

## HEALTHY EATING DESPITE COMPLICATIONS

As a parent, you want answers and information you can put into practice—menus for proper nutrition, daily exercise routines and detailed school accommodation plans. Unfortunately, there is no single “recipe for success” that accounts for all of the different variables that come with having juvenile myositis. There are, however, general ideas and practical suggestions for dealing with the issues that crop up throughout your lives with JM.

One common issue for children who have JM is sticking to a healthy eating plan, especially for those children on prednisone or related medicines. Throw in the stomach complaints and swallowing problems, and following proper nutritional guidelines becomes a greater challenge. As nice as it would be, this article does not map out a specific weekly menu but instead shares ideas from nutrition professionals and families who have dealt with dietary issues related to JM.

### The root of the problem

There are a host of nutritional problems children with JM might face—being overweight or underweight, having trouble swallowing, or being unable to properly digest foods, to name just a few. It is important to accurately recognize the problem to best resolve the specific issues.

The muscle weakness and inflammation that accompany JM are the culprits for a number of digestive issues; medicines used to treat JM can play a role as well. Weakness in the muscles of the esophagus disrupts normal

swallowing; weakness in stomach or gastrointestinal tract muscles results in food lingering in the stomach too long. [Swallowing and digestive problems are discussed in the Spring 2007 *JM Companion*.]

With or without a diagnosable problem, children who have JM should focus on a proper diet as a part of their overall health plan.

### Well-balanced diets help the whole family

No matter where your child’s digestive problems originate, choosing a healthy eating plan benefits the entire family. More emphasis is now put on healthier alternatives, so finding the right foods is much easier than it has been in the past. You just need to know where to look.

TMA’s Winter 2006 *OutLook Extra* discusses nutrition, including what foods to avoid and which ones to include in your diet. There is also a wealth of information online touting the merits of good eating and exercise habits. See [www.myositis.org](http://www.myositis.org) for articles on nutrition and JM.

Converting general recommendations into daily practice is not always so straightforward. Some healthy dietary tidbits:

- Sneak whole grains into breakfast. Read labels for whole grain ingredients in breads, pancakes and cereals.
- Try lean cuts of beef rather than marbled varieties.
- Bake, broil or grill fish high in omega-3 fatty acids (like salmon).

- Satisfy your family’s sweet tooth with melons or fresh fruit smoothies.
- Offer a variety of vegetables, choosing different colors to be sure your family takes in different vitamins and nutrients.
- Avoid processed foods, which have added salt to help prevent spoiling.
- Look out for “partially hydrogenated” or “shortening” listed in the ingredients, as these contain trans fats. [See *Look at the label*.]
- Stay away from sodas and junk foods that have little nutritional value but a lot of unhealthy additives, including high fructose corn syrup.

Before making any major changes to your family’s diet, talk to your child’s doctor about how these changes might affect your child.

### Look at the label

How can you be sure you’re choosing the healthiest alternatives? One way is to carefully read the food labels.

Especially important in JM:

**Serving size.** This gives the amount of food used to determine the nutrition facts listed. This is not necessarily the size or amount of the daily recommended servings given by the U.S. Department of Agriculture, nor is it equal to what you might consider an average helping. Since the listed items are based on the serving size, it is important to know what this amount is so you can calculate the rest. [See *Keep an eye on portion size* in *Transitions*, page 6.]

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*Kathryn Spooner with sons Calum,  
Rhys and Caden*

Dear Families:

I hope many of you have taken advantage of having *Myositis and You* available now. This book provides a reliable background into what juvenile myositis is, how it is diagnosed and treated, and what you can do to help your child, your family and yourself deal with the physical and emotional challenges of JM. Sneak a peek inside the book on TMA's web site ([www.myositis.org](http://www.myositis.org)). And if you haven't already done so, order your copy today!

Also on TMA's web site are updated pages specific to the unique needs of the JM community. You'll find articles geared toward parents and other concerned adults, teenagers and young adults, and younger children. See "What's new online" (cover) for more on what the web site offers every member of your family. Please email me at [kathryn@myositis.org](mailto:kathryn@myositis.org) with any comments you have or suggestions for new topics you'd like to see covered here.

This issue of the *Companion* focuses on developing independence throughout the course of JM, as well as nutrition and dietary concerns. I hope the materials are helpful to each of you as you explore different options for your children and family.

Wishing all of you a pleasant summer!

Warmly,

Kathryn

### Healthy eating

continued from cover

**Fats.** Total, unsaturated, saturated and trans fats are typically listed separately. Your body needs some fat for energy and insulation. Saturated and trans fats are unhealthy fats; unsaturated fats are considered "good" fats. Find foods with very little saturated and trans fats. [Even though some labels will list trans fat as zero, check the ingredients list for "partially hydrogenated oils." This means at least a small amount of trans fat is in the product—and small amounts add up.]

**Sodium.** Sodium is a component of salt, and people taking prednisone are told to eat as little sodium or salt as possible. Sodium is important to keep fluids in your body balanced, but too much leads to problems like water retention and weight gain.

**Sugars.** The amount of sugar listed can be a bit tricky. Fruits have sugar naturally but are healthy snacks. Sodas and "junk" foods have added sugar, so again check the ingredients for sugar, corn syrup or cane juice. Avoid added sugars when possible.

**Protein.** Protein is used for energy and makes up the muscles, skin and immune system. High-protein diets are usually suggested for anyone taking corticosteroids.

Vitamins, minerals and other categories are listed here. Many of these, like calcium and vitamin D, are also important to monitor and are often listed as percentages of the daily recommended amounts.



# Helping your child take charge

It is never too early to start thinking about your child moving from pediatric to adult health care, from childhood to adulthood. Even when your child is young, there are steps you can take to ensure your child is ready for this transition when the time is right.

The main goal is to encourage independence early on. You do this at home every day, whether by design or by a more indirect route—teaching your children to make decisions on their own by offering choices, reinforcing that their actions and choices have consequences, and showing them how to take care of themselves, including when to ask for help.

These are important lessons for all children as they grow up. Children with JM can relate these life lessons to their health care management.

## Age-appropriate considerations

Once children reach about 6 to 8 years of age, they are able to begin taking on more responsibility for themselves, says Patty Rettig, RN, MSN, CRNP, Nurse Practitioner at Children's Hospital of Philadelphia. At this age you can:

- Allow your children to communicate directly with doctors, nurses and other professionals by having them ask and answer questions for themselves.
- Teach them more about juvenile myositis, the medicines used to treat it and how both of these might affect their physical and emotional well-being.
- Support their need for normalcy by giving them age-appropriate tasks to do around the house.
- Let your children make mistakes and learn from them.
- Help them practice making healthy choices in terms of diet, sleep, exer-

cise, sun protection, and more—by modeling good habits and offering a variety of healthy options.

Some children appreciate taking on a bigger role in their care—keeping their own medication schedules and journals, scheduling their doctor's appointments, or reading more on their own about JM and sharing this information with family, friends and classmates.

It becomes especially important in older childhood and teenage years to strengthen your children's understanding of JM and their unique needs related to having a chronic illness. Encourage children to participate in meetings about school accommodation plans, keep their own detailed notes and medical records, and learn more about adult health care options and needs. Help them find support through e-pals, message boards and support groups.

Many children prefer not to focus on JM. While still respecting their feelings and desires, says Rettig, discuss the importance of health care and the need for them to take charge of the different parts of their care.

The more they understand their own needs and the options available, the more in control they will feel.

## Web extra

Find more materials related to developing independence while growing up with JM on TMA's "JM Book Resources" page at [www.myositis.org/jmbookresources.cfm](http://www.myositis.org/jmbookresources.cfm) (see Chapter 31 resources):

- Transition Timeline for Children and Adolescents with Special Health Care Needs (Patricia Rettig, RN, MSN, CRNP)
- Moving on: transferring from pediatric to adult care

## HOW TO CONTEND WITH TEASING

Summer vacation is often no vacation from teasing, as children are in new circumstances: camps, day care, or trips to the pool or park. At some point, almost all children have to endure teasing from friends and strangers, and children with a chronic illness may be especially sensitive to looking different or having to move more slowly, stay out of the sun, or rest frequently.

For some children, teasing by others is temporary, and they are able to handle it with little difficulty. For other children, though, teasing is more frequent or more hurtful.

The Center for Creative Parenting tells us that when teasing is frequent, the victim needs family help. Teasing can be very painful for children, affecting their self-esteem and how they relate to other people.

The best thing parents can do, says the Center, is teach constructive ways to respond. For more information, go to the Center's web site, [www.parenting-ed.org](http://www.parenting-ed.org). Some tips:

- **Teach appropriate responses.** Parents can teach their children to ignore teasing by turning and walking away without saying a word, or to develop a quick response.
- **Practice.** Try role-playing situations. Practice allows the teasing to actually become less upsetting.
- **Provide lots of love and encouragement.**
- **If an adult is involved at a supervised setting, discuss it.**

"Parents often feel helpless and don't know where to begin to help their child cope," says Dr. Meline Kevorkian, an education specialist. She says parents should recognize hidden signs of bullying: trouble sleeping or wanting to stay home excessively.

# REPORTS IN JM RESEARCH

## A closer look: JM antibodies

Lisa G. Rider, MD, long-time TMA Medical Advisor and Deputy Chief of the Environmental Autoimmunity Group (National Institutes of Health), recently reviewed juvenile myositis, discussing the various subsets of patients with distinct clinical signs and symptoms, disease courses, responses to therapy, immune and genetic factors, and prognoses. Scientists have long searched for clues as to what triggers JM and what might act as risk factors for developing the disease.

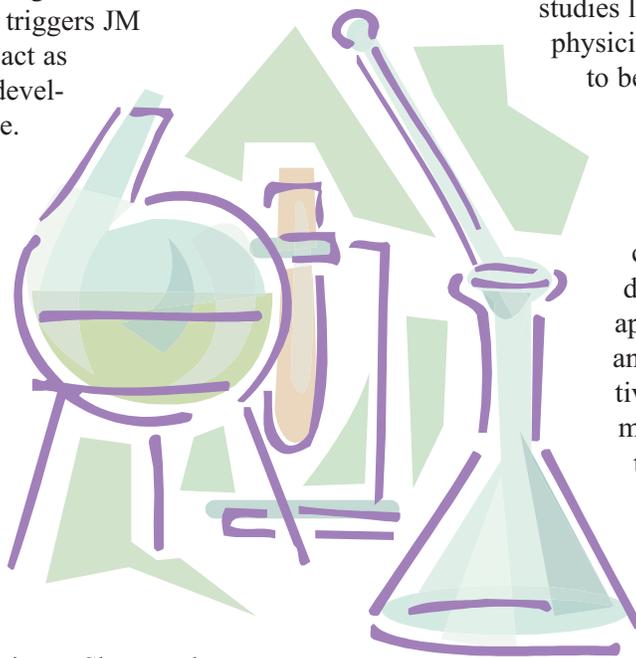
In this review, Dr. Rider highlights anti-p155, a myositis-associated autoantibody seen in 20-30 percent of both juvenile and adult dermatomyositis patients. She noted possible risk factors of a specific human leukocyte antigen and its linked alleles, along with potential environmental exposures. The role of environmental exposures remains poorly understood, but Dr. Rider points to growing evidence of infectious agents and ultraviolet radiation playing roles in the onset of JM.

## TMA-funded researcher collaborates

Gulnara O. Mamyrova, MD, PhD, Research Assistant with Dr. Rider at NIH, contributed to finding that anti-p155 plays a role in JM. In 2002 Dr. Mamyrova was awarded a two-year \$90,000 fellowship through TMA's

grants and fellowships program. The goal of her fellowship was to complete the database for the Childhood Myositis Heterogeneity Study sponsored by the Environmental Autoimmunity Group at NIH, and to further define the clinical, immunological, and immunogenetic groups of patients with JM.

These funds supported Dr. Mamyrova's and her colleagues' discovery of the association between anti-p155 and JM. Through studies like this, physicians hope to better



understand the disease process and develop appropriate and effective treatment protocols. JM treatment continues to

rely on corticosteroids and immunosuppressants, with additional therapies for skin symptoms and rehabilitation. New therapies using biologic agents are currently under study.

## Find out more

Rider LG. The heterogeneity of juvenile myositis. *Autoimmunity Reviews*. 2007 Mar;6(4):241-7. [Find the abstract on [www.pubmed.gov](http://www.pubmed.gov).]

Also read about Dr. Mamyrova's research efforts under Research, TMA Grants & Fellowship, at [www.myositis.org](http://www.myositis.org).

## The diversity of JM: Ten-year retrospective study

A group of physicians reviewed 21 juvenile dermatomyositis patient charts from National Taiwan University Hospital. At diagnosis, the most common skin symptoms were Gottron's papules and facial rash. The most noted systemic feature was myalgia, or muscle pain, with arthralgia (joint pain) and dysphagia (trouble swallowing) also found in about 20 percent of the patients.

Six patients had calcinosis. Lung and gastrointestinal complications were noted in a few cases. Five of the 21 patients achieved drug-free remission. "The long-term outcomes in this study," write the authors, "are thought to be good. Because the understanding of the pathogenesis of JDMS is limited, certain complications are still troublesome clinically."

## Read the abstract

Chiu SK, Yang YH, Wang LC, Chiang BL. Ten-year experience of juvenile dermatomyositis: a retrospective study. *Journal of microbiology, immunology and infection*. 2007 Feb;40(1):68-73.

## Assessing bone density

Researchers at Cincinnati Children's Hospital Medical Center hope to take the guesswork out of evaluating children's bone health. Having good bone density is a concern for children with juvenile dermatomyositis, as both the inflammation and medicines to control it can negatively affect a child's bone mass.

The researchers, led by Heidi Kalkwarf, PhD, Associate Professor of Community and General Pediatrics at Cincinnati Children's, are looking into what "normal" bone density is for

children of different ages. Doctors cannot accurately determine if a problem truly exists without having a normal value for comparison. The idea of this research is to develop standardized data on bone mass by age, gender and race to be used as a screening tool for bone health.

Data was collected from different parts of the body to help clinicians identify where a problem lies, as some skeletal areas may be more affected than other areas. Doctors now have a yardstick to more accurately monitor children for normal bone health or for potential problems that need further investigation.

### Check the web

Read Cincinnati Children's Hospital and Medical Center's news release: <http://www.cincinnatichildrens.org/about/news/release/2007/6-bone-density.htm>

## The importance of swallowing studies

Researchers in the United Kingdom and Argentina sought to determine if there is a relationship between scores of muscle weakness/function or scores of general disease activity/function and children at risk for swallowing abnormalities.

Videofluoroscopy swallow studies (VFSS) were performed on 14 children upon diagnoses of juvenile dermatomyositis or disease flare. Eleven of the 14 children showed abnormal swallowing function by this testing method. Two of the 11 children with abnormal results were asymptomatic at clinical assessment; the three par-

ticipants with normal VFSS findings exhibited disease symptoms.

Therefore, no relationship was found between swallowing scores by VFSS and objective measures of strength, function or disease activity.

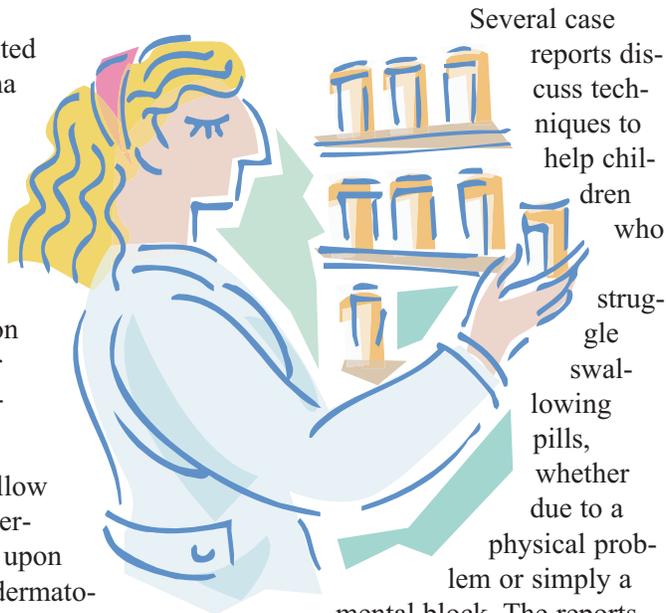
This research highlights the need for all children with juvenile dermatomyositis to undergo testing for potential swallowing problems as clinical assessments are not predictive of swallowing function.

### Look it up

Find the abstract online at [www.pubmed.gov](http://www.pubmed.gov) or on TMA's web site at [www.myositis.org](http://www.myositis.org) under Research, Published Research, Juvenile Dermatomyositis.

## A hard pill to swallow

You know your child needs to take a pill to feel better—he or she knows this, too—but every day you dread treatment time.



suggest you start by having your child swallow small candy sprinkles and progress to licorice cut into quarter-inch pieces and then candies like Tic Tacs.

Other hints from researchers and parents:

- Model taking pills for your child—placing it on your own tongue and tilting your head backwards to swallow.

- Place the pill in applesauce, yogurt or similar foods. Don't crush or split pills without first checking with the doctor or pharmacist.

- Plan for your child to take pills when there are fewer distractions and when you can take the time without rushing the process. Rushing leads to added frustration and anxiety.

- Explain that they need the medicines to help them feel better. Help them to fully appreciate the need to take medicine.

- Give them some responsibility, no matter how big or small. Have them help maintain their own medicine schedule or set out their pills at medicine time. This gives them an important role, and possibly some distraction from the task of swallowing the pill.

## MYOSITIS AND YOU

*Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers*, is available from The Myositis Association. Visit [www.myositis.org](http://www.myositis.org) or call 800-821-7356 to order your copy today. [*Myositis and You*, published by The Myositis Association, \$25 plus \$5 shipping; call for information on bulk discounts.]

All proceeds from the sale of *Myositis and You* benefit further research into juvenile myositis.

## Eating away from home

Kristie faced more than the typical challenges when she began college life. She had recently been diagnosed with dermatomyositis and had to focus on her medical needs as well as her education.

One trouble spot for many college students is eating right, and Kristie knew with her diagnosis that she had to be especially mindful of making healthy food choices. Kristie and her mom brainstormed ways to avoid potential temptations.

Most college dining halls offer buffet lines, Kristie said, so she resolved to go through the line only once. On days when the choices are not particularly healthy, she takes a soft tortilla to create a wrap from the salad bar.

“It’s well known on college campuses,” she said, “that if you want students to show up to something offer free food, which usually consists of desserts or pizza.” The challenge, then, is not necessarily the lack of nutritious foods but the availability of unhealthy choices. Eat these foods in moderation—this restraint will help you feel better overall, even when you do sneak one cookie or piece of pizza.

## Go ahead—grab a snack

Snacking is actually good for you. Healthy snacks keep your blood sugars steady and help prevent overeating at your next meal. It is all a matter of which snack foods you choose. Many snacks have loads of sugar, salt and/or fat. Kristie takes an apple or orange out of the dining hall for a smart afternoon snack to help her avoid freezer foods like pizza rolls. Other

snack ideas for added variety: apple or banana with peanut butter; yogurt with granola; pita chips and hummus; cereal and dried fruit; and popcorn with no added salt or butter.

Stress can trigger extra snacking and overeating—and typically leads people to choose comfort foods. The transition from high school to college is certainly a stressful event. Instead of picking up a salty or sugary snack, reach for water. “I have found having the water bottle keeps cravings away better,” Kristie said. Learn to read your body’s signals: are you really hungry, are you thirsty, or are you bored, upset or anxious?

## General tips

- Eat slowly, paying attention to every bite so you enjoy your food. This allows your body time to “feel full” before heading back for seconds.
- Dine at regular times each day.
- Control your portion sizes—if you pile a heap of food on your plate, you’re likely to eat all of it. Be aware of what you need and serve appropriate helpings.
- Don’t deny yourself some treats, but don’t overdo it either.
- Cut out soda and other sources of “empty calories,” or foods with high calorie totals and low nutritional content. Likewise, curb your taste for ketchup and condiments with added sugar.
- Don’t starve yourself. If you feel hungry, grab a healthy snack to tide you over.
- Talk to dining services at your

school about any special dietary needs, especially when also dealing with conditions such as celiac disease or diabetes.



## Keep an eye on portion size

Restaurants seem to have their own ideas about portion sizes. Some pile food on large plates, offering more than the recommended serving size. Here are some examples to help you follow the recommended daily intake of specific food groups\*:

**Grains.** At least half of your grains should be whole grains. One small muffin, five whole wheat crackers and three cups of popped popcorn are each one serving of grains; one large bagel, four servings.

**Fruits.** One large banana or one small apple meet the criteria for one serving of fruit.

**Vegetables.** One medium baked potato is one serving; one cup of iceberg or romaine lettuce, ½ serving. For most other vegetables, a one-cup serving amounts to one cup of the 2 ½-cup total recommendation.

**Meats and beans.** One small lean hamburger and one soy patty each equal 2 to 3 ounces; one can of drained tuna, 3 to 4; 2 tablespoons of hummus, one. A typical recommendation is a total of five ounces daily.

\* Always follow the advice of your own doctors as they know your medical history, current disease activity and possible complications.



# JUST FOR ME

Fun facts and news for children affected by JM

## Break it down

Have you ever wondered what how they came up with some of the words used to describe juvenile myositis, or JM? Many words can be broken down into parts, and the meanings of these parts are then put together.

A short definition of dermatomyositis is swelling in the muscles and skin. Broken down into its parts, dermatomyositis is:

dermato = skin

myos = muscle

itis = inflammation or swelling

Here are some other words...

**Polymyositis:** poly = many; myos = muscle; itis = inflammation (swelling).

Polymyositis is swelling in the muscles and involves many muscles in the body.

**Autoimmune:** auto = self; immune = protected from something harmful.

JM is considered to be an autoimmune disease. This means your immune system is making a mistake and trying to protect you from your own “self” cells—cells that it sees as being harmful to you.

**Calcinosis:** calci = to change into a hard substance by building up calcium; osis = diseased condition.

Calcinosis is the name given to the hard “lumps” of calcium some people have under their skin. These bits of calcium are not supposed to be there—a “diseased condition.”

**Intravenous:** intra = within; venous = of a vein.

When you take intravenous (IV) medicines, the medicines are given within the vein through a needle.

**Myopathy:** myo = muscle; pathy = disease.

A myopathy is simply a muscle disease, and JM is one type of inflammatory myopathy, or muscle disease where there is swelling.

**Vasculitis:** vasculum = small blood vessel; itis = inflammation (swelling). Vasculitis is swelling of your small blood vessels, which causes a skin rash.

## Do you want to read more about juvenile myositis?

Check out [www.myositis.org](http://www.myositis.org).

There are new pages under “Kidstuff”—with stories about staying safe in the sun, having pets, how art can help you feel better, and more.

You’ll also find a page of “JM Friends,” where children from around the world tell you about themselves. Share your own story with everyone else!

Let us know what you want to see on these pages. Email me at [kathryn@myositis.org](mailto:kathryn@myositis.org) with your ideas.

## BRAIN BUILDERS

Want to play some games that are fun and keep your brain “moving” over the summer? Try these:

**What’s missing?** Have your parents, brothers, sisters or friends place a number of objects in a box. Go through the box, remembering what objects are there. Cover your eyes (don’t peek!), and ask them to remove one item from the box and hide it. Look back through the box to see if you can figure out which object is missing.

**Story time.** Make up a story with the help of other people. Have one person start a story, saying only one sentence. Pass the story on to the next person, who makes up the second sentence, and so on. Keep going around to everyone until you’ve reached the end of your one-of-a-kind story. Write them down to share!

## What's new online

Check out [www.myositis.org](http://www.myositis.org) for updated materials and features. Find Children and Families pages under “Patients, Families & Caregivers.”

Parents pages focus on what to expect when your child is diagnosed with juvenile myositis (JM), how to talk to your children about it, what strategies other families have used to deal with the challenges of chronic illness, and practical solutions to everyday obstacles. Pages for teenagers and younger children are aimed at their unique age-related concerns and questions, with some web extras for fun.

Don't pass over the rest of the site—there are materials specific to those newly diagnosed, a glossary of commonly

used terms related to myositis and easy-to-read diagnostic criteria for all types of myositis, including JM.

Your individual “My TMA” pages (in the Community section) have been expanded. As a member of the *Keep In Touch* support group program, you can share a photo of your child or family with other JM members as well as adult members living within your support group area. Simply post your photo and a personal note on these pages and get to know other members there as well. What a great way to connect with one another—and

put faces to names you've read and voices you've heard.

Check back often for updates and additions. We welcome your feedback.

The screenshot shows the homepage of The Myositis Association. At the top, there is a navigation bar with links for 'TMA Home', 'News & Events', 'Marketplace', 'Contact Us', and 'Language Index'. Below this is a search bar with the username 'kwarminsky' and a password field. A navigation menu includes 'About Myositis', 'Health Professionals', 'Patients, Families & Caregivers', 'Community', 'Research', 'Get Involved', 'Resources', and 'About TMA'. The main content area features a large photo of a group of people, a search bar for the TMA site, and several news items. One prominent item is about the 'Myositis Center at Johns Hopkins University', which opened in March 2007. Other items include a '2007 Conference' in Seattle, a 'Research Challenge' with a \$500k prize, and 'Myositis Ribbons'. A sidebar on the right contains a 'Community' section with a 'My TMA Message Board' and a 'Crescent Healthcare, Inc.' advertisement for IVIG.



THE MYOSITIS ASSOCIATION

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# JM COMPANION