THE MYOSITIS ASSOCIATION

JM COMPANION

FALL 2004

For patients, families and friends affected by juvenile myositis

Back to school tips: backpack basics

Editor's note: The following health and safety tips are excerpted from the American Academy of Pediatrics (AAP) web site at www.aap.org:

- Choose wide, padded shoulder straps. Narrow straps can dig into shoulders, causing pain and restricting circulation.

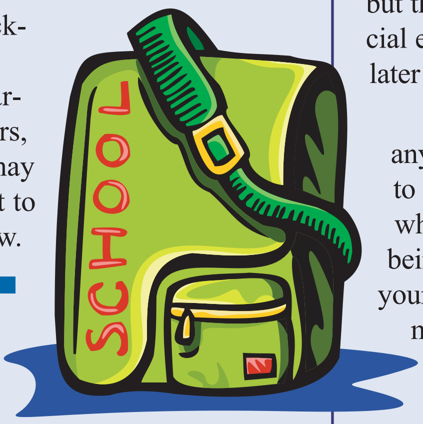
- A padded back protects against sharp edges on objects inside the pack.

- Pack light. The backpack should never weigh more than 10 to 20 percent of the student's body weight.

- Always use both shoulder straps. Slinging a backpack over one shoulder can strain muscles and may increase curvature of the spine.

- Organize the backpack to use all of its compartments. Pack heavier items closest to the center of the back.

- Consider a rolling backpack. Remember that rolling backpacks still must be carried upstairs, and they may be difficult to roll in snow.



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Working with your child's school

School is a large part of your child's day, so having a good environment is essential. Though many children don't need special accommodations now, it's a good idea to talk to the school counselor before your child absolutely needs them.

Taking the first step

"I can't emphasize enough," says Marie Ritzo, clinical social worker at Children's Hospital in Washington DC, "to get in touch early in the education process." Talk to the principal, teachers and other staff who will be working with your child. Communicating with the schools early on will lay the foundation for possible future needs. Talk to them about what your child might need and how you can all help to meet these needs.

How to achieve your goals

Whether you're asking for the school's help now or just talking about some options, take someone with you to any meetings you have with school officials. The staff may be well-intentioned, says Ritzo, but it can still be intimidating as you're on "their turf." You don't necessarily need a lawyer or advocate with you in the beginning, but there are those who work with special education issues if you need them later in the process.

Don't feel like you need to sign any papers immediately; take time to review them and think through what's included. "Don't think you're being difficult," says Ritzo. You are your child's voice in this situation, so make sure you're comfortable with what's been decided.

Most importantly, document everything. There may be time limits in which the school must respond to your requests, so remember to sign in at the office every time you visit and keep records of all meetings.

Stay in the loop

Once you've obtained a plan, whether it's a 504 plan, Individualized Education Programs or another, stay in contact with the school to make sure these accommodations continue to meet your child's needs.

Resources

The Myositis Association: Find sample letters online, or call to receive a copy by mail; www.myositis.org; kathryn@myositis.org; 800-821-7356

National Dissemination Center for Children with Disabilities: 800-695-0285; www.nichcy.org; nichcy@aed.org

Guide to IEPs: This guide from the U.S. Department of Education explains the basics of Individualized Education Programs (IEPs), including writing and implementing your plan; www.ed.gov/parents/needs/speced/iepguide/index.html

Section 504: This web site, from the U.S. Department of Health and Human Services, describes your rights under Section 504 of the Rehabilitation Act of 1973; www.hhs.gov/ocr/504.html.

IDEA:
www.ideapractices.org/law/index.php.

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Dear Families:

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

Working on this issue of *Companion* was especially gratifying, as I spoke to five children and teenagers who live with juvenile myositis. They were all so genuine and candid as they recalled the first day they heard the words "juvenile dermatomyositis" or "juvenile polymyositis" and how they decided to respond. They have faced the many challenges of this disease head-on, with much more courage and determination than you'd imagine people so young could possess.

We often use the word "inspiring" to describe how people react to difficult situations, but this word truly fits these five remarkable children - and the countless other children around the world who deal with JM. I hope you will find as much pleasure reading about these children as I had working with them.

On these pages, we also offer tips for dealing with schools, from talking to school officials to packing healthy lunches. We have posted materials on the web site and plan to include more to help your family deal with matters that arise at school and in other activities.

As always, I encourage you to work with me and share your thoughts to make all our JM-specific programs as valuable as they can be.

With warmest regards,
Kathryn

Fight obesity: make those back-to-school lunches healthy

Back to school means back-to-school lunches. With childhood obesity rates on the rise, parents need to be conscientious about steering their kids toward healthy eating habits, says Lona Sandon, a registered dietitian and assistant professor of clinical nutrition at UT Southwestern Medical Center at Dallas.

Ms. Sandon recommends lunches that include such items as small containers of cottage cheese, fruit cups, puddings made with skim milk, single-serving packages of pre-cut carrots or celery with dip, and yogurt in a tube.

A classic sandwich - made from whole-grain, whole-wheat bread with lean meat and low-fat cheese or peanut butter - provides protein and other nutritional benefits. Yogurt smoothies can be substituted for soft drinks, wheat crackers for potato chips. And, of course, fresh fruits and veggies are still among the best options.

"A healthy lunch not only keeps the body going but also the brain," says Ms. Sandon. "Kids who eat regular healthy meals often do better in school."

She adds: "If your kids insist on chips and candy, go with the baked chips rather than the regular and fun-size candy bars instead of king-size."

Excerpted and reprinted with permission from the University of Texas Southwestern Medical Center, Dallas.

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More back to school basics

The start of a new school year is exciting and fun, but it can also be challenging if you anticipate your child facing obstacles throughout the year. Here are some ideas to consider when deciding what's right for your son or daughter.

Planning Ahead

What you can do

- Identify someone at your child's school - teacher, principal, social worker or counselor - who will act as your primary contact.

- Encourage communication among your child's doctor, the school and your family. Ask the school to let you know when anyone in the school is sick, not just in your child's classroom, and to report any changes in your child's behavior.

- Inform them of new treatments. Let them know how you'd like them to handle particular situations, especially if you're unavailable.

- Include your child in the planning. Let him or her choose from acceptable options.

- Help your child learn how to talk to teachers and classmates about the disease. Role-playing may help younger children.

- Educate your child's classmates and others about JM and include your child in this if he or she is comfortable.

What's available

What you request depends on your child's needs. Your child can:

- Leave class early to get to another class.

- Have a friend help carry books, lunch tray and more.

- Rest during activities and take time to visit the school nurse, if necessary.

- Sit in a chair during story times instead of on the floor.

- Keep a second set of books at home.

- Have a friend take notes.

- Choose a locker that is easily accessible to avoid bending down or reaching up.

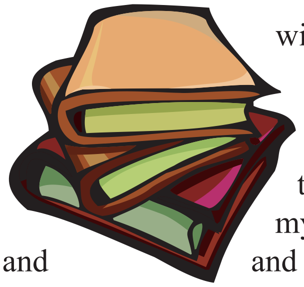
- Sit away from windows and use sunscreen when outdoors. (Some parents have had success putting UV light filters in classrooms.)

* * *

Member-to-member

Q: I relapsed last fall and had to withdraw from classes at my community college. I really want to go back, but what should I tell the administrators? I will have a handicapped parking sticker for my car so I don't have to climb the stairs. I "look" normal except for the moon face, camel hump, and extra weight, but the campus is made up of hills. I am afraid of what will happen once winter comes. Should I enroll under their disability registry or just see what I can do and come to them if I have problems? - **Kim, JDM**

A: *Kim received a number of responses from Bulletin Board users. Here is a sampling:*



Better to let them know upfront. You never know about the future with myositis. - **Tricia, DM (adult)**

As a retired college history prof, I shared with my classes that I had IBM and things weren't all they would have been otherwise. My suggestion is to let your instructors know the extra burden of your situation, just in the event you do have some problem along in the term. They'll be more ready to understand. - **Charlie, IBM (adult)**

I know that psychologically this can be difficult, especially when you don't look disabled. Do whatever is necessary to help yourself accomplish your goal. It is also an opportunity for you to share information about myositis with those who may never hear about it. - **Harriet, JM family**

I've had to take a lot of time off from school as well, and my counselor is very supportive. When you go back to school, just fill them in on what's going on. They have to accommodate you, whether it be homework extensions or walking into class late. I know it's especially difficult because you don't look "disabled" and neither do I. I've gotten so many strange looks handing my forms to new professors or putting up a handicap placard. Hang in there. - **Susan, PM (young adult)**

Editor's note: It's not always easy letting others know that you have myositis. Visit www.myositis.org, email kathryn@myositis.org or call 1-800-821-7356 to find materials you can share with teachers, classmates or counselors.

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In their own words: children and parents discuss JM

by: Kathryn Spooner

With each article I write, email I exchange, or phone call I make, I find out a little more about the lives of those with JM. In speaking recently with a 4-year-old, 7-year-old, 8-year-old and two 16-year-olds, all with JM, I have learned that none of them thinks about JM every day or lets it take over their lives. These children live in the moment, not thinking about past troubles or looking too far ahead. They learn how to be stronger, more accepting, and more cooperative. They learn that their condition is just a part of them.

There are obviously tougher times for children when they're experiencing a flare or the initial onset of JM, but their attitudes remain optimistic and their spirits strong.

Here are some thoughts, straight from them:

Megan: a 4-year-old's (very few) words

I spent the better portion of my phone call with Megan listening to her blow into the receiver on her end then giggle when her dad repeatedly asked her to stop. Most of her answers to my questions were "I don't know" - a typical response I've learned from having a 4-year-old myself. That's about how focused she was on JM in her life.

Megan McKeever

Megan was diagnosed at the age of 2 ½ and struggled with a few setbacks along the way. She was originally misdiagnosed as having an allergic reaction until a doctor at Children's Hospital in Texas diagnosed her at first glance. Her muscle weakness had come on quickly, and in retrospect, her father says she had the classic signs - muscle weakness, skin rash, trouble swallowing and some difficulty breathing.

But to Megan, playing with her friends is more important than thinking about how tired she felt or how much discomfort her IVs caused her small veins.

Colby: a 7-year-old's thoughts on JM

Colby Andresen

"I didn't know what it was," said Colby, now 7. He was only 5 when he found out he had juvenile dermatomyositis, and he took things in stride. What worried him most was the thought of spending the night in the hospital. Luckily, he didn't have to do that.

In contrast, the first days were filled with anxiety, worry and fear for the rest of the family. Colby's brother Kyle, only 8 at the time, said to his mom, "I'm just glad it's not life-threatening." Kyle, always very aware of things around him, was scared for his brother.

Colby was starting kindergarten just after his diagnosis, and his excitement provided a welcome distraction. For Colby, even now, JM is what it is. "Kids are so in the moment," said Donna, his mom. "He's doing well now, so he's not focused on his JM."

What would he say to other children just diagnosed? "Do your exercises," he said. Exercises, medicines, breaks and candy are what Colby remembers helping him along the way.

Colby now enjoys the pleasures of a typical 7-year-old: skateboarding, playing outside, swimming, camping, and going to the park. He still has to take his medicines and remember his sunscreen, but he chooses not to linger on these thoughts: "I think about doing fun stuff."

Taylor: what JM means at 8

Taylor only "sort of" understood what was going on when she found out she had JM at the age of 4. Her parents and doctors explained things to her, but she just felt mad: "Mad that they said that. Mad that I had it." She was also mad that she had to take medicine.

She never had the telltale skin rash juvenile dermatomyositis children typically have. With juvenile polymyositis, the signs were less obvious. "She was so tall, we just thought she was clumsy," said her dad. "Right off the bat, she responded to the medicines. Then she crashed. She hasn't been as good since then." She does feel better, though, and isn't mad anymore. What helped? "Mom, Dad and my blanket." (Her dad was happy, and possibly a bit surprised, he came before her blanket.)

Taylor Cammack

She recently enjoyed meeting other children at TMA's conference for JM families. "We talked about each other," she said, "how we felt." Children like Taylor are a real treasure for newly diagnosed children, optimistic in their outlook. Asked what she would tell others who have JM, she said without hesitation, "That I had it and there's nothing to worry about. You'll be okay."

Zach: a 16-year-old looks back

"It took me 20 minutes to put on my socks," said Zach, now 16. That was the big clue at 12 that something was wrong. He soon discovered he had JM but didn't have a big problem with it. His medicines alleviated his symptoms but brought about the classic weight gain: "It bothered me, but my friends helped me. They didn't make fun of me." He was in fifth grade at the time.

Zachary Rausis

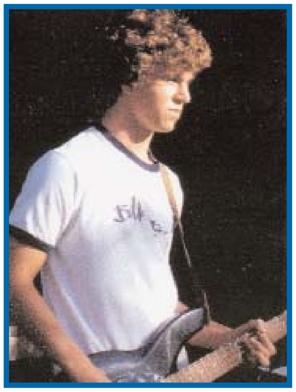
Zach doesn't feel like he had to make many changes because of his JM. His school district has been accommodating, allowing him extra time on tests - it's difficult for him to hold pencils for long - and giving him some leeway with physical education classes, though he rarely had to take advantage of this.

He has always been fascinated by video games, engrossed in Unreal Tournament when we talked. That's still his passion, and his JM hasn't disrupted that. At camp this summer, he met others with JM, but they didn't bother talking much about it.

He's very matter-of-fact in his advice to others: "Don't worry about it. Trust your doctor, especially if it's Dr. Sherry."

Forest: sharing his story at 16

Forest, now 16, was told he had JM when he was 12. At first, he didn't understand what was happening. Shooting a basketball had become a struggle, and that was emotionally draining for him. Once diagnosed, he started on prednisone, accompanied by the face swelling and weight gain. Unfortunately, his new appearance brought with it name-calling. People didn't take the time to understand his situation. Even with this disrespect, Forest kept his head up. "I realized that even though JM was a horrible disease," he said, "that there are much worse things that could happen to me in life, and that if this is the worst, then I'd have to say that I have a great life ahead of me."



Forest Gallien

His friends helped him the most. "They treated me as if nothing was wrong," he said, "and I was able to feel accepted and more confident about myself." This confidence led him to music, and music has become his new passion.

Forest is no longer taking medicine for his JM. Though JM was a difficult experience, he has taken a lot from it: "I learned to be comfortable with myself; I learned hard work always pays off; I learned that there is nothing more important than friends and family; but most of all, I learned to love life and live it to the fullest."

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How do you feel about JM?

The following article was written with younger children in mind, and I hope you'll enjoy reading this slightly shorter version with them. If your child has something he or she would like to share, I encourage you to email me at kathryn@myositis.org.

I had the chance to talk to five people who have juvenile myositis (JM). They talked about finding out about JM, but mostly, they talked about the things that are more important to them:

Megan is 4 years old but has had JM since she was 2. She had all the normal signs of JM - weak muscles, skin rash, and trouble swallowing. She feels a lot better now that her medicines are helping. Playing with her friends and her toys is more important to her than thinking too much about her JM or her medicines. Her family just moved, so she misses her friends, but she enjoys meeting new ones.

Colby, 7, loves the outdoors, especially camping, skateboarding and swimming. He does have to be careful when he's outside, so he wears sunscreen and special clothes with both sunscreen and bug spray right in the clothes themselves. Even though he remembers to take care of himself, he doesn't spend too much time thinking about it. "I think about doing fun stuff," he says.

Taylor, now 8, remembers feeling mad about having JM, but she doesn't feel that way any more. She recently met others close to her age with JM. They talked a little about JM but worked mostly on arts and crafts together, getting to know each other better. She's in the third grade now and likes to watch Spongebob and to swim. "She's real confident in the pool," says her dad. "Swimming is her thing."

Zach is 16 but has been dealing with JM since he was 12. Zach didn't have to give up what he loved - he enjoys video games, especially those with lots of action. He went to camp this summer and met others who have JM, too. "We don't bother with talking about myositis," he says. "We do what you'd expect at a summer camp."

Forest, also 16, found out that if he worked hard enough, he could get back to the things he loves, including baseball, swimming and water polo. But he also discovered something new. He started playing bass, guitar and piano: "Music then became my love and passion, and I am now heavily involved with it." He plans to continue focusing on music, taking it as far as he can.

Ask the Doctor with Lisa Rider

Dr. Lisa Rider is Deputy Chief for the National Institute of Environmental Health Sciences (NIEHS) at the National Institutes of Health (NIH) and a long-time member of TMA's Medical Advisory Board. Frank Pucino, PharmD, is Ambulatory Care Clinical Pharmacy Team Leader and Program Director for the NIH Clinical Center Pharmacy Department.

Q: Some of you have expressed concerns about accelerated infusion rates in giving intravenous immunoglobulin (IVIg), causing unwanted after-effects. Parents may be hesitant to approach the hospital staff. Some JM parents are reconsidering the use of IVIg, worried that it's too risky. One person recognized that reactions can occur with IVIg under the best of circumstances but asked if faster infusion rates made these unwanted effects more likely.

A: "Fast infusions are a problem," said Lisa Rider, MD (NIH). Both hospitals and families have pressures to get patients in and out quickly. "The reality," she said, "is the infusions may go much better if they're slower." Slower infusions help children tolerate the relatively large amount of medicine they're receiving.

Side effects - like skin flushing, fever, chills, changes in blood pressure, rapid heart beat, chest pain or tightness, breathing problems, feelings of discomfort, headaches, back pain, and nausea - can occur during or after infusions of IVIg, and may be related to fast infusion rates. Some experience energy boosts afterwards, while others remain sick for a couple of days, said Dr. Rider. Altering the speed of the infusion helps both short- and long-term effects. Different brands influence how children react to the treatment - for example, some preparations have lower sucrose to prevent negative effects on children's kidneys, she said. Premedication also alleviates side effects, and doctors often choose Benadryl, Tylenol or the child's scheduled treatment of pulse steroids before giving IVIg to prevent unwanted sickness afterwards. These are typically given about thirty minutes before the infusion, added Frank Pucino (NIH). Since infusion rates are based on the weight of the patient and vary from product to product, he strongly recommended following each manufacturers' guidelines for infusion rates. An example of an infusion: a patient (weighing 55 kg) receives 1 gm/kg infused at 15 mL/hr for 30 minutes, and if tolerated, the rate is increased by 15 mL/hr every 15-30 minutes to a maximum rate of 80 mL/hr.

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Eating healthy during the holidays

Parents who are trying to make healthy eating a lifelong habit for their children face particular challenges at the holidays as they attempt to set a festive table as well as a good example, says Alice Baker, a registered dietitian at Wake Forest University Baptist Medical Center. But with careful planning, you can prepare some creative, nutritious meals your children will love. Here are some suggestions from Baker:

- Choose a menu with a few well-prepared items rather than a large selection.
- Present food in a pleasing way. Plan foods of different colors and textures, and use garnishes, both to add a spot of color and to take up a little space on the plate.
- For an appetizer, use cut vegetables and low-fat salad dressing, not dishes of nuts, chips, or candy.
- Decrease the fat in your recipes. Many recipes taste great using half the amount of cheese, butter or cream.
- Serve vegetables that are steamed, grilled or baked with a little added fat.
- Try mashed potatoes made with chicken broth instead of milk or cream and butter.
- Avoid heavy sauces or gravy - try a low-fat recipe or slightly thickened chicken or beef broth.
- Serve vegetable soup or consomme as a first course. This can be filling.
- Serve appropriate portions.
- Make one dessert (even if it's rich) instead of several.
- Be prepared with a few conversation topics, and let everyone concentrate on conversation rather than food.
- Plan activities other than eating for family gatherings - walks on snow-laden streets, charades, board games or cards.
- Let your kids be involved with cooking. Teach them healthy principles as they help.
- As a family, eat a light breakfast and lunch. This will prevent ravenous hunger and overeating at your holiday meal.

Parents can create memorable, healthy holiday traditions that the entire family can enjoy.

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JUST FOR ME

FALL 2004

Fun facts and news for JM patients and friends

IT'S ABOUT THAT TIME: Heading back to school

The school year has begun for many of you and will soon be starting for others. Seeing old friends. Meeting new ones. Learning different things. School is full of exciting times. How can you make school even better?

- Listen carefully. Teachers often explain important classroom rules on the first day of school. Make sure you understand all of them, and ask them to repeat things you can't figure out.
- Be ready. Get a good night's sleep and eat a healthy breakfast every day throughout the school year. If you're rested and well-fed, you'll have more energy to learn and play.
- Have fun. School is a lot of work, but you can have a good time, too. You'll learn lots of neat facts you can share with your parents, brothers, sisters and friends.

Concerned about starting a new school?

If you're nervous about going to a new school, remember other children in your class are probably just as nervous as you are. Stick with a buddy if you can, but don't shy away from meeting new friends, too. You're all probably feeling just about the same - excited and nervous.

Teachers know that students will be a little uneasy, especially on the first day of school. They'll do what they can to make everyone feel good about the year ahead.

You're bound to meet new friends and take part in new activities. So even though it's normal to feel a bit scared, you'll forget all about your worries before you know it.

After-school activities: get involved

There are so many activities you can choose to take part in, like school sports, yearbook staff, music lessons and other clubs. Decide what you really enjoy doing, and then find a place you can do it.

Some JM members of The Myositis Association take swimming lessons, which not only keeps them active - it gives them a chance to meet new friends. Others have joined their school's band. One girl found she could play on the volleyball team, where she didn't have to do as much running but could still be a valuable member of the team. Learning new things, discovering new activities and meeting new friends is what school's all about.

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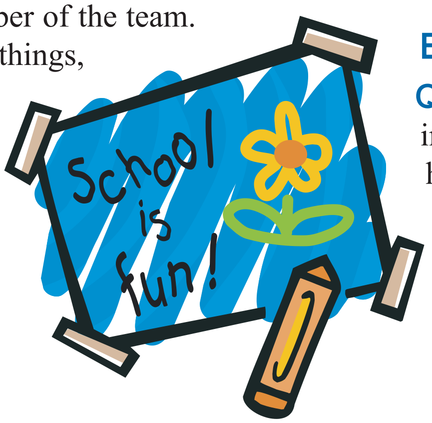

Did you know?

The first pencil was really just a group of graphite sticks held together by a string. Someone decided to push the graphite into a hollow wooden stick, making the pencil more like you know it today.

(From www.didyouknow.cd/kids)

Word find

Search up, down, forwards and backwards for the words listed below:

FUN, FRIEND, SCHOOL, LEARN, BUS, PLAY

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

Brain teaser

Q: A magician walked into a room and claimed he could stop a light bulb from shining with his bare hand. How did he do this?

A: He flipped the light switch.

TMA to hold west coast JM Conference

TMA will be holding a conference on the west coast in 2005 devoted exclusively to juvenile myositis. As we did in Washington, DC this year, the JM Conference will focus on the medical issues as well as the emotional and social issues of the disease. This conference will be in addition to TMA's Annual Conference. Dates and locations for the JM Conference and Annual Conference will be determined before the end of 2004 so that there is sufficient notice to plan accordingly. There will also be a component of the Annual Conference devoted exclusively to JM. We are pleased to be able to announce that a $10,000 donation received from a JM family will be used to help underwrite the costs of the JM Conference in 2005.

THE MYOSITIS ASSOCIATION

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JM families gather in Pittsburgh

Suzanne Printz, whose 8-year old daughter has JM, recently put together a fun and meaningful event to help JM families at Children's Hospital in Pittsburgh. The families spent several hours learning from each other and hospital staff, including the clinical director of rheumatology.

Once she felt able to focus her attention on planning this event, Suzanne contacted the hospital's social work department. She says her biggest concern initially was finding a date and getting people to come, but with the help of the hospital staff, local doctors and parent volunteers, she was able to arrange a get together at the hospital that was truly special and helpful for some of the JM families in the Pittsburgh area. Seven families attended, with 21 people in all. "It was a great event," said Suzanne. "It is definitely manageable and so worthwhile!"

TMA staff is seeking to help arrange similar opportunities in other areas of the country where there are concentrations of children with juvenile myositis. For anyone wanting to assist or to learn more, we encourage you to contact Kathryn Spooner at kathryn@myositis.org or 202-887-0088, extension 601.