

## Dedicated JM web pages

In our continued efforts to improve and expand services to JM families, we've created a special JM section on the TMA web site! This section is divided into three distinct areas for parents, teens and kids. Each offers age-specific materials including program updates, disease definitions, informative articles and more.

Parents can conveniently locate articles and materials relevant to their family. We'll continue to post updates on JM programs, including the JM book, summer camps and JM research funding. You can browse through articles on important issues such as childhood depression, dealing with healthy siblings, and talking with your children about their illness.

The "Teen" section is continuing to be developed, and we want your suggestions! If you are a JM patient age 12-18, let us know what you would like to see in this section. After all, it's for you!

Younger JM patients should enjoy browsing the star-studded "Kids" section. This section includes photos and stories of JM patients and encourages children to submit their own. More articles written in an easy-to-read style answer common questions about JM. Games and jokes will be added soon. If your child has a joke to submit, please send it!

More than anything, we want this JM section to reflect the interests and needs of our JM community. We want your faces and stories to drive its design. Please send your comments and suggestions to [jami@myositis.org](mailto:jami@myositis.org).

## Why camp? Camp director and former JM patient tells his story

Wade Balmer directs Camp JRA in Eastern Pennsylvania, and he has a unique perspective on camps, chronic disease and childhood: "I know what it's like to feel different," Wade said. "Diagnosed with dermatomyositis at age 5, all I've ever known is what it's like to stand out from everyone else.

Questions like 'Why are your joints so red?' 'Why can't you play sports with us?' or 'Why are you so tired all the time?' filled my childhood."

Wade remembers feeling very much alone: "No one could personally understand what I was facing with my disease – not my friends, not my teachers, not my doctors or my family. I never met any other children with juvenile dermatomyositis, so as far as I was concerned, I was the only kid in the world who knew what life was like with this disease. I knew I was different, and I never truly understood what it meant to be accepted. All that changed when I attended Camp

JRA for the first time in 1997."

Camp JRA – for "Juveniles Reaching Achievement" – is now in its eighth season. It's a place where children come year after year to have fun while being around other campers and counselors with similar challenges. The camp this year is from July 12-18,

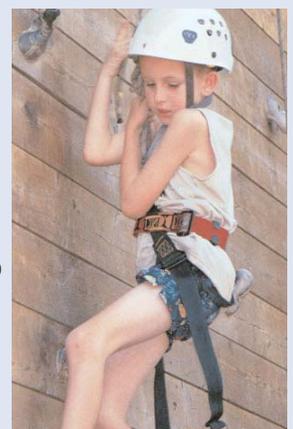


2003, in Millville, PA.

The stories are the same year after

year, Wade says: "The campers tell us it's the one place on Earth where they feel as if they truly fit in." For Wade, Camp JRA was a miracle. "Not only was I feeling accepted but understood as well." In the first camp season in 1996, Camp JRA began with 20 campers. Since then, it's grown and this year will host 95 campers.

TMA is helping children with myositis go to Camp JRA and other camps. To find out more, call 540-433-7686 x14, or email [tma@myositis.org](mailto:tma@myositis.org).



# WHEN YOUR SHIRT IS ALSO A SUNSCREEN

## SUN-PROTECTIVE CLOTHES FOR THE WHOLE FAMILY

### Why choose sun-protective clothing?

As concern for skin cancer grows, so does the number of products available to help prevent it. Some of these items, including the increasingly popular sun-protective clothing, are great for juvenile myositis patients.

The American Academy of Dermatology (AAD) estimates that by the time a child is 18, he or she has experienced 80 percent of a lifetime's sun exposure. This reinforces the need to protect children.

Though sunscreen is still essential for those body parts exposed to the sun, what you wear can actually protect you and your family. Your clothes act as a physical barrier to the sun, and the protection won't wear or wash off like lotions. A normal white t-shirt only provides a Sun Protection Factor (SPF) of 6, not nearly enough for adequate protection.

For exposed body parts, follow the AAD's general recommendations:

- Use broad-spectrum sunscreen with an SPF of 15 or higher, except for children under six months of age.
- Apply the same amount of sunscreen as you would lotion for dry skin. Be sure to cover all exposed areas of skin, including ears, nose and lips (but not eyelids).
- Reapply sunscreen at least every one and a half hours, or more after activities, even on cloudy days.
- Wear tightly woven clothing, as well as hats and sunglasses.
- Limit your time in the sun

between the hours of 10 am and 4 pm, and avoid being in direct sunlight for long periods of time. Find shade when you can.

- Stay away from tanning beds.
- Watch for sunburn or freckles, both signs of sun damage. Although it might not seem harmful now, the damage builds up over time.



### What are sun-protective clothes?

The increasing emphasis on sun safety has spurred companies to create more stylish, comfortable sun-protective clothes. You'll find swimwear, business and polo shirts, track pants, hats, and much more. It's important to understand the labeling, which the Federal Trade Commission monitors carefully.

The Ultraviolet Protection Factor, or UPF, measures how much of the sun's radiation is absorbed by the fabric. So a UPF of 20 means that 1/20th of the radiation passes through the clothing; or in other words, the fabric reduces your exposure by 20 times. A UPF value of 15-24 is considered good protection against UV rays; 25-39, very good; and 40-50, excellent. Keep in mind that some UV protection may be lost if the clothing is overly worn or washed, wet, or stretched out.

### Sun products on the market

A search of the Internet will produce literally thousands of online stores

selling sun-protection products, including:

- Coolibar, [www.coolibar.com](http://www.coolibar.com), 1-800-926-6509
- Solar Eclipse, [www.solareclipse.com](http://www.solareclipse.com), 1-800-878-9600
- Solartex Sun Gear, [www.solartex.com](http://www.solartex.com), 1-877-476-5789
- Solumbra, [www.sunprecautions.com](http://www.sunprecautions.com), 1-800-882-7860
- Sun Clothing, Etc., [www.sun-clothingetc.com](http://www.sun-clothingetc.com), 1-540-842-4583
- Sun Emporium, [www.sunemporium.com](http://www.sunemporium.com), 61-7-5597-0005 (Australia)
- Sun Grubbies, [www.sungrubbies.com](http://www.sungrubbies.com), 1-888-970-1600 (within US) and 1-858-268-1600 (outside US)
- Sun Protective Clothing, [www.sunprotectiveclothing.com](http://www.sunprotectiveclothing.com), 1-800-353-8778

Enter "sun protective clothing" in your search engine to find other possibilities.

### Educate your children

The more advanced products on the market make it easier to safely enjoy the sunny outdoors. Still, one of the most important things you can do as a parent is to educate your children about sun safety. Make sure they understand the importance of sunscreen, finding shaded areas, and protecting their skin now.

As with many lessons, you set the example for good sun health. If you plan to be outdoors for more than twenty minutes, show your kids the importance of sun safety by wearing proper sunscreen and clothing and using an umbrella for shade. Follow the AAD's guidelines, and remember that fluorescent lights can also emit harmful UVA and UVB rays.

If your child will be going to camp this year, talk to the counselors about the added importance of sun protection for your child.

## Long-term study reports on JM outcomes

A recent Canadian study shows just how much the outcomes for JM children have improved in the past few decades. The study's authors note the previous scarcity of this sort of information, and tracked a multi-center study that followed children seen between 1984 and 1994 at four Canadian pediatric centers. On average, the study followed the children for seven years and evaluated their medical progress and ability to lead normal lives. There were a total of 65 patients. At follow-up 47 – or 72 percent – were free of disability or had only very slight disability; only five had moderate to severe disability.

The authors identified a troubling problem, one for which there is still no solution: they found that calcinosis developed in 34 percent of the children. Calcium deposits were first noticed at a median of 3.4 years after the beginning of the disease. The patients described the calcinosis as being “moderate” in 9 out of the 22 affected and severe in only one. Treatment with intravenous corticosteroids did not protect children from developing calcinosis in this group; and calcinosis couldn't be predicted by age, sex, type of treatment or speed of diagnosis. Its causes as well as its treatment remain a mystery.

At the time of follow-up, all patients were either attending school or had finished secondary education. No patient reported that the disease had interfered with his or her ability to work. Despite the overall good outcomes in the study, there were some lingering effects. Fifteen patients, or 23 percent, reported muscle weakness, and 26 (40 percent) had episodes of rash. The rash was mild in 22 of 26, and weakness was predominantly mild, with only 6 patients reporting moderate weakness and only one patient reporting severe weakness.

Researchers found that 23 of the

65 patients continued to take either methotrexate (eight patients), hydroxychloroquine (one), cyclosporin (one), and prednisone (one); the other 12 patients took a combination.

## Medications affect sun sensitivity

Most JM patients need to avoid sun exposure to keep from aggravating their rashes or having them return. Those taking certain medicines, including methotrexate and certain NSAIDs (like ibuprofen), should take extra care in the sun. These drugs heighten your sensitivity to the sun and can cause severe burns or reappearance of a previously healed rash.

Many health-related organizations generally recommend using broad-spectrum SPF 15+ sunscreen, reapplying sunscreen often, avoiding exposure between 10 am and 4 pm, and wearing proper clothing. Following these familiar guidelines should provide protection for everyone, even those using medicines, as long as you follow them strictly. If your child's symptoms seem to improve with some sun exposure, talk to your doctor to make sure you're still adequately protecting your child.

## Tacrolimus ointment helped 10 JDM patients

Tacrolimus in ointment form, a substance that's been used successfully in treating eczema, may also help skin rashes in juvenile dermatomyositis, a study of 10 patients shows. In the study, patients who ranged in age from three to 20 with skin symptoms that had never been treated or resisted conventional treatment used tacrolimus ointment once or twice a day, with significant improvement. The rash of three patients went away altogether; all showed some improvement. None of those studied had serious side effects.

Tacrolimus is an ointment that decreases inflammation. Researchers

called for further studies of the safety and effectiveness of tacrolimus in JDM.

## Calcinosis Study

Calcinosis specimens from myositis patients which have been surgically removed or biopsied are needed for a study. The goal is to better understand the causes of calcinosis and find improved ways of treating it.

To refer samples or for additional information, contact Lisa G. Rider, MD, National Institutes of Health, DHHS, Building 9, Room 1W107, MSC 0958, 9 Memorial Drive, Bethesda, MD 20892.

Phone: 301-451-6272; Fax: 301-480-4127; Email: RIDER@niehs.nih.gov

## Need a way to explain things to siblings or classmates?

Like anything new and different, JM brings about many questions. The answers can be especially difficult when dealing with younger JM patients and their siblings and friends.

There are web sites geared toward those with JM: visit [www.myositis.org](http://www.myositis.org) to read the stories of children with JM, then add your own. Find a link to “Julia's JDMS Diary” in the Resources section.

Books are available to help other kids learn about those with special needs: “Susan Laughs” (by Jeanne Willis) shows that every kid laughs, cries, plays, and gets into trouble. In “Friends at School” (by Rochelle Bunnett), friends with different abilities work together to get things done.

There are numerous books for kids ages 4-8 to teach them more about children living with certain challenges. Visit your library or online bookstore for more ideas, and let us know what you find!

# You're invited. . .

...to share your JM experience with us - through stories, poetry, drawings, or photos!

**We need your help producing a book on juvenile myositis.** We've lined up experts from all over the world to help teach families about juvenile myositis. But there are other experts - you and your family - who know what it's like to live with myositis day-to-day.

If you're interested in contributing to this book, please email a 400-word article describing your personal experience to [tma@myositis.org](mailto:tma@myositis.org). Send your artwork to: JM Book Project, The Myositis Association, 755-C Cantrell Avenue, Harrisonburg, VA 22801.

For more details, including copyright information, visit our web site at [www.myositis.org](http://www.myositis.org) or contact Kathryn Spooner at [kathryn@myositis.org](mailto:kathryn@myositis.org) or 540-433-7686 ext 15.

Thanks for your help with this historic project. We're excited to learn more about you!



THE MYOSITIS ASSOCIATION

755-C Cantrell Avenue  
Harrisonburg, VA 22801

**JM COMPANION**



# JUST FOR ME

Fun facts and news for JM patients and friends

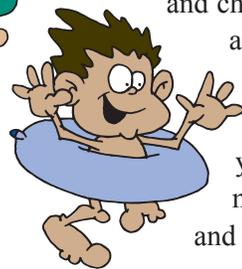
## CHECK OUT THE POOL FOR SUMMER FUN AND EXERCISE

If you've been sidelined from baseball or soccer because of weak or sore muscles from myositis, you may find that swimming is a whole new ball game. That's because the water supports your weight, making it easier for your muscles to move. The gentle resistance you find in the water may also help build up muscles that have been weakened from a wintertime's worth of rest.

Even if you can't swim laps, you can exercise in the pool or hot tub, and feel better after you do.

Since only your doctor knows the details about your disease, check with him or her first about possible effects on your muscles and skin. Let your parents know what you're planning and enlist their help for your summer water exercise program.

If your doctors recommend water exercise, they should be able to suggest some good exercises that will fit your strength and the state of your disease. If a physical therapist, family doctor, or specialist prescribes regular water exercise for your myositis, the purchase of a hot tub for your home or membership in a pool may be tax-deductible. Talk to your parents about this possibility. Remember that a spa or hot tub provides warmth that helps you relax and exercise your joints, but pools offer more space for exercises.



If your doctor says water exercise is safe, remember these tips:

- Very hot water is not safe and you don't need it to get results. Warm water is just as effective and easier for the body to stand.
- The water temperature should feel soothing and comfortable, not hot or freezing cold. Water temperatures should be comfortable for exercise.
- If you're a new hot tub user, you should slowly change the temperature and length of time in the tub until you know what is most comfortable. Start with a few minutes and stretch your time as you feel comfortable. Make sure someone is around to help you.
- Remember that you get overheated and chilled faster than adults and may need to exercise for less time.
- Never swim when you are home alone. You may need help getting in and out of the spa or pool.
- Once you have your doctor's okay, report back if your skin feels more irritated or your condition changes. Stop exercising if you notice bad effects on your skin or muscles.
- Take time when you first get in the pool to let the water relax your muscles. When you feel comfortable, slowly begin your stretching and exercising. Also stay in the pool after completing your exercises for a few minutes to relax again.

### Can't decide what to do for the summer?

Many people pass the time by flipping through the TV channels or surfing the Internet. Why not pick up a book instead? Read about famous people, or explore new places to visit. Find out more about a hobby you have, or start a new one altogether. Form a book club with your friends to talk about what you've read.

Or read books to others who can't read themselves – through children's programs at your local library or programs at a nearby hospital or nursing home. There are countless places in need of volunteers – animal shelters, food banks, Special Olympics, libraries, literacy programs, retirement homes, and more.

Help younger myositis patients by sending encouraging letters or emails. Touching the lives of others is an amazing and uplifting experience. Volunteering now can help you decide what you do and don't like to do. It's never too early to start planning for your future career!

Let us know what fun things you accomplish over the summer so we can share your stories with others!

## SUNBURN HURTS NOW AND LATER

It's hard to imagine that something you do - or don't do - now can make a big difference to you later.

With JM, your skin is more likely to burn when you're in the sun. So here are some things to remember:

Don't be outside for long periods between 10 in the morning and 4 in the afternoon. If you are, choose a shaded area out of direct sunlight.



Use proper sunscreen (with SPF 15 or higher). Coat your whole body with plenty of sunscreen.

Wear clothes that fight the sun's rays. If you're really sensitive to the sun, there are special clothes that work better than regular t-shirts and bathing suits. Remember hats and sunglasses, too.

Stay away from surfaces (like water) that will reflect the sun's rays back to you, even if you're in the shade.

If you burn your skin now, you're more likely to get wrinkles and other skin problems earlier than you should. So have fun outside, but be smart in the sun!



## Brain Teaser

**Q** Cindy, Andy, and Julie were all over at John's house when a package was delivered. Each child guessed what was in the box, but only one of them was right. Using their guesses as clues, can you figure out what was in the box? Cindy said, "It's a laptop computer." Andy said, "I'll bet it's a pizza." Julie said, "I think a picture or a laptop computer is in the box." "It's a picture, for sure," said John.

**A** A pizza was in the box. Right away, you can tell that Julie can't be right, because if she is, then John would also be right (they both said picture), and no more than one child can be right. And since Julie is wrong, then Cindy is wrong, too. Because they both said laptop computer — er. That means that Andy is correct — it's a pizza.

## Tell us about it! Your JM story can help others

Please help us write a book that will help children with JM and their families.

Not sure of where to start? Here are some ideas:

■ Can you remember when you knew that you were not feeling right? How did you know? What happened when you told your parents? If you can write about what went on in your life when you first found out about JM, it will help other children know what to expect.

■ What about the rash? What did you think when it first appeared? What seemed to help or hurt? How did you tell your friends? If you have pictures of yourself with a rash, could we see them? Or draw us a picture of how you looked with your rash at its worst.

■ What was going to the doctor like? What did he or she do that was helpful? Not helpful? How did you feel when you were first taking the medicine? Your memories about visiting the doctor, clinic, physical therapist or hospital will help teach us what works best for children who are sick.

■ What did friends, relatives, neighbors, teachers and family do that helped you get through this? What hurt the most? What advice would you give to younger children just starting out with JM?

Please email your experiences to [kathryn@myositis.org](mailto:kathryn@myositis.org), or submit through the TMA web site at [www.myositis.org](http://www.myositis.org). Pictures and artwork can be sent by mail to Kathryn Spooner, TMA, 755-C Cantrell Avenue, Harrisonburg, VA 22801.

You can help children with myositis everywhere.

