What's happening in 2005?

We're looking forward to an exciting year ahead. Here are just some of the things you can look forward to in 2005:

- Regional events for JM families. With a successful get-together in Boston (see JM gathering, page 5) this past December, we're now actively planning events in Cincinnati, Raleigh-Durham and Philadelphia, with other cities to be announced later.

- Juvenile Myositis Conference in Los Angeles, April 30 - May 1, 2005. This two-day event will feature pediatric specialists speaking on a wide range of topics important to families living with myositis. There will also be time to get to know other JM families and opportunities to visit some of the sites in L.A.

- Myositis and me, TMA's book on juvenile myositis. The medical and copy editors are actively working to produce the final text for this unique and valuable resource for families and physicians.

TMA continues to increase its focus on children and families dealing with myositis, and we encourage you to let us know what we can do to help you as much as possible.

If you're interested in helping with a JM regional event in your area, contact Kathryn Spooner at kathryn@myositis.org or (202) 887-0088 ext 601. We'll be happy to work with you to make an event in your area a reality.

Painting a picture of JM

You as an individual are the one who can best educate those around you about juvenile myositis. Start with family, friends and neighbors, and then educate others in the larger community. Harris Teller, PhD, a patient advocate and IBM patient, talks about the importance of putting concepts into terms your audience can understand. (See Grassroots efforts in TMA's Winter Outlook. This is easier said than done: myositis isn't easy to explain to adults, so how can you possibly explain the weakness, skin rash, medicines, and other aspects of juvenile myositis to your children's friends?

Many parents have spoken at their child's school, which is ideal because it helps children understand your child's situation and educates parents and teachers, too. Tailor your presentation to the appropriate age group, using examples from daily life they'll be able to picture. If the class is studying a relevant subject, relate JM to that topic. Younger children don't necessarily need to know JM is thought to be an autoimmune disease or even that it's a disease at all, but children in a middle or high school health class might be more interested and able to learn.

Depending on the age group you're addressing, here are some questions for which your child's friends may want some answers:

- Why can't we do things like we used to do together? Why can't we play outside as much?
- Why does my friend miss school or have to rest in the nurse's office?
- Will I get JM, too?
- Will my friend get better?

Using familiar examples

Molly Tereck, mother of Annalise (8 years old), shared the fun, memorable concepts they used in talking about JM: "We made a 20-minute presentation to Annalise's class about why she isn't taking gym right now and about germs (since children with JM are more susceptible to infections). I didn't mention the disease by name or even say 'disease.' We talked about antibodies. We had spray bottles that sprayed three feet and we sprayed all the kids (and coughed at the same time). If they got wet, they got our germs!"

Shari Weber, whose son Ricky has JDM, spoke at an assembly at his school. She advises parents to literally get on same level as the children, making eye contact while you're speaking to them. Involve them whenever you
Dear Families and Friends:

I hope you all enjoyed a nice, relaxing holiday season.

In this issue of Companion, you'll find Dr. Robin Goodman's suggestions for avoiding stress when facing a new situation; Dr. James Jarvis' reasons for conducting research into juvenile myositis among Native American tribes; a mom's reflections on her family's 12 years with JM; and Dr. Ann Reed's answers to your questions about medicines, lab tests and more.

I hope you'll continue to send your suggestions, ideas and questions for making the JM Companion better with each issue. We anticipate a productive year ahead as we all continue to work to bring families together, reach out to those newly diagnosed or in need of support, and move closer to a cure. Happy New Year!

Warmest regards,
Kathryn

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Pediatricians address shortage of rheumatologists

More than 150,000 children in the United States are affected by rheumatic diseases such as juvenile rheumatoid arthritis, lupus, dermatomyositis, scleroderma, and systemic vasculitis. Because of a shortage of pediatric rheumatologists in the country, a majority of these children are not followed by pediatricians trained in the subspecialty, often leading to improper diagnosis and treatment. In an effort to improve care for children affected by rheumatic disorders, the American Academy of Pediatrics (AAP) wants to educate general pediatricians about important presenting features of these disorders. Gloria Higgins, PhD, MD, of Columbus Children’s Hospital, discussed specific cases of childhood rheumatic diseases at the AAP National Conference and Exhibition in San Francisco.

"The shortage of pediatric rheumatologists means that when a child suffers from a rheumatic disease, they are often treated by adult rheumatologists or general physicians," said Dr. Higgins, pediatric rheumatologist at Columbus Children's Hospital and associate professor of pediatrics at The Ohio State University College of Medicine and Public Health. "Infants and children of all ages can be affected by rheumatic disorders, and often their symptoms mimic those of other illnesses. Pediatric rheumatologists are not only trained to make appropriate diagnoses, but are also adept in addressing issues that are different from those in adults, such as limitations as the children grow."

Currently in the U.S., there are only 160 board-certified pediatric rheumatologists, with many concentrated in big cities. In Ohio, the Rheumatology Center at Columbus Children's Hospital is one of three in the state. Reasons for the shortage can be linked to the subspecialty's short history. Board certification in rheumatology was only introduced in 1992, and one-third of U.S. medical schools do not offer programs focused on rheumatic studies.

To help compensate for this shortage and ensure children affected by rheumatic disorders receive the best care possible, Higgins is using the...
Shortage, continued from page 2

AAP's Annual Meeting as a forum to educate primary care pediatricians. Recognition of childhood rheumatic disorders will help these physicians to make appropriate referrals to specialists.

Reprinted with permission of Children's Hospital of Columbus. More information is available by calling (614) 722-KIDS (5437) or through the hospital's web site at http://www.columbuschildrens.com. The next AAP national conference will be held in Washington, DC, from October 8-11, 2005.

Picture of JM, continued from cover

can, she says, and demonstrate the actions you're asking them to do - raising their hands, standing from their chairs. For one illustration, Shari asked volunteers to "wall sit." With their backs against the wall, the children slid down to a seated position. After a few minutes, she had the children explain how their legs felt. "This is the way the whole body feels for a child with myositis," she said.

To further illustrate her point, Shari told the group: "Now imagine that you just played two games of soccer back to back. You just want to get home. You find out you have to walk up three flights of stairs, but your legs are so tired that you don't think you can do it. All you want to do is stay on the couch until dinner-time. You know that you'll feel better after dinner. That tiredness is how a child with myositis feels, but they don't get better after dinner."

Editor's note: TMA has JM-specific brochures and other materials available online for you to print and distribute. Please contact us at 1-800-821-7356 or kathryn@myositis.org with questions.

Ask the doctor with Ann Reed

Dr. Ann M. Reed is head of pediatric rheumatology and associate professor of pediatrics at the Mayo Clinic in Rochester MN and has a special interest in JM. She is a member of TMA's Medical Advisory Board as well as a co-author for TMA's upcoming book on childhood forms of myositis.

Q: Is there anything you would recommend to lessen stretch marks that can appear due to rapid weight gain from prednisone - either during or after the treatments?

A: There are no clear-cut ways to prevent or treat stretch marks. First, prevention includes closely monitoring weight gain. It will not prevent stretch marks altogether but can help you get fewer.

If you have them, the only known successful study shows that while they are developing (in the red-purple phase), topical Retinol A might help minimize them. Laser treatment has been proposed to help, but nobody knows if this is only the short-term cosmetic changes and after five years or so the marks would be the same as someone who had no treatment.

Q: If children are sick, when should this prompt the doctors to hold their current JM medicines?

A: The answer is complex because it depends on the medications being given, the severity of the infection, the type of infection, and the JM itself. When a child is on daily steroids, they need to be continued in almost all cases because of the adrenal suppression and serious nature of stopping steroids abruptly. However, if they are high-dose steroids such as IV pulses and there is not a worry of adrenal suppression, then stopping the steroids with a severe infection (bacterial, viral or fungal) or an infection that will not resolve is reasonable.

In terms of stopping other medications, different medications have different levels of risk for infections becoming more serious, and most traditional medications used to treat JM (i.e., plaquenil, IVIg, methotrexate) are not usually stopped. Medications such as anti-TNF treatment or cytoxan would be held if the infection warranted. When treatment is being held for a prolonged period of time, other treatments such as IVIg might be considered.

With most childhood infections that are mild and self-limiting, medications are continued. A few big exceptions are serious bacterial infections and some viruses such as chickenpox.

Q: What are important laboratory markers for a child with JM?

A: This is a very difficult question to answer because the laboratory test is just one of many parameters that the doctors should use to assess disease activity. Laboratory values differ based on the normal values established when they are performed.

Having said that, some values are more specific for muscle disease activity than others. AST/ALT/LDH are all enzymes that can be elevated with abnormalities that are not related to the muscle. CK (creatinine kinase) levels may be abnormal early in disease. Later, elevated CK levels are less likely from inflammation; they can be from normal exercise, daily activities, steroid myopathy, or tendencies in certain racial groups, in which case the elevated levels are non-specific. CK needs to be assessed in conjunction with the physical exam and history. The aldolase, if elevated, is usually more specific for muscle inflammation but still not entirely specific - even a slight elevation can be related to active muscle disease.
Families learn and grow even in difficult times

Fight wintertime blues

Winter is often associated with the blues. Whether it's the cold weather or cabin fever, depression and sadness seem to accompany winter months more so than other months.

Balancing needs of family, friends, and work can be challenging, says Dr. Robin Goodman, Associate Professor in Psychiatry, New York University Medical School. Add a child with a medical illness and the challenges are even more complex, but families can work together to find meaning and joy even in difficult times, she says. "In general, when making and adjusting plans to fit a new situation, keep the following ideas in mind: provide choice, anticipate glitches, maintain some part of familiar traditions, provide structure, make room for fun, be flexible." Dr. Goodman shared her thoughts on avoiding stress:

Find out what's most important to everyone in your family, then focus on those things that are possible, she says. Parents often try to do whatever they can to please everyone in the family, and this task is exhausting. Concentrate on what you can do.

Stick to routines whenever possible. "Children do best and feel most calm when they know what to expect and there is some routine to their day," says Dr. Goodman. "It's helpful to keep some sense of a normal routine whenever and wherever possible. This can be as simple as sticking to the usual bedtime or the same childcare help."

"Understand that different does not always mean disappointing," she says. "There is truth to the saying that when life gives you lemons, make lemonade."

"Listen and promise only what you can: It is tempting to ease a child's or sibling's sadness or a parent's guilt about changed plans by offering gifts or making promises," she says, "but making promises you can't keep can lead to more disappointment. In addition to being a cheerleader and encouraging positive coping, it's important to acknowledge and soothe the sadness rather than attempt only to avoid or brush aside any bad feelings."

Plan ahead as much as you can. It's helpful to think ahead and let everyone know of possible conflicts in advance. There are plenty of changes you'll encounter, but discussing possibilities may lessen some of the disappointment of changed plans.

Maintain perspective, she says. Even in the best of times, we're often influenced by the images of what's ideal. But reality is rarely the same as what we see. Each family has its own challenges and ways of dealing with these challenges. Managing expectations will help keep things in the proper perspective.

"Address the stress and refresh: It's important to take stock of what's causing stress and remember how you have managed it in the past," she says. "Taking time for yourself, finding your own ways to relax is a great investment. It may mean taking a nap, getting to the gym, meeting friends, or seeking support from someone else who is in a similar situation. Giving to yourself will generate its own reward."

"Give and receive: Many parents are quite comfortable in the role of giver. They give to children, to friends, even to medical staff who help with the journey. When a parent has a medically ill child," she says, "the giving can sometimes lead to exhaustion. It's important to realize when to say 'no' to invitations and when to say 'yes' to offers of help. When hours or even days are suddenly filled with extra trips and waits at the doctor's office or clinic, it is reasonable and necessary to seek help and accept offers."

As parents, you no doubt have a number of suggestions for others to avoid stress as much as possible. We're always pleased by the openness and understanding families share on TMA's bulletin boards and in face-to-face meetings. Each family is different, and we appreciate hearing what's worked for each and every one of you.

Dr. Goodman's remarks are excerpted from a longer article and used by permission of Starlight, Starbright, a foundation benefiting chronically ill children. For the full article and many other resources for sick children and families, go to www.slsb.org.

Illness, behavior and long-term emotional health: what parents can expect

Researchers at Columbus Children's Hospital expected that children with chronic illnesses would be more vulnerable to emotional problems than healthy children as they grew older. In studying a group of 18- to 20-year-olds with a history of chronic illness and comparing them with children without chronic illness, the research team discovered this was not the case. "We found no difference between healthy kids and those with chronic illness," says Cynthia Gerhardt, PhD, pediatric psychologist at Children's. "Overall, we found that the effects of chronic illness do not necessarily lead to severe psychological impairment. These young adults were amazingly resilient."

The study examined depression, anxiety, post-traumatic stress disorder and other psychological symptoms. "Research such as ours can help parents and healthcare professionals identify risk factors and set realistic
When should you discipline your child’s bad behavior and when should you let it go?

"I usually tell our families that they need to be consistent with limit setting," says Joyce Sundberg, RN, Division of Immunology/Rheumatology, Children's Memorial Hospital, Chicago, "and what was acceptable behavior before the illness should be the same during and after the illness, regardless if they are on meds or not."

Dr. Lefebvre agrees that even though medicines can lead to irritability, moodiness and other negative feelings, it's important for parents to be clear about what can be tolerated and what is unacceptable. "For instance," she says, "shouting and tears may be excused, but physical aggression leads to consequences just the same as for other kids in the family. Mom or Dad can say they understand why Johnny is frustrated but he's got to express this anger more appropriately."

Encourage your children to communicate how they feel, Sundberg says, whether they're sad, angry, or happy. Talking about all of your feelings - including how parents, brothers and sisters are feeling - is important.

It's a natural reaction to want to help your children when they struggle, but overprotecting them - like allowing them to act inappropriately - can do more harm than good in the long run. If negative behavior gets out of hand, consider counseling, Sundberg says.

What about “treats for treatments”?

"We just go from doctor to doctor-adding more meds every time we go," says Kelly. "Not sure how much more she can take as well. I am to the point of promising to buy her something after the doctor visits if she will just go and see one more doctor."

Sundberg says it's fine to give special treats while your child is undergoing treatments, but be sure any foods you use as treats are healthy and not full of salt or sugar, especially when your children are taking steroids. Dr. Lefebvre suggests stickers or bravery beads: "This way the courage is acknowledged and praised without loading kids with sugar or running the risk that siblings will feel it's not fair."

Some families have found that the prospect of visiting their child's favorite store helps get them through the treatment. The anticipation of the therapy can be overwhelming, and having something to look forward to can ease some of their anxious feelings.

"I try to distract him by talking about a favorite vacation spot," says Shari. "We go into detail about it (color of water, type of sky, smells...). It doesn't always work but sometimes it does. He also knows that afterwards he gets a free trip to the local fast food chain for his favorite drink - a cherry slushy."

JM families gather in Boston

Nine families met at Children’s Hospital Boston in December for a regional juvenile myositis event hosted by TMA. The concept of regional meetings, originally carried out by Suzanne Printz in Pennsylvania, was well received and will be repeated in other areas.

Dr. Robert Sundel, Director of Pediatric Rheumatology at Children’s, discussed the challenges of JM, prospects for recovery, recommended treatments, and the risks of not treating the disease early. With current treatments and a better understanding of JM, he remains optimistic that children can now expect a full recovery with little risk of future flares. He stressed, however, that the key is early, aggressive treatment and continuing treatment until the disease is fully eradicated. He compared JM to a house fire: if the house is on fire, you douse the flames with all available resources, monitor until the flames are no longer smoldering, and don’t assume it’s safe to move back in until you are certain there are no longer any burning embers.

Lisa Luke, a patient of Dr. Sundel’s, illustrated Sundel’s point that children can recover fully. Ms. Luke’s discussion of the course of her disease, and the support she received, was inspiring and offered hope to the younger children, who were in earlier stages of treatment. Of course, all patients are unique, with no standard path for all children with JM. Susan Riley, PT, physical therapist at Children’s, addressed the importance of being in close contact with the treating physician and the need to withhold exercises during periods of active inflammation. Endurance-increasing exercises, including walking, biking, and swimming, are helpful for JM patients as well as therapies like yoga. When looking for a physical therapist, Ms. Riley suggested that knowledge of myositis itself is less important than being sure the therapist is very familiar with treating children and is knowledgeable about the effects of medications.
Looking Back: Our Lives with JM

By Sharon Massey, mother

Jessica was a happy 10-year-old, just finishing 5th grade. I noticed subtle changes in her playing - when a playmate would come over, she would sit around instead of playing - and she cried easily. She ran a low-grade temperature and would say, "I feel hot inside but cold outside." This never made any sense to us. We continued taking her to doctors at least once a month hoping they would see a change in her. She was losing muscle, becoming weaker, and running low fevers. The doctors couldn't find anything wrong.

After six months, we demanded some explanation for what was happening to her. They sent us to Duke University Hospital, where doctors diagnosed her within an hour with dermatomyositis. We were both relieved and scared. What did it mean?

We stayed at Duke for three days, and it took me that long to learn how to pronounce this new word that had invaded our lives. Jessica was a frail 45 pounds and 4'5" tall. She was immediately given IV prednisone intravenously and stayed on heavy doses. By the third day, she had improved, able to walk without limping or lagging behind. This is the beginning of our long journey, which has now lasted 12 years.

The School Years

Jessica remained on prednisone for four years, gaining 45 pounds, but not growing taller. We tried to keep her on a good diet, but she was always hungry. She had stomachaches, reflux, nausea, and felt lousy. Prednisone did make her stronger, able to do most things, and the trade-off was worth it.

We saw an endocrine specialist at Duke to discuss growth hormones. They had never treated a child on prednisone with growth hormone, but we decided to start daily hormone injections. She was 4'6" when she started and reached 5 feet after three years - with no side effects. Everyone was pleased with her growth; this was a good choice for us to make.

It was an effort going to school but she managed. She missed class a lot, but the teachers were understanding. It helped to have her identified as "other health impaired," which allowed her more time for tests, tutors and other considerations. Her true friends remained loyal, visiting, bringing homework, and calling.

High school proved to be another hurdle. Jessica's treatment was trial and error, and these adjustments took their toll on her education, having fun, being with friends, and taking part in activities. She struggled through these four years, but she had finally made it to graduation. What would be next?

An Eye Toward the Future

Jessica's grades were not at the top, but she had made great strides in accomplishing all of her work. We began to explore smaller colleges and found a perfect fit for her - a small women's college in downtown Raleigh. She entered Peace College in the Fall of 2000 and was scared to death; so were we. She was still on methotrexate and Voltaren (a non-steroidal anti-inflammatory drug, or NSAID) when she started school, weaning after two years. After living on campus for two years - doing well and loving it - she moved into an apartment with friends.

She graduated from Peace on May 8, 2004, with a degree in Marketing and Communications. We had a big celebration at our home because this was a celebration like no other. She's now working part-time as a Marketing Coordinator until a full-time position is available - she'd love to be in New York. She currently lives at home until she finds a roommate.

We've had many ups and downs, and we're not yet in the clear. She is in physical therapy for juvenile rheumatoid arthritis, and she has learned to warm her fingers and relax. She turned 23 in August and moved to adult doctors instead of pediatricians. I was especially anxious, as pediatricians are so gentle with younger patients, especially helpful during emergencies. We're satisfied, though, with her new doctors and hope to continue without any complications.

We take each day and embrace it when it is good and when it is bad. She continues to go full steam ahead with all her activities. She is no longer on any medications but continues to have problems with contractions and reduced range of motion in parts of her body. We are so grateful that she has improved so much since she was diagnosed at 10. We have certainly come a long way but never alone, with our church, doctors and friends always by our side.

Read Jessica's and other young adults' stories online at www.myositis.org/community/teen_stories.cfm. The Juvenile Programs pages of the web site are geared toward parents, teens and kids. Write to us with your ideas for tailoring this site to the needs of all of our JM families.
Clues may teach about JM

The Apache, Cherokee, Cheyenne, Chickasaw, Choctaw, Creek, Pawnee and Seminole nations are among the more than 67 Indian nations that live in Oklahoma, the largest number of Native Americans in any state. The Apache Chief Geronimo is buried there, and the state has many places where you can see and learn about the history of the Great Plains people. The Great Plains tribes have many different beliefs, but they all share a love of nature and a belief that spiritual and physical healing are related.

When Dr. James Jarvis came to work with the children of the Great Plains people, he began to learn about them. He learned that the Oklahoma tribes are poorer than people in the rest of the country, and that they suffer from the loss of their lands, hunting grounds, buffalo and their way of life. Most of the Native Americans don't live on reservations but in small towns. They have more of certain illnesses than the rest of the country.

Dr. Jarvis learned that there is more heart disease, diabetes, and autoimmune disease in Indian country. While he was working with Indian children, he was surprised to see how many of them have juvenile dermatomyositis. One day, he saw three Native American children with JM in the same afternoon, and they were all from the same tribe. His assistant, who knew the patients, told him that all three children were related. The adults in the family didn't have myositis, but they had other autoimmune diseases like lupus and rheumatoid arthritis.

TMA awarded Dr. Jarvis a grant to study children that have JM at the tribal clinic. By learning why so many children there have JM, he hopes to find out what happens in families with a lot of autoimmune disease and to someday be able to prevent JM.

Fun facts

Though each Native American tribe has its own way of life, all of the tribes have some things in common: they love and respect the land where they live, they pass on their traditions and histories by telling stories, and they feel a strong connection to nature and the natural world. Here are some tidbits about Native Americans and Oklahoma:

- Oklahoma comes from the Choctaw words okla for people and humma for red, together meaning "red people."
- "The Trail of Tears" refers to the forced movement in the 1830s of the Five Civilized Tribes from the southeastern United States to the Indian Territory in Oklahoma. The five tribes are the Cherokee, Chickasaw, Choctaw, Creek, and Seminole.
- Thirty-nine Native American tribes and nations are headquartered in Oklahoma, more than any other state in the U.S.
- The Oklahoma state wildflower is the Indian Blanket, or Gallardia.
- In the center of the Oklahoma state seal is a star, showing a pioneer and a Native American shaking hands. The five points of the star symbolize the Five Civilized Tribes.

For more information online, visit:
- www.fivetribes.org
- www.cherokee.org
- www.chickasaw.net
- www.choctawnation.com

DREAM CATCHER PROJECT

Dream Catchers are from Native American lore; they trap bad dreams and let the good dreams filter down to the sleeper.

For each dream catcher you will need:
- a bendable twig about 1 foot long
- a few inches of thin wire
- some twine
- beads with large holes
- a few feathers

Building your dream catcher:
- Make a hoop from a twig and wrap a short length of thin wire around the overlapping ends.
- Cut a few feet of twine. Tie one end of the twine to the twig hoop.
- String beads on the twine and then wrap the twine around the far side of the hoop. Repeat until you have an interesting webbing design.
- Tie a short length of twine on the hoop. String a bead or two on it and then tie a feather onto the end. Repeat this a few times (2 or 3 hanging feather strings look nice). Hang the dream catcher near your bed!
Build your brain muscle with these cool puzzles...

Word search

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

CHOCTAW
CREEK
CHIEF
BUFFALO
PASHOFA
(traditional Chickasaw food)
TRIBAL
POW WOW
MARBLES
(traditional Cherokee game)

Why is it better to have round manhole covers than square ones?

Answer: A square manhole cover can be turned and dropped down the diagonal of the manhole. A round cover cannot be dropped down the manhole. So for safety and practicality, all manhole covers should be round.

What's in a name?

Does your first name have another meaning? As in Norm and average? Frank and earnest? (Or, Ernest and frank?) See how many words and first names you can identify. And remember, spellings may vary.

1. Something you wipe your feet on at the door, starts with an M.
2. Something you eat on a bun, also called a hot dog, starts with an F.
3. To hold something while going somewhere, starts with C.
4. The winner!, starts with V.
5. A hard, translucent yellow to brown fossil resin, starts with an A.


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J M C O M P A N I O N

www.myositis.org
For patients, families and friends affected by juvenile myositis