

## Answering tough questions

Why is the grass green? Where does rain come from? When is it going to be my birthday again? These are some of the burning questions children ask their parents again and again.

Questions about nature and time are hard enough, but when your child is diagnosed with a chronic disease like juvenile myositis (JM), the questions become even more difficult. How do you explain this complex and confusing condition? Just like each case of JM, each child is different, so explaining it depends a lot on your child's own nature. "I think a mother knows her child the best and can gauge what are the right words for that child's personality and coping abilities," says Karen Horan, whose 6-year-old son Quinn has JM.

## Use past experiences

Quinn is intuitive and worries more than most children his age, Karen says, so she decided not to tell him that he had a disease with a name: "I only told him that we had to go back to the hospital daily so that the doctors could figure out why his bones were hurting him."

The family's dog had recently died, so Karen had to explain to Quinn that the medicines the doctors gave his beloved pet couldn't fight off the bad cells. After going through the battery of tests and beginning IVIg treatments, Quinn applied these past events to his own situation: "My fighting cells in my body are being tricked. They think my muscles are the

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## Ask the Doctor with Dr. Pachman

Dr. Lauren Pachman is Professor of Pediatrics at the Feinberg School of Medicine at Northwestern University in Chicago. She works with families dealing with juvenile myositis at Children's Memorial Medical Center. We thank Dr. Pachman for volunteering her time to answer these questions.

**Q** Once your child is in remission, how long should you continue to use sunscreen, sun clothing, etc., along with the supplements and vitamins?

**A** This is an excellent and difficult question to answer. Part of the answer hinges on the definition of "remission". Some people use the term "remission" if the child has no symptoms but is still on medication. Others use the term "remission" to define the child who has no symptoms and is not taking any medication, which is the use that I prefer.

Another part of the puzzle is that some of the laboratory tests that are commonly used – the muscle enzymes, ESR, etc. – may be within normal limits, but some tests of immune function are still abnormal. There is not yet agreement within the medical community concerning the extent of laboratory testing that is both useful and cost effective in determining if a child still has signs of inflammation. Our center tends to use tests such as von Willebrand Factor Antigen and flow cytometry to see if these components of the JM child's immune response are in fact "within normal range".

A third part of the puzzle with respect to sun protection concerns

your own child's clinical course — was the skin highly involved in the past, are the nailfold capillaries still abnormal? There is a lot of evidence that shows that sun exposure is harmful, even for normal skin, so that protection now may prevent skin cancer later. Given this background, it seems logical to continue to use sunscreen at SPF 30 or more.

Finally, if the tests for inflammation associated with myositis are now normal (inflammation can make the bones weaker), the bone density is within normal range for your child's age, your child's calcium intake will continue to be in the recommended daily requirement (for healthy children) and your doctor agrees with you, then you might consider no longer taking calcium and vitamin D. The need for other vitamins depends on the child's diet and preferences.

**Q** When should you consider a port or PICC line for children?

**A** There are several important factors to consider: the age of your child, the state of the current illness, problems with access to your child's veins, how your child responds to having blood taken, and, critically, the overall plan of therapy. Is your doctor planning treatment for a short term (a few days or weeks) or for a longer period of time?

The PICC line is less permanent, is exterior,



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## Dear Families:

TMA continues to work hard to give all JM families the best service and support we can offer. To continue this, we need your help.

The JM Companion is a valuable resource for families dealing with juvenile myositis. We plan to include 'Ask the Doctor' and 'Kids Helping Kids' sections in each newsletter. These interactive features allow you to question our medical experts, and allow your children to ask other children what has helped them cope and learn. Children often feel more comfortable talking to other children instead of 'grown-ups.' Kids Helping Kids gives them a chance to respond in their own words.

The Juvenile Programs portion of the TMA web site will always be a work in progress. Help us format the information to best suit your needs. With areas for parents, teens and kids, this site will continue to grow and improve.

Many medical specialists have donated countless hours on a book TMA is producing, which is focused on juvenile forms of myositis, but we're especially excited about the part you're writing. Thanks so much for all the personal stories you've submitted for this book, making it a truly comprehensive and personal resource for families dealing with JM.

Other JM programs continue to develop with your help. Children can now participate in the e-pals program, and several parents have volunteered to contact JM families new to TMA. We're still planning more for the year ahead, so please feel free to let me know what you'd like to see from TMA.

I look forward to hearing from more of you in the year ahead.

With kindest regards,  
Kathryn Spooner

## Answers, continued from front cover

virus. The medicine I get in my port is telling my fighting cells to stop going after my muscles. They are not the virus. Boy, that is tricky." He went on to say it was like his dog, but the medicine would work for him.

### Call it by name

"Because Sarah is 4, it is difficult for her to understand what's going on with her," says Donna Haller. "For a long time, whenever we talked about it and I mentioned JDM she would say 'what's JDM?' And we would explain it to her again." As they continued to explain JDM to her, she gradually began to understand that her rash was because of her JDM. At such a young age, it's often enough to know that your rash and weakness are because of something with an actual name. Other children may want more, asking "why" in response to any answer you give.

### Give them a sense of control

Quinn's home health nurse includes him in her treatment – he helps mix the medicines, flushes his port, and takes inventory of the medicine cart. This gives him a sense of control, Karen says, and shapes how well he handles and understands his situation.

Some hospitals and clinics reward children for remembering the names of their medicines. "It is a very subtle way to help the children be responsible and increase their knowledge of their illness," says Lyn, whose son Miles has JDM.

### Choose your words carefully

There's more to explain than just the disease itself. If you have an infant or toddler with JM, the disease, tests and treatments may become "the norm" for your child.

Children will endure a number of

tests, and you can make some of them more interesting and less intimidating, depending on the words you choose, says Donna. "When [Sarah] had an MRI, we said that it was a big camera that took pictures of her muscles to look at her JDM," she says. "For her EMG, the doctor (a pediatric neurologist) explained he needed to 'listen' to her muscles – she thought the 'sound' they made was pretty cool!" Her daughter is much more comfortable with things if they explain them to her first, she says.

Kris Clark, another JDM mom, doesn't let her younger son know about his shots or tests too far in advance: "The anticipation is often worse than the actual procedure." And Karen Horan 'waters it down' to keep the concepts from becoming too scary. "Keep things as normal as possible to remind him to be a 6-year-old kid," she says. "Let someone else worry for him."



## POINTERS FROM PARENTS

- Trust your instincts. You know your children and how they will handle the situation.
- Use words and concepts they'll understand. There may be past experiences that you can use to help.
- Repeat it. Just like any new lesson, repeating it helps them learn.
- Stay positive, but be honest and open about things.
- Include them. Nothing is scarier than watching your parents whispering about the unknown. Let them hear what you have to say, and give them the chance to make some decisions on their own. This will also give them a sense of control.



## “I’m going to DisneyWorld!”

This may be the most common phrase we hear from athletes after they win their sport’s championship. It’s also the most requested wish made to the Make-A-Wish Foundation.

The Foundation grants wishes to children ages 2 ½ to 18 who struggle with serious, life-altering conditions. So what would you wish for if you had one wish to make? That was the dilemma for several TMA members:

Abby Printz and her family traveled to DisneyWorld, staying at an impressive resort and enjoying the thrills of the theme park and surrounding areas. “It was a once in a lifetime opportunity,” says her mother, Suzanne.



Abby Printz poses with Aurora.

Sydney Kavanaugh also chose DisneyWorld, so the Foundation planned a seven-day, six-night trip. “We’re on cloud nine and haven’t even gone yet,” said her mother, Jennifer, before they left.

Chris Graves dreamed of meeting Los Angeles Lakers’ star Kobe Bryant. Make-A-Wish arranged for Chris and his family to watch an NBA game then meet Kobe in person.

### Deciding on your wish

“Chris had a hard time choosing,” says Joyce Graves, his mother. “He got ideas from the Make-A-Wish web site, where children share their story.” He decided on meeting the rising NBA star since that’s not something the family could have saved enough money to do. “Meeting someone you really admire is only possible through this kind of program,” says Joyce. The Foundation presented his wish to him at a ‘wish party,’ with cake, ice cream and other treats. The family even received money for souvenirs.

### A wish come true

When the day arrived, a limo picked

up the entire Graves’ family. They drank soda from champagne glasses, bought shirts and souvenirs to be signed, and sat in premium seats at the game. A representative stayed with them to help with anything they needed during the game. Afterwards, they all waited in the locker room for Kobe. “Our girls were so cute,” says



Joyce. “They were messing around by the door, and when Kobe came in, he scared them! It broke the ice and we all laughed and enjoyed the time immensely.” Kobe was friendly and made Chris feel “like a million bucks,” she says.

Other families echo this excitement: “We all had a huge ball and were so humbled and in awe of how well everyone, from the resort folks, to the DisneyWorld staff, just everyone, treated Abby and all of us!” says Suzanne Printz.

To refer a child for a wish, visit [www.wish.org](http://www.wish.org) or call 800-722-9474 for more information. Do you want to read more stories about TMA members who have experienced wishes like these? Visit the Kids’ pages of the Juvenile Programs section of [www.myositis.org](http://www.myositis.org) for more!



## Doctor, continued from front cover

and is more likely to become infected in the course of daily living. The port placement requires anesthesia in an operating room, is more permanent, and allows the child to swim and lead a relatively normal life. Both lines allow administration of IV medications and blood draws for testing, which lessens the anxiety children experience. Our children have reported problems with body contact (getting hit in the area) with both types of devices. The only other option for IV medications is to have an IV started at each visit, and sometimes the child’s veins do not withstand this approach.



## Consider camp – we’ll help

We’re looking ahead to summer and invite you to send your JM child to camp. TMA’s JM families have told us that camps provide a wonderful experience for children with chronic disease. Most of the special camps run by the Muscular Dystrophy Association (MDA), Arthritis Foundation (AF) or local hospitals have the ability to work with any child, and you’ll have a chance to discuss your child’s specific needs when applying. We recommend camps for JM children even if they don’t appear to be markedly different from their classmates. Camp may be the one time during the year that they can talk openly about their fears with other children with the same concerns.

Because TMA does not have the financial resources of larger organizations, JM children usually choose a camp run by MDA or the AF who will pick up all or part of the costs.

To make sure every child has this opportunity to attend camp, TMA will pay whatever part of the cost falls to the camper’s family, up to \$250. Simply find a camp appropriate for your child and ask for an application. MDA pays the full camper fee. AF camp directors will send us a form for camp funding once your child completes the camp. You’ll also be asked to fill out a brief report on your child’s experience at camp. If you or the camp director have any questions, call TMA at 202-887-0088, ext. 601; or email [TMA@myositis.org](mailto:TMA@myositis.org). You must be a TMA member to be eligible, but you can join now. We will award the “camperships” as they come in, so don’t delay.

### Camp information sites

MDA: [www.mdausa.org](http://www.mdausa.org)

Arthritis Foundation: [www.arthritis.org](http://www.arthritis.org)

Easter Seals: [www.easterseals.org](http://www.easterseals.org)

American Camping Association: [www.acacamps.org](http://www.acacamps.org)

Kids Camps: [www.kidscamps.com](http://www.kidscamps.com)

## Chickenpox vaccines

There has been some concern over whether you should vaccinate anyone in your house for chickenpox (varicella) or other conditions when you have a child with JM. TMA medical advisors recently addressed this issue (summarized here): Remember that the chickenpox vaccine is a live virus, so anyone receiving this vaccine will shed the virus for several weeks. Although it isn't typical for someone to develop chickenpox after someone else has been vaccinated, there is a remote concern for a child with JM whose immune system is suppressed. Talk to your child's doctor before vaccinating anyone in your household, and contact the doctor if your JM child is exposed to anyone who has the chickenpox.

Plenty of parents addressed this

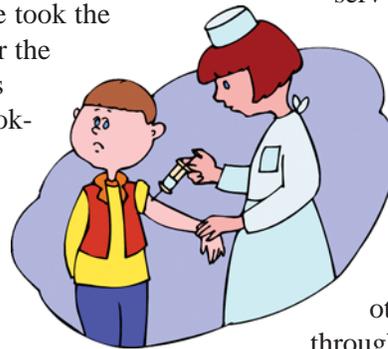
issue on the JM email listserv:

"He was previously vaccinated against chickenpox prior to the onset of JDM," says Sharon of her son. "Unfortunately, this past December, he contracted chickenpox, but not from anyone he lives with or even knows. It was a child in his school, not even in his classroom, that somehow passed it through carriers to him." Sharon was advised not to give her son the methotrexate he was taking for his JM while he took the anti-viral medicines for the chickenpox. She urges parents to be on the lookout not only at home but at school as well.

Shari decided to have her son Cole, who does not have JM, vaccinated while she and Parker

(JDM) were away for a week. Cole did develop a rash, so Parker started a course of medicine to keep him from getting sick. "If he did [develop chickenpox]," she says, "they would start infusions of VZIG (varicella-zoster immune globulin)."

If you're a TMA member but are not included in the TMA email listserv for JM families, please contact [kathryn@myositis.org](mailto:kathryn@myositis.org) to add your name to the list. The listserv allows you to communicate with a large number of other JM families through a single email!



THE MYOSITIS ASSOCIATION

1233 20th Street, NW, Suite 402  
Washington, DC 20036

# JM COMPANION

For patients, families and friends affected by juvenile myositis

## Say what?!

That's what many of you hear when you tell your friends you have juvenile dermatomyositis or juvenile polymyositis (JM, for short). Not only is it a strange disease, it's a mouthful to say!

Some of you have told us how you let your friends know about JM:

"I just say I have a disease, I couldn't walk," says Alison, now 9 years old. "I don't really give them the whole story." Alison also has an older sister, Lauren (13), whose friends would sometimes ask what was wrong with Alison when she had trouble walking. Lauren told them that she had juvenile dermatomyositis, which made her muscles weak, and they didn't ask much more about it.

"We let everyone know what was going on right from the start," says Riley's mom. Riley is also 9 years old and has known he has juvenile dermatomyositis for just over a year now. By telling others, their friends offered to help in a lot of different ways.

Some children don't want to tell others about JM, though. "I get really mad when my parents tell other people about my illness," says Chloe (9). Chloe's best friend and classmates know she can't always do some of the things they do in recess, and they all help out when they can.

How do you tell your friends and others about JM? Send us an email at [kathryn@myositis.org](mailto:kathryn@myositis.org) or write to us at TMA, 1233 20th Street NW, Suite 402, Washington DC 20036 to let us know so we can help other children to talk about JM with their friends.

## Kids Helping Kids

This section of the Companion lets you ask questions for other children to answer, or you can answer questions they've asked here. Many families have found online diaries – like Julia's JDMS Diary – very helpful in finding answers to just about any question. Julia welcomes emails from anyone with questions or anyone who just wants to write to her.

If you have a question to ask or want to answer one of the questions below, please email [kathryn@myositis.org](mailto:kathryn@myositis.org) or mail to TMA, c/o Kids Helping Kids, 1233 20th Street NW, Suite 402, Washington DC 20036.

Thanks for making Kids Helping Kids work for you!

**Questions:** How did you tell your friends about your JM?  
How do you let them know when you need to rest?

**Do you have a question you would like others to answer?**



### PROFILE: CHRIS GRAVES

We often write about how juvenile myositis (JM) changes your lives in some way. But JM doesn't change who you really are! This section will let us help you get to know other young people with JM by telling you more about what they are like, not just about their JM. Tell us more about yourself for this section in future newsletters. And find more profiles in the Kids' pages of [www.myositis.org](http://www.myositis.org). Email [kathryn@myositis.org](mailto:kathryn@myositis.org) or send your information to TMA, 1233 20th Street NW, Suite 402, Washington, DC 20036.

Chris Graves, now 14, has battled juvenile dermatomyositis (JDM) for almost two years, but he is feeling better now than when he first found out he had JDM. He was in the hospital for almost two

months before the medicine he took started to work.

Now Chris can again enjoy the things he's always enjoyed. He likes basketball cards and is a big Los Angeles Lakers' fan. He and his family were able to meet one of the star basketball players on the Lakers' team – Kobe Bryant. Chris' wish to meet Kobe was granted by a special group called Make-A-Wish®. (Read more about his and other kids' wishes on page 3.) He also likes the Philadelphia Eagles, Cleveland Browns and Cleveland Indians.

Chris has a large family, with an identical twin brother Kevin (14), a younger brother Sean (13), and twin sisters Shannon and Stephanie (9). The family lives in California, where Chris has even been in TV shows and movies!

# Meet new friends this summer

Do you ever feel like you're all alone? Being sick makes everyone feel that way sometimes. That's why we want you to meet other children at camp this summer. There are camps in every state for children who have juvenile myositis or other conditions. You'll find great kids who have learned how to have fun; and you'll be able to help kids who are just starting out.

Don't worry if you get tired easily, or need a lot of medication. These special camps are set up with you in mind. Some of the children will be in wheelchairs, some will have trouble eating, some will need to rest for part of the day. All of them will understand what your life is like. You'll make friends and have fun.

If you want to help your parents find a camp for you, go to the sites listed on page 3 of the Companion. TMA will help pay for camp, up to \$250.

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## Car games

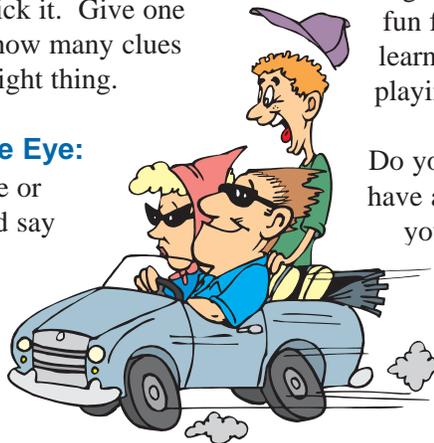
If you're driving to summer camp or just going to the grocery store, here are some fun games to pass the time in the car.

### Guessing Game:

Think of something – anything at all – then share three clues to help your friends or family guess what it is. For example, if you think of a soccer ball, you might say it's round, it's black and white, and you kick it. Give one clue at a time to see how many clues it takes to guess the right thing.

### I Spy with My Little Eye:

Find something inside or outside of the car, and say "I spy with my little eye something that...." – then you can give the color or the first letter



## Getting ready for camp

Camp counselors will send you a list of things to bring with you (including a doctor's note for any medicine you're taking). Camps are exciting places with fun activities and adventures planned throughout the days and nights. You'll meet new friends from different places, learning more about them – what they like to do and where they live. Take along an address book so you can keep in touch with everyone even when you've all gone back home. Take a camera, too, to remember all of your new friends. You can share these pictures and camp stories with your family and friends back home.

Most importantly, be ready to have a great time. Camps give you so many fun and exciting things to do, and you'll learn so much living with the other campers.

Enjoy your time at summer camp!

of the word. So if you see a red cup in the car, you can say something that's the color red or something that starts with the letter "c."

### Alphabet Soup:

Starting with the letter "a," take turns finding things (or just coming up with words) that begin with each letter of the alphabet. Some letters can be tricky, so be creative. [Parents, with younger children, I've found that using letter sounds is just as fun for them, and they learn a lot while they're playing.]

Do you and your family have any other fun games you play while you're on the road? Let us know.

## CHOOSING THE RIGHT FOODS

With fast food places on every corner, it's hard to eat right. Many people with myositis have told us that eating the right foods makes them feel better overall. So watch what you choose from the school cafeteria or to pack in your lunch.

Your doctor may tell you to stay away from certain foods – like foods with a lot of salt or fat – but it's also important that the foods you do eat are good for you.

You may have heard of the "food pyramid." This is a chart that helps you decide on the right foods to eat every day. Foods are split into different groups:

**Grains**, bread, cereal, rice, noodles

**Vegetables**, carrots, broccoli, squash

**Fruits**, bananas, oranges and apples

**Dairy**, milk, yogurt and cheese

**Protein**, meats, eggs, beans, nuts

**Fats**, butter and candy

You need to make sure you eat certain amounts of food from each of these groups, and choose a mixture of different foods. Many doctors and nutritionists (people who study what we eat and how it helps or hurts us) want children to eat at least 5 foods from the vegetable and fruit groups and 2 from the dairy group. Don't eat 3 servings of carrots, though, just because they're your favorite. Eat other vegetables, too.

If you don't eat meat, make sure you get enough protein in your diet. Choose peanut butter or black beans.

You should eat very little from the "fats" group, but it's okay to eat some. Pick the foods that are in the first groups (grains, vegetables and fruits) over those that are in the "fats" group.

You can find out more about the food pyramid online at <http://www.usda.gov/cnpp/KidsPyra/LtlPyrBW.pdf> (for children 2 to 6) or <http://www.nal.usda.gov/fnic/Fpyr/pmap.htm>. Or visit your library.