!

What is a **palindrome**?

A palindrome is a word, phrase, verse, or sentence which reads the same backward or forward.

Some examples of palindromes are: mom, dad, eye, and racecar. Can you think of more?

Test your knowledge

Here are two **palindrome riddles**:

1. What word, when written in capital letters, is the same forwards, backwards and upside down?
2. What word becomes a palindrome when viewed upside down and backwards?

**Find the answers on the back cover.*

Focus on exercise

Is it important to stay active?

Most doctors agree that it's good to be as active as you can be, but you also have to know yourself. If you feel especially tired or sore after doing something, you may need to find a different activity until you're a little stronger. As long as you feel okay doing certain things, though, it's probably okay to keep it up. These activities may just help you feel stronger and better overall.

What kinds of exercise should you do?

The answer to this question depends on a lot of things – how old you are, how much exercise you did before you found out you have juvenile myositis, and how strong and healthy you're feeling now. You might not be able to play baseball or soccer, or to keep dancing or swimming right away, but if you do what your doctor or physical therapist says, you may be able to do these things sooner than you think. Anything that keeps you moving can help, even if it's just a little bit every day.

How do you know when you've done too much?

It's important that you don't do too much. If you feel totally drained or if you're in a lot of pain after you do certain things, don't push yourself. Decide what you can do, and don't get discouraged by what you can't do. Start slowly, and you should be able to add more and more to what you can do as you start to feel better.

Make an impression - Art Project

What you'll need:

- Leaves and/or flowers you've collected
- Colored construction paper
- Glue
- Tape

What to do:

1. Put a small dot of glue on the leaf or flower and place it on the construction paper. (Try to find leaves and flowers that will lie as flat as possible against the paper.)
2. Tape the paper to a window that gets a good amount of sunlight, with the leaf/flower side facing out.
3. Leave the paper on the window for 3 or 4 days.
4. After 3 or 4 days, take down the paper and carefully remove the leaf/flower.

Your leaf or flower print should be close to the original paper color, while the rest of the paper has faded with the sun's rays. Try this with different items and see what one-of-a-kind artwork you can dream up!

Answers from page 7: 1. NOON 2. SWIMS

Creative snacking

Frozen juice pops

What you'll need:

- Any type of plastic container (yogurt, applesauce – whatever you can find)
- Cardboard
- Popsicle sticks
- Juice

What to do:

1. Cut the cardboard so that it fits on top of the plastic container openings, overlapping slightly so that it doesn't slip inside.
2. Cut a small slit in the center of the cardboard and slip the Popsicle stick through the hole.
3. Fill the containers with the juice of your choice.
4. Place the stick in the juice so the cardboard is holding the stick upright.
5. Freeze and enjoy!

Yogurt-fruit cones

What you'll need:

- Yogurt
- Fresh or frozen fruit, or fruit preserves
- Paper cones (or other containers)
- Popsicle sticks

What to do:

1. Fill the bottom third of the paper cone with yogurt.
2. Add a layer of fruit or preserves.
3. Repeat with yogurt then fruit until the cones are almost full.
4. Place a Popsicle stick in the center of the yogurt-fruit cone.
5. Again, freeze and enjoy!



THE MYOSITIS ASSOCIATION

1233 20th Street, NW, Suite 402
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JM COMPANION

For patients, families and friends affected by juvenile myositis