

## Learning and having fun as a family

TMA's 2006 Annual Conference features Daniel Lovell, MD, MPH, Professor of Pediatrics at Cincinnati Children's Hospital Medical Center. Dr. Lovell will address the families as a part of the medical panel and in question-and-answer periods. Other sessions focused on the needs of JM families include adaptations for daily living, water therapy, family dynamics, and more.

After the Conference sessions each day, take the whole family to nearby attractions for evening fun:

**LEGO® Imagination Center** (2 miles from hotel); 407-828-0065; [www.lego.com](http://www.lego.com). In the Downtown Disney Marketplace, see a T Rex, robots and other creations made from LEGO blocks. There are hands-on events and demonstrations.

**Putting Edge at Festival Bay Mall** (9 miles); 407-448-0700; [www.shopfestivalbaymall.com](http://www.shopfestivalbaymall.com). Enjoy glow-in-the-dark miniature golf at the Festival Bay Mall.

**Orlando Science Center** (18 miles); 888-672-4386; [www.osc.org](http://www.osc.org). Take a 3-D journey through the circulatory system, put together a skeleton, or learn about digestion and nutrition in a fun way.

This is just a sampling of what's to come, both at the Conference and in the area surrounding the hotel.

We hope that you will join us in Orlando to learn about juvenile myositis from Dr. Lovell, from various healthcare professionals, and from one another.



## Solutions for your child's changing needs

When children have juvenile myositis (JM), they may need some modifications to their usual routines or some devices to help them get through their day. These aids are usually temporary, but they can ease children's frustrations and make difficult situations a little easier.

### Questions to consider

*What activities are causing my child the most trouble? Once you figure this out, decide what adjustments will make these activities easier while still encouraging your child to be as independent as possible. (See *Advice from parents.*)*

There may be only one option, or you may have choices.

No two children with JM have exactly the same needs, and your own child's needs may change over time as strength improves. Specialists recommend introducing the least restrictive devices necessary for your child to get through the day. Too many devices or modifications can hold children back from normal development and from strengthening muscles weakened by JM. Discuss your child's needs with the doctor or rehabilitation therapist. Use TMA's online bulletin boards or call your local rehabilitation center to find out what other parents have found useful.

*Will your child need these devices for a short time or for a longer period?* This will help you decide whether to buy or rent equipment, especially larger items such as strollers and wheelchairs. Re-evaluate your child's needs throughout

the disease course to be sure you're providing the best options at each stage of JM.

Again, your child's doctor or therapist will help you determine the most effective and helpful items and adaptations for your child.

### Advice from parents

In just about every aspect of JM, children have individual needs.

This is also true of the products that will help them throughout their journey with JM, but there are some fairly common needs that parents have noted over the years. Here is some of their advice:

- Use lightweight cups with a textured surface for an easier grip.
- Pad cutlery handles with extra foam to improve your child's grasp on the cutlery. Non-slip placemats or bowls and plates with suction cups keep them from sliding around while your child is eating.
- Choose high-backed chairs to help support your child's neck when

See Solutions on page 2



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*Kathryn Spooner with sons (left to right) Caden, Rhys, and Calum.*

Dear Families:

If you haven't decided whether you're coming to the Annual Conference in Orlando, I encourage you to consider it. Conferences are great places to meet other children and families, forging important and often lasting relationships. These friendships can support you through some tougher times. You also have the chance to help someone else with similar experiences and familiarity with juvenile myositis.

For this year's Conference, we've planned a medical panel presentation by Dr. Lovell (see cover), a hands-on session for JM families with an occupational therapist, a discussion of family dynamics when one child has JM, and a poolside session on water exercise for JM. We're also taking advantage of our surroundings with presentations on Florida wildlife and the Everglades to appeal to the entire family.

Conferences are a way for me to learn more about you as well. I have thoroughly enjoyed meeting the remarkable children, parents, brothers, and sisters who have attended conferences in past years and hearing everyone's stories. I look forward to meeting new people this year.

Whether or not you can come to the Conference in Orlando, I hope you will continue to share with me your challenges, successes, strategies, and ideas to help other families through their own struggles with JM.

Thanks for all that you do for TMA!

Warmly,  
Kathryn

## Solutions,

continued from cover

- sitting. Add pillows for support if needed.
- Be sure to put non-slip mats in bathtubs and showers to prevent falls. Bath seats are also helpful when your child is especially weak.
- Try an electric toothbrush to reduce the strain of brushing.
- Buy a long-handled brush to help your child reach her hair more easily. Reachers are also available to avoid the pain of reaching up or down.
- Talk to your children. Explain what situations may require extra caution, such as walking long distances without support, and suggest ways to adapt to these different situations, such as taking a walking stick or asking a friend to walk close by.

*There will be several occupational therapists at the Annual Conference to speak with individual families about the needs of their children. If you would like a consultation Friday or Saturday, email TMA.*



## A closer look

What causes juvenile myositis? How can doctors most accurately measure its progress? As more research is completed and shared with other scientists, the bank of information about JM grows, a promising step toward finding answers to these and many other unanswered questions.

In one study looking at the largest group of JM children evaluated in Europe to date, LJ McCann, AD Juggins, Susan Maillard, Lucy Wedderburn, Joyce Davidson, Kevin Murray, and Clarissa Pilkington sought to identify characteristics of JM in clinical and laboratory settings. Using this data, they hoped to better understand the typical course and appropriate management of the disease.

The researchers found that the most common features at disease onset were characteristic rashes, weakness, tiredness, Gottron's papules, and muscle pain. Results from muscle biopsy, magnetic resonance imaging (MRI), and muscle enzyme tests were often abnormal, though not always. Disease activity was not adequately measured by muscle enzymes or erythrocyte sedimentation rate.

The researchers noted the information collected would help determine treatment: "Prospective data collection will allow a fuller analysis of poor prognostic features, impact of therapy, and variable outcome of childhood myositis."

*From McCann JL, Juggins AD, Maillard SM, Wedderburn LR, Davidson JE, Murray KJ, Pilkington CA. The Juvenile Dermatomyositis National Registry and Repository (UK and Ireland)—clinical characteristics of children recruited within the first 5 yrs. Rheumatology (Oxford), 2006 Mar 27; [Epub ahead of print].*



## Meeting Ike

Alissa Lewis loves to fish. At 4 years old, she holds 25 fishing records from the Texas Parks and Wildlife Department, and she got them after she was diagnosed with juvenile myositis (JM).

Her mom, Mindy, says she fishes as an escape—a diversion from the treatments she must undergo for JM. At one point during her illness, Alissa required a feeding tube because she was too weak to feed herself. Luckily, she has improved since then and is able to fish when she feels stronger. JM keeps her from fishing on occasion, but it certainly doesn't hold her back for long.

Alissa had the chance to meet a fishing icon in May. Mike Iaconelli, or Ike as he is sometimes called, is known as a talented and gregarious competitor on the fishing circuit. Mike, 2003 Bassmaster Classic Champion and current points leader on the Bassmaster tour, competed in the Bassmaster Memorial Tournament



in Fort Worth, Texas, where he gladly accepted TMA's invitation to meet the Lewis family at the tournament. A day of fishing with Mike was the prize in a raffle organized by the New

Jersey *Keep In Touch* support group last year, so Mike was already familiar with the disease and the need for greater public understanding of it.

Jeff Campbell, a former Board member of TMA and an

adult with JM, also met with Alissa's family and Mike. Jeff presented Alissa with an autographed copy of Mike's latest fishing book, and Mike spent considerable time talking with Alissa and getting pictures made of two fishing champions together. This is a fishing tale that Alissa can share with her classmates and it is all true!

Alissa's mom said this was also the first time Alissa had a chance to meet anyone over the age of 18 with the disease.



### RESEARCH ON THE WEB

*Duration of Illness:* Researchers, including TMA Medical Advisor Lauren Pachman, MD, concluded that the time between the first sign of JM (rash or weakness) to the diagnostic visit is an important factor and needs to be considered in determining diagnostic criteria and the intensity of therapy for children with JM.

*Endothelial Cell Activation:* A group of researchers that includes several TMA medical advisors (Lisa

Rider, MD, Frederick Miller, MD, PhD, Paul Plotz, MD, and Ingrid Lundberg, MD) studied molecular changes contributing to vascular and immune abnormalities in both juvenile and adult dermatomyositis.

*Read the abstracts and/or full articles of these studies online at [www.myositis.org](http://www.myositis.org) on the Parents Pages of the Juvenile Programs section.*



# School days: new and review

Going to school should be a time of friendship, discovery and fun for children. Unfortunately, this isn't always the case for children who live with juvenile myositis (JM). Some children with JM miss many days of school for scheduled treatments or when they're feeling especially sick or weak. Many children continue to go to school even when their energy is low. Children may fret that they'll fall behind in their schoolwork or not be able to spend enough time with their friends.

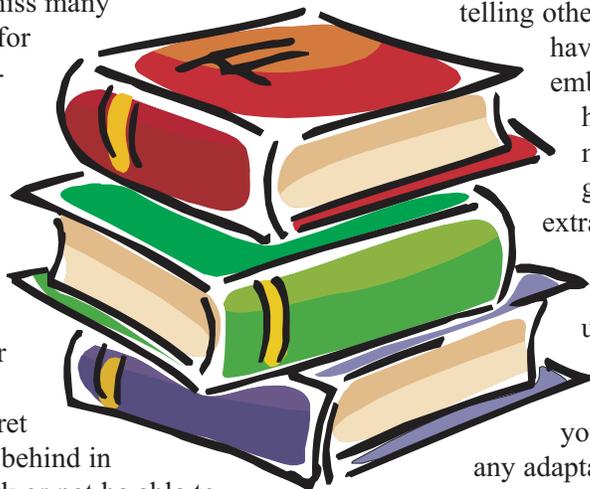
Open communication between the school and family is the key to alleviating much of this worry. Working with your children's schools early to prepare for what they need now and what they may need in the future is important and should relieve a lot of anxiety you may feel. The following points are those frequently made by parents and experts as important for your child's school year.

## Speak up

Communicate with every staff member who interacts with your child at school. Tell all teachers and school personnel about JM and complications that might arise, and reach an agreement about accommodations that would involve them. Include teachers for art, music, physical education, and library. Classes often have assistants and/or student teachers at different points throughout the school year. Remember the school nurse, guidance counselors, bus drivers, lunchroom attendants, and anyone who might work directly with your child. Let them know about your child's JM so that they'll understand

more quickly and clearly if problems do come up later in the year.

You know your own children better than anyone, and they may be reserved or self-conscious about



telling other people they have JM—embarrassed at having to take medicines or getting any extra attention.

Keep your children's unique personalities in mind when you work out

any adaptations or schedule adjustments. Request the school's staff be discreet in dealing with any special accommodations.

Families have given us their tips for working with schools:

- Identify someone at the school as your "point person" who will work closely with you and with other school personnel. This person will help advocate for your child in your absence.
- Keep in touch with the school when there are any changes in your child's medicines, treatment schedule, behavior, physical therapy, or anything that may affect your child at school. Ask the school to do the same by communicating any changes they notice, no matter how big or small.
- Take someone with you to all school meetings that concern your child. Though these are typically friendly, informal meetings, it's still best to have someone there for support and as an extra "memory."
- Document your meetings and make sure the school has records as well. Sign in when you have a meeting at the school so there is a

record of your presence, and send a follow-up letter to the school to summarize what was decided upon in each meeting. Keep copies of these for yourself.

- Be the enforcer. This doesn't mean you need to be overly aggressive. Simply make sure the school is keeping to the agreed upon accommodations by checking in regularly and updating these adjustments as needed.
- Familiarize yourself with the laws in your state so that you're prepared to introduce different sections that might apply to your child's situation.

## What to ask for

Many parents write to us wondering what types of accommodations they should be seeking. This is a difficult one to answer as each child has different needs, but one theme runs throughout our responses: plan ahead. It's better to discuss things that your child might need in the future, even if he or she doesn't currently require a particular accommodation. Work out these arrangements as a safeguard for the possibilities that lie ahead.

Practical examples of what you can request from the school to accommodate your children, depending on their individual symptoms and limitations:

- Extra time to take tests, turn in homework or finish classroom work
- Someone to help carry books from class to class and to carry lunch trays in the cafeteria
- Leaving class early to walk to the next class—to avoid bumping others in the hallways as well as to have extra time to accommodate walking more slowly; if stairs are required, allow more time or ask about using an elevator, if avail-

able; try to schedule classes within certain areas of the school

- Rest times during the day as needed, either in the classroom or in the nurse's office
- Opportunity to stand and stretch when needed to avoid stiffness
- Physical therapy sessions or alternate activities in place of physical education classes, recess or active play periods—some children may need to stay indoors to avoid the sun and often are allowed to choose a classmate to join them
- Time to apply sunscreen before going outdoors (or to have the nurse do this)
- Schoolwork sent home in case of absences
- Chair available during library time, circle time and other classes where students are expected to sit on the floor
- Classmate to take notes and copy for your child
- Signal for answering questions other than raising his or her hand, which can be exhausting and discourage your child from participating in class
- Second set of books to keep at home so that your child will not have to carry books back and forth
- Easily accessible locker, in terms of proximity to your child's classes and height to avoid reaching up or bending down

### Teachers are resources, too

Though your child's teachers have probably never heard of juvenile myositis, if they have been teaching for any length of time, chances are they've held similar meetings with parents whose children have attention deficit disorder, juvenile rheumatoid arthritis, juvenile diabetes, food allergies, and a host of other childhood conditions. The symptoms and needs are different for each condition, but

the idea is the same—these children want to go to school and participate just like everyone else but may require a bit extra in terms of monitoring, awareness or special care. Your child's teachers can suggest particular accommodations or modifications based on their own experiences with other children.

Mention to the teachers and other staff members that even though the JM rash isn't always obvious, there are hidden symptoms like muscle weakness, soreness or pain, stomach upset, moodiness, and fatigue. Emphasize that your child shouldn't be treated differently than other children in most ways; however, it's important to recognize signs of the JM. Again, they've dealt with similar issues in the past and may be able to share their own strategies and ideas with you.



### WEB ALERT

Visit TMA's Juvenile Myositis pages for sample letters to send to school personnel and a brochure written for teachers. One letter introduces your child and his or her medical situation to a principal, teacher or other staff member. You can modify this for your own situation as your child enters kindergarten or a new year, and revise the language to send at the start of every school year.

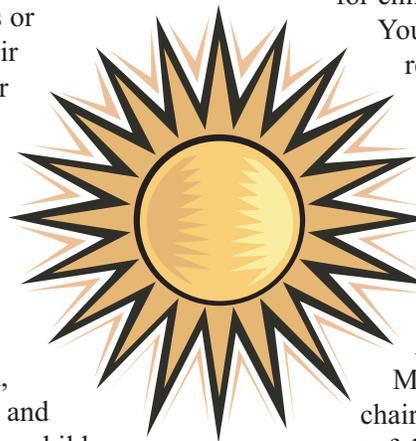
A second letter summarizes what you discussed in a school meeting so that everyone has a record of what was accomplished and decided upon.

If you cannot access the web site, contact TMA for copies of these sample letters and other school-related materials.



## Vitamin D and the sun

You have no doubt heard the warnings to keep your child out of the sun, with an even greater emphasis for children with JM.



You may have also read reports that the sun is the best source of vitamin D, which is important for strong, healthy bones. Barbara A. Gilchrest, MD, professor and chair of the department of dermatology at

Boston University School of Medicine, reviews some common misconceptions regarding the sun and vitamin D.

### Is it better to spend more time in the sun to ensure you're getting adequate amounts of vitamin D?

"Most people, especially fair-skinned Caucasians, get more than enough incidental sun exposure to manufacture the vitamin D they need, so there is no reason to intentionally seek the sun," Dr. Gilchrest said. "Even with a sunscreen, spending a total of 30 minutes outdoors over the course of the day will likely achieve this maximum."

**Is exposure to the sun the best source of vitamin D?** You can get plenty of vitamin D through diet and supplementation. In fact, Dr. Gilchrest said, any "extra" vitamin D produced from sun exposure is not stored for later use but instead converted into inactive compounds. Good sources of vitamin D are salmon and other fatty fishes, fortified milk and orange juice, eggs, and fortified cereals.



## Being a teenager with JM

Ballet is her passion. It also served as her “red flag” when she could no longer do the simplest stretches while warming up to dance. At 15 years old, six months after noticing the first symptoms, Sarah Davis was diagnosed with juvenile dermatomyositis (JM).

Like most people with JM, she began her treatment with prednisone. It took a while to start working, but within a few months, it worked so well that she was able to begin lowering her dose. Even so, the list of side effects she experienced is, as expected, quite long—heartburn, weight loss followed by weight gain, backaches, mood swings, panic attacks, irregular menstrual cycles, food cravings, and the dreaded “moon” face. And tapering the medicine played havoc with her moods. “I had lots of manic phases and was depressed the rest of the time,” she said.

Add being a teenager with its own complexities. “I think the most difficult thing is that as a teen, you are so busy with your life,” Sarah said. “It’s really hard to slow down or even stop.” Luckily for Sarah, her family and true friends stepped up.

### Support from family and friends

Sarah found that JM touches the lives of everyone around her. “Having JM really told me who my friends were,” Sarah said. Her best friends Ann and Emily stuck by her side through her ups and downs. “They know everything I’m going through,” she said. “They don’t freak out when I tell them stories about my doctor’s visits or when they see all my ugly scars.

They know I’m crazy and they don’t care.” In other words, they accept Sarah for who she is, even when her manic phases hit.

Sarah has built special relationships since her diagnosis. Her ballet class, now mostly younger girls she hasn’t danced with in the past, cheered her on as she was able to dance a little longer each time until one day she stayed for the entire dance class—an hour and fifteen minutes. “They kept saying over and over that they knew I could do it,” she said.

Obviously, parents are a major source of support and comfort. Sarah’s mom is no exception. She was there for all of her shots and lab work. “She gave me back rubs, told me stories, and laid down with me to help me go to sleep,” she said. These feelings of being safe and secure have led Sarah to reconsider her college and career paths.

### Plans for her future

Since her diagnosis, Sarah has begun focusing on colleges closer to home. In case anything should happen, she is reassured that help is close at hand.

Before Sarah had ever heard of JM, she wanted to do her part to help but didn’t know how. Now she has one place to start. With her plans to become an actress on Broadway on hold for now, she intends to take an active role educating the public about juvenile myositis. “I want to create more awareness about JM,” she said, “so other people aren’t caught unaware like me.”

## Choosing the right lotion

Moisturizers and lotions line the shelves in stores today. How do you choose what’s right for you? Moisturizers are more effective than they were in the past, said Zoe D. Draelos, MD, Clinical Associate Professor of Dermatology at Wake Forest University School of Medicine. They soften and moisten your skin, protect it from the sun, and provide foundation to mask any imperfections, she said.

Some tips to remember when choosing a moisturizer:

**Remember sun protection factor (SPF).** With juvenile dermatomyositis (JM), your skin requires extra attention. It’s important to always use sunscreen with an SPF of 30 or higher and with both UVA and UVB protection. Luckily, some companies are now adding SPF to their moisturizers, so you may be able to meet your skin’s moisturizing and sun protection needs with one product. (Moisturizers may only protect against UVA rays, so read carefully. You may need additional sunscreen.)

**Know your skin type.** Be aware of what type of skin you have—is it dry, oily, or normal? Choose your moisturizer based on this. Newer moisturizers contain products that soothe irritated skin, Dr. Draelos said, as well as products that can tan your skin without the sun.

**Decide what else you need.** Some lotions also contain foundations, which help cover up the JM rash or redness. Creams are made specifically



# JUST FOR ME

SUMMER 2006

Fun facts and news for children affected by JM

## Be smart in the sun!

In most places, the weather is warming up and people are spending more time outside. If you have juvenile myositis, you know how important it is to be careful in the sun.

To make sure your summer is fun, remember:

- Always use sunscreen. Even if it's cloudy outside, the sun can get to your skin.
- Find shade. Whenever you can, choose to be in the shade rather than in the direct sunlight.
- Wear hats and sunglasses. Hats will help cover your face and neck, and sunglasses

(as long as they protect against UV rays) shield your eyes.

- Choose your clothes with care. There are clothes with sun protection right in the fabric. You can wear long-sleeved shirts or clothes that are better at keeping the sun's rays away from your skin. (Your parents can help you find clothes to protect you against the sun—clothes with tightly woven fabric, that aren't stretched out, and that haven't been washed too many times.)

Have a great summer!



## Chicken noodle soup in a jar

Need a small present for someone who has helped out? Here's an idea that's sure to be a hit.

### What You'll Need:

- 1/4 cup of red lentils
- 2 tbsp. dried onion flakes
- 2 1/2 tsp. chicken bouillon powder
- 1/2 tsp. dried dill weed or dill seed
- 1/8 tsp. each celery seed and garlic powder
- 1 cup medium egg noodles (approximately)
- 1 bay leaf

### Directions:

1. In a two-cup jar, layer from the bottom in the order listed, then seal the jar.
2. Include these instructions on a gift tag attached to the jar:  
Bring 8 cups of water to a boil in large saucepan. Stir in entire jar of soup mix. Cover, reduce heat, and simmer for 25 minutes. Discard bay leaf and stir in 1 1/2 cups of frozen corn or mixed vegetables and 2 cups of cooked, diced chicken or turkey. Simmer for five minutes or until vegetables are tender and chicken is heated through.



## Summer reading fun

Reading and fun really can go together. Pick some books you'd like to read, and have your brothers, sisters, and friends read them, too. Get together to talk about the books, or read them together. It's fun—and it will keep your parents happy since you're using your summer to learn while still spending time with your friends!

If you're just learning to read, there are plenty of "I Can Read" books on just about anything you can think of to help you practice reading. If you're into chapter books, consider the Junie B. Jones and Magic Tree House series.

Talk to your friends and have everyone pick a book or two to read.

*Parents: Professor Jennifer Turner of the College of Education at the University of Maryland suggests making your children's book clubs even more fun by letting them choose their own books and (maybe more importantly) serving snacks! Have your snacks related to the theme of whatever books they've read.*



## Add these books to your reading list!

Visit [www.bookadventure.com](http://www.bookadventure.com) for more books listed by reading level (up to eighth grade) or category.

*Grade Book, Author*

- K-1 *Frog and Toad*, Arnold Lobel
- If You Give a Mouse a Cookie*, Laura Joffe Numeroff
- 2-3 *Fantastic Mr. Fox*, Roald Dahl
- Cloudy with a Chance of Meatballs*, Judith Barrett
- 4-5 *Alice's Adventures in Wonderland*, Lewis Carroll
- A Wrinkle in Time*, Madeleine L'Engle

(Editor's Note: These are not specific recommendations but simply examples of what you'll find on the Book Adventure web site.)

## PRODUCTS FOR THE SUMMER

Children with JM must avoid the sun's harsh rays year-round, but summertime is especially important since kids spend more time outdoors and the risk is greater. Some companies offer sun-protective clothing, laundry additive, and other items to help your child get through the summer:

**Coolibar:** 4206 Park Glen Rd, St. Louis Park MN 55416, Attn: Customer Service; 800-926-6509; [www.coolibar.com](http://www.coolibar.com)

**Frogwear Sun Protective Clothing:** 800-328-4440

**MasqueRays:** PMB #242, 3525 Del Mar Heights Rd, San Diego CA 92130; 877-786-7848; [www.sunproof.com](http://www.sunproof.com)

**REI [Ex-Officio BUZZ OFF Clothing]:** 800-426-4840; [www.rei.com](http://www.rei.com) (Click "Kids' Clothing & Gear" then "Boys' and Girls'

Clothing." Choose the "Narrow by Brand" tab to find all Ex-Officio brand clothes.)

**RIT Sun Guard [laundry additive]:** 866-794-0800; [www.ritdye.com/sun\\_guard](http://www.ritdye.com/sun_guard)

**Solar Eclipse:** P.O. Box 13102, Scottsdale AZ 85267-3102; 800-878-9600; [www.solareclipse.com](http://www.solareclipse.com)

**Solartex Sun Gear:** P.O. Box 36050, Richmond VA 23235; 877-476-5789; [www.solartex.com](http://www.solartex.com)

**Solumbra/Sun Precautions:** 2815 Wetmore Ave, Everett WA 98201; 800-882-7860; [www.sunprecautions.com](http://www.sunprecautions.com)

**Sun Clothing, Etc.:** 540-842-4583; [www.sunclothingetc.com](http://www.sunclothingetc.com)

**Sun Emporium:** 12 Hermitage Close, Ashmore, Gold Coast, Queensland 4214, Australia; 61-7-5597-0005; [www.sunemporium.com](http://www.sunemporium.com)

**Sun Grubbies:** 5519 Clairemont Mesa Blvd #163, San Diego CA 92117; 888-970-1600 (within US); 858-268-1600 (outside US); [www.sungrubbies.com](http://www.sungrubbies.com); For Solarweave fabric, visit [www.sungrubbies.com/Solarweave.htm](http://www.sungrubbies.com/Solarweave.htm)

**Sun Protective Clothing Ltd:** 598 Norris Ct, Kingston ON K7P 2R9 Canada; 800-353-8778; [www.sunprotectiveclothing.com](http://www.sunprotectiveclothing.com)



## Lotions,

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for hand care. Dr. Draelos advises people to use moisturizer every time they wash their hands to minimize water loss. Some TMA members recommend using a thick layer of moisturizer on your hands at night and wearing cotton gloves to bed.



THE MYOSITIS ASSOCIATION

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