

New directors bring JM perspective to board

The TMA Board of Directors has added two representatives with experience and interests especially important to families affected by juvenile myositis.

Shari Weber and her husband Ken have two boys. Their 9-year old son Ricky was diagnosed with juvenile dermatomyositis in the

summer of 2001 after six months of searching for a diagnosis. Shari works part-time at Siemens, Inc., Medical

Solutions, as a Quality and Productivity Manager. "I look forward to serving the TMA membership and representing the JM community," she says.

Jeff Campbell has dealt with juvenile myositis for more than 30 years, ever

since he was diagnosed with juvenile dermatomyositis at the age of 3. He actively seeks different challenges and completed the Chicago

Marathon in 1998. He works at the JC Penney corporate office in Texas.

Welcome to Shari and Jeff!



Shari and Ricky Weber



Jeff Campbell

All in the family: JM affects everyone

As all of us know, a sick child can have a profound impact on your whole family. We hear from you about many hardships, but you have also told us that this experience has strengthened your families in many ways.

At the Annual Conference, JM families got together to talk about how they deal with the daily challenges of balancing family, doctor visits, work, and everything else. They came to learn from one another, to hear what others have done. With the help of Shari Weber and Andrew and Denise Lucht, parents of JM children, all of the parents shared their own tips on managing different aspects of the disease.

What you can do as parents

One way to minimize stress is to stay organized. Document everything. Don't take anything for granted – write it all down, including information from nurses, blood work results, and a journal of questions and answers. In your journal, keep track of all physical changes so you're more aware of the gradual changes you may not otherwise notice.

Here are more of your suggestions:

- Create a file of medical information and keep it handy. If you need to visit a doctor while away from home, it will always be with you.
- Be open and honest with all your children. Explain things in a way they will best understand what's happening and what to expect.

- Keep things as normal and routine as possible for everyone.

Brothers and sisters feel it, too

Brothers and sisters are also concerned – will they also get it? How is their brother or sister really feeling? What can they do to help?

It's important that brothers and sisters feel like they're part of things, whether it's discussing new medicines or school issues. The more they know, the less anxious they'll feel, and the less likely they'll feel left out when they understand the need for you to give attention to your JM child.

Remind them that they're brave, too. There are bound to be some conflicts along the way, but being honest and prepared can ease the stress.

Keep teachers and classmates in the loop

You can relieve some of your own worry by keeping teachers informed. Take written summaries to them so they'll understand how the medicines and the JM itself may affect your child. Remind them that even though your child may look well, it doesn't mean the muscles are no longer weak or your child won't continue to tire more easily.

If your child is in middle or high school, meet with a counselor who will be an advocate for your child. Report any changes to the counselor or teachers so they're aware of any potential complications.

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Dear Families:

In the year ahead, I hope to hear from many of you with your ideas and suggestions for TMA's juvenile myositis programs. It's important for TMA to concentrate on what will benefit you the most.

As the TMA coordinator for JM programs, I want to get to know you better. What can we do to best serve you? And how can you help us reach out to other families?

I started working with the Association in 1999, first in finance, then member services, and now communications. Though this may seem like an unusual path, it has helped me learn more about TMA. And this path has allowed me to develop my skills while working from my home in rural Virginia. As the parents of two young boys (Caden, 3 ½ yrs and Rhys, 9 mos), this has been very important to my husband Ian and me. I'm able to be with them as they grow and discover new interests. Caden enjoys playing soccer, "working" on the computer, and having fun with his cars and trains. Rhys takes it all in, watching his big brother intently and joining in when he can.

I am keenly interested in children, and I've enjoyed getting to know some of your families already. I've always loved working closely with children, and now I'm able to do just that - but in an even more rewarding way than I had ever considered or imagined.

I encourage you to contact me with any concerns or insights you may have. I look forward to working with you all!

With kindest regards,

Kathryn



Rhys, Kathryn and Caden Spooner

Ask the Doctor with Dr. Ann M. Reed

Ann Reed is a pediatric rheumatologist at the Mayo Clinic in Rochester MN. She is the head of pediatric rheumatology and associate professor of pediatrics, and she has been a long-time friend of The Myositis Association. She participated on the medical panel at the 2003 Annual Conference, and this information comes from her question-and-answer period with JM families.

Q: Can we expect our child to go into an extended remission? What do we look for in terms of the disease returning once our child has reached remission?

A: One-fourth of the JM patients will be diagnosed, treated and then reach remission. Remission is considered when a child no longer needs medicines to control the symptoms of the myositis. Some children may need a maintenance dose of medicine, or a low dose that they continue to take to keep the disease under control. Typically, this dose will be small enough to avoid some of the more common side effects, like the weight gain or moodiness that can accompany prednisone therapy.

When strength returns, it does so from distal (further from the trunk of the body, i.e. hands) to proximal (closer to the trunk, i.e. quadriceps) muscles, ending with the trunk and neck muscles. The abdominal and neck muscles tend to be the first ones affected by the disease. In general, males have a harder time going into remission, and adolescent onset of the disease (between the ages of 13 and 18) tends to be harder to control.

When new things happen – sudden trouble swallowing or the reappearance of a rash – it's important to step back and examine what caused this flare or return of a particular symptom. Consider all of the possibilities.

Keep track of these changes, and get in touch with your doctor to decide on the best course of action.

Send in your questions

Please email any general "Ask the Doctor" questions you may have to kathryn@myositis.org. We'll include as many as we can in upcoming newsletters.



All in the family, continued from front

Classmates are important, too, so pass out materials that they'll understand. Both the Luchts and the Webers led sessions to educate their children's classmates. Karen Adelman, whose daughter has JM, made a video of Lauren receiving her IVIg, showing her classmates that this was just a part of her routine. "Have your children concentrate on getting people to know them," said Shari.

Remember yourself

These tips have helped others as they faced the daily challenges of JM, but in all of this, don't forget about yourself! Make sure you give yourself time each day, as hard as it may seem to find that time. Do something you really enjoy – take a bath, read a chapter in a book, or just sit and listen to music. You can even include your children in these activities. The idea is to do something that isn't hectic or rushed – to rejuvenate yourself.

It's so important to be your child's voice in many situations, and as your child grows, he or she will learn to be his or her own advocate, too. This takes energy, so be sure you have a good support system around you.

"It was very valuable to hear about other families' experiences and methods for coping," said Shari of the gathering. "It was nice to hear about situations and be able to say, 'yeah, me too,' or 'I should try that.' I felt like I was not as alone anymore."



Hold the salt! Sodium feeds prednisone bloating

Prednisone – the medication we all love to hate – affects your child in many ways, but the most visible effect is usually the weight gain that follows the initial high doses used to treat JM. Patients report obvious – even dramatic – weight gain after taking high levels of prednisone as prescribed. This common problem is caused by two properties of the drug: it makes your child ravenously hungry, and it also makes your child retain fluids. That’s why doctors ask that your child follow a diet in which salt – or sodium – is restricted during the time he or she is on prednisone. Normally, a doctor will advise you and your child to avoid foods with added salt. With a little research and patience, you can find foods your child likes. It helps to talk to your child about the importance of this dietary change, and to offer similar foods to the whole family.

Avoiding salt is not as easy as it used to be. Before there were so many packaged and convenience foods, it was safe to assume that anything that tasted salty was full of salt; and the reverse: anything that didn’t taste salty probably was safe for those on restricted diets. Now, the practice of salting strongly flavored pre-packaged foods means that almost anything is liable to have a good portion of extra salt.

Some examples of foods that usually have hidden salt are canned foods like processed vegetables, meats, and mixed pasta meals; processed deli foods like bologna, pepperoni, salami, hot dogs, and sausage; boxed mixes with cheese; dried pasta and rice mixes; canned and dried soups; snack foods like chips, popcorn, pretzels, cheese puffs and salted nuts; and dips, sauces, and salad dressings. You can be sure that anything labeled “teriyaki,” “smoked,” or “cured” is full of sodium.

So what’s left? Foods low in sodi-

um are most breads, cereals, rice and pasta; vegetables and fruits (fresh or frozen); fresh cuts of meats; milk and yogurt; and drinks like juices, tea, fruit drink or punch. Sports drinks have added sodium, so these should be limited. Fluid replacement drinks for children recovering from colds and viruses also tend to have a great deal of salt.

If you want to duplicate your child’s normal diet, you may have to be creative; for instance, making homemade chicken strips and French fries without salt. But many children are content with simple substitutions like a sandwich made with reduced-salt peanut butter and jelly.



Making sense of food labels

Bring your reading glasses to the grocery store. You’ll need them to make sense of the confusion surrounding the salt content of various prepared foods. Understanding these common terms will help you assess the desirability of each product at a glance:

- Sodium-free – Less than 5 mg sodium per serving
- Salt-free – Meets requirements for sodium-free
- Low sodium – 140 mg sodium or less per serving
- Very low sodium – 35 mg sodium or less per serving
- Reduced sodium – At least 25 percent less sodium when compared to regular version
- Light in sodium – 50 percent less sodium per serving when compared to foods with more than 40 calories per serving or more than 3 gm of fat per serving
- Unsalted – no added salt

SAMPLE LOW-SALT, CHILD-FRIENDLY MEALS

Breakfast

Orange juice

Cereal with low-fat milk

Toast with unsalted butter or margarine and jelly

Lunch

Beef patty on hamburger bun with mustard and ketchup

Sliced tomato and lettuce

One cup low-fat milk

Snack

Low fat cheese

Low fat, no sodium crackers

Dinner

Three ounces homemade, baked and breaded chicken strips

Half-cup oven-baked French fries, homemade

Green beans

Dinner roll

Apple juice

One-half cup frozen yogurt

Snack

Fruits, unsalted nuts and popcorn

Give us your ideas

We want to make this newsletter as valuable as possible, so we'd like to hear from you. Let us know what you want to see covered in future issues of the Companion. We've already had some great suggestions, but we always welcome more.

For the Spring edition, send us what has worked and what hasn't in explaining JM to your child. Please include your child's age at diagnosis so other parents can adjust your ideas for their own children.



LIGHTENING THE LOAD: ROLLING BACKPACKS OR EXTRA BOOKS?

If you participate in the juvenile myositis email listserv, you may have been a part of the discussion on how heavy schoolbooks are, especially once your child is in middle school. So what can you do about it?

Some parents have suggested buying rolling backpacks. However, children may feel this makes them different from their friends. “I bought her a rolling backpack at the doctor’s recommendation,” says Karen, whose daughter has JM. “She used it for one week and then refused because she didn’t want to be different than the other kids.” These backpacks can also be too large to fit into your child’s locker, adds Mary Lou, another JM mom.

Others have had success getting a second set of books – one to keep at

home, one at school. This can be expensive, unless the school offers to pay for the extra set.

“My daughter Maria has a prescription from her doctor for a second set of books,” says Elaine.

“The guidance department was responsible for getting them to us.” This may not be as easy in every school system.

Some parents brought up Section 504: “Doing a 504 plan with the school that includes having a second

set of books may be the way to go if they are reluctant to just give you

one,” says Donna, whose son has JM. In short, Section 504 of the Rehabilitation Act specifies that no one with disabilities can be denied an equal opportunity to participate in any activity or program receiving Federal financial assistance. Check with your doctor to see what he or she recommends.

If you’re a member of TMA and are not currently on the JM email listserv, send your email address to kathryn@myositis.org. The listserv allows you to correspond with every TMA member affected by juvenile myositis with a single email.



THE MYOSITIS ASSOCIATION

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JM COMPANION

For patients, families and friends affected by juvenile myositis



JUST FOR ME

Fun facts and news for JM patients and friends

ALL IN THE FAMILY: WHAT YOU CAN DO TO HELP

If you have juvenile dermatomyositis or juvenile polymyositis (both called JM here, for short), there's probably nothing your family wouldn't do to help you. And you can help them, too!

Always let your parents know how you feel and what you think might make you feel better. Don't try to do too much, even if you think you need to do more. You need to make sure you stay rested as much as possible.

Your brothers and sisters, especially if they're younger than you, may not understand everything about your JM or your medicines. Explain things to them so that they know what's going on. They may not know how to ask, or may not be sure if you want to talk about it, but talking to them will make them feel better. Remember to thank them for all that they do for you.

Help your teachers, classmates and friends by telling them more about JM. Let them know how JM and your medicine make you feel. They don't understand that

even if you sometimes look fine, you may feel weak and tired. The more you can explain to them, the less worried they'll be. Some parents have made videotapes to show to their children's classes or visited the classroom to explain more about JM. TMA can help, too, so let us know if you need more information to take to your school.



Keep a journal

Write down (or have someone write it for you) how you feel each day – what hurt, what felt better,

what medicines you took, and what you did that day. This helps you figure out what you may need to do to be more careful. This can also help your doctor decide if the medicines are working like they're supposed to be.

Be yourself

It's hard sometimes for you and those around you not to think about your JM too much. Be matter-of-fact about it. Explain that it's something you have, but it's not all there is to you. Let people know more about you – what you like to do or play. Then just tell them when you need to rest.

Did you know...

Ever wonder why we say certain things the way we do?

“Spill the beans” is a phrase we use when someone tells a secret. In ancient Greece, people voted by putting a bean in the hat of the person they wanted to win the election. The person with the most beans at the end won. He poured the beans out of his hat and put the hat on his head, letting the people know he had been chosen. Since “spilling the beans” let people know he was the winner, we now use this phrase when someone lets a secret slip out.

From “Common Phrases and Where They Come From” by Myron Korach (The Lions Press).

Kids Helping Kids

Do you have a question for other children, teenagers, or young adults with myositis? Send it to kathryn@myositis.org, and we'll include a question or two in each issue of the Companion. Those who read your question can answer it for the next edition.

Keep checking this section to see if there's a question you can answer to help others out, too! (Send all questions and answers to kathryn@myositis.org. We'll include only initials rather than complete names in both questions and answers.)

LESS SALT = LESS SWELLING

There's a reason why we all want salt. It's been an important part of the meals we eat in every culture and in every time period. That's because salt saves and flavors food and helps our tissues hold on to fluids. That last part is where the problem comes in if you're taking prednisone. The medicine already is "telling" your body to hold on to water and other liquids, resulting in that puffy, swollen look we all know so well.

How can you fool your taste buds into liking food with less salt? For a start, don't eat fast food, which uses salt to make the food taste better. Especially stay away from any food that mentions soy, teriyaki, smoked or cured to describe it. You won't miss the salt so much if you use other flavors instead of salt. The following recipe for chicken fingers is an example.

Cornflakes make a crispy coating for the chicken without the high fat and salt of fast food chicken fingers. To crush the cornflakes, put them in a large plastic bag and roll over them with a rolling pin. To separate the egg, crack the egg and carefully pour the white away from the yolk (yellow part of the egg) into a bowl. Pour the yolk from one half of the shell to the other, letting the white part drip into the bowl until only the yolk remains.

Refrigerate the yolk in a plastic bag to use later. To cut the chicken into strips, put it into the freezer until the chicken is almost frozen. A sharp knife will cut the icy chicken easily.

Oven-baked crispy chicken fingers (serves 2)

Ingredients:

- 1/3 cup crushed cornflakes or breadcrumbs
- 1/2 teaspoon paprika
- 1/4 teaspoon dried oregano, crushed (or parsley, chili or Cajun seasoning)
- 1/4 teaspoon garlic powder (not garlic salt)
- Dash ground red pepper (optional)
- 1 slightly beaten egg white
- 8 ounces skinless, boneless chicken breast halves, cut into 1-inch pieces

Directions:

1. In a plastic bag combine crushed cornflakes, paprika, garlic powder, oregano, and, if you like your food a little spicy, red pepper. Place egg white in a small bowl.
2. Dip chicken pieces into egg white, letting them drip over the bowl before putting them in the bag. Add pieces, a few at a time, to cornflake mixture; shake to coat well.
3. Place chicken pieces in a single layer in a shallow baking pan. Bake in a 450 degree F oven for 7 to 9 minutes or until chicken is no longer pink. Makes 2 servings.

Nutritional Information

Nutritional facts per serving

Calories: 191, Total fat: 2g,

Saturated fat: 0g,
Monounsaturated fat: 0g,
Polyunsaturated fat: 0g,
Cholesterol: 66mg, Sodium:
228mg, Carbohydrate: 13g, Total
sugar: 1g, Fiber: 0g, Protein: 29g,
Vitamin A: 0%, Vitamin C: 2%,
Calcium: 2%.

Fruit Smoothies

Ingredients:

- Fresh or frozen fruit, any kind
- Yogurt, any flavor
- Ice



Fruit smoothies are a fun and easy snack, and you can be creative with what you put in them each time you make them.

Choose fresh or frozen fruit - whatever you have handy. Adding bananas is a great way to make the drink thicker. Put the fruit in a blender with any flavor yogurt (including plain), and blend it all together. You can add ice before you blend it, if you'd like.

Create new flavors every day by using different fruits or mixing the fruits together. Play around with how much fruit and yogurt you use to make it just the way you like it. For a real thick shake, peel and freeze overripe bananas and add by thirds to the blender. Vanilla, lemon juice and cinnamon add flavor to the fruit and yogurt.

[Parents: The food values for salt and sugar depend on the type of ingredients you choose, so read the labels carefully for any packaged foods.]