THE MYOSITIS ASSOCIATION

JM COMPANION

SPRING 2008

For children, families and friends affected by juvenile myositis

TMA Celebrates Progress in JM Research, Support, Advocacy

Why celebrate?

There have been many accomplishments in the decade and a half since TMA was first founded (see OutLook, page 1). Some of the organization's proudest moments have been providing information, support, and research into better treatments on behalf of the youngest members of the myositis community. Some high points:

Research: Although a great deal of general myositis research ultimately benefits children with juvenile myositis, TMA has funded a number of research grants and fellowships specifically for juvenile myositis, including:

- Patient trials to determine the effectiveness of treatments in new-onset juvenile myositis.
- Several studies examining the role of maternal cells found circulating in the blood of juvenile myositis patients. TMA's medical advisors were among the first in the scientific community to pursue the meaning of this phenomenon, called chimerism, in the inflammatory process.
- A multi-center European study that followed former juvenile myositis patients to examine the impact of the disease on their future life and health, and a national study testing JM patients ten years after their initial diagnosis.
- A study examining the frequency of juvenile myositis in children from certain Native American families.
- Several comprehensive studies examining genetic and environmental factors for clues to who gets juvenile myositis and why.

Collaboration: In cooperation with dedicated pediatric rheumatologists, dermatologists and neurologists all over the world, TMA has played a pivotal role in recruitment of children for a national patient registry and other efforts to gather medical information. TMA helped coordinate a historic series of meetings where the world's major juvenile myositis experts hammered out criteria for assessing both disease damage and improvement, an enormous step towards giving researchers the ability to effectively measure the success of patient drug trials. TMA continues to collaborate with national and international coalitions of juvenile myositis experts at meetings and seminars. One important new trial to come out of the major collaborative efforts of these groups is the largest trial ever conducted for myositis, the multi-center rituximab trial, which includes children (see page 3).

Education: Ever since the first newsletter dedicated to juvenile myositis (then called the JM Messenger) was printed in 1996, TMA's juvenile myositis families have received periodic information about research, treatment, and adjustment to the huge emotional and logistical challenges inherent in coping with a challenging disease. TMA regional and national conferences offer cutting-edge information delivered by world experts. In 2006, copies of Myositis and You rolled off the presses. This ground-breaking book has already made a huge difference in the confidence and competence of families struggling with juvenile myositis.

Support: TMA offers online support from staff, access to medical advisors, member to member support on message boards, regional support groups, and opportunities to meet face-to-face and share experiences at the Annual Conference (see Denver, below). Any family, parent, or juvenile myositis patient with a creative idea for an innovative support group is invited to get in touch with Quineesa Smith, TMA's new member services manager. For more information, see Smith's introduction, in OutLook, page 8.

Don t miss Denver!

Family-friendly fees are designed to encourage families on a budget to join TMA in Denver September 18-21 for a rewarding and enriching experience.

For as little as $15, family members can attend the series of valuable, informational sessions and informal exchanges that make TMA Conferences so valuable. For those who have travel or school concerns, a special, intensive program for families will be offered on Saturday, tailored specifically to the ages and concerns of your family. TMA staff members have already been in touch with some of you. Register now and let staff know that what concerns you'd like us to address at the Conference: tma@myositis.org.

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Stories from Seattle

Some of the families who attended the 2007 Conference in Bellevue came for the whole event; others had children in school and came for the intensive Saturday session, which included a pediatric rheumatologist, a psychiatrist, an immunologist, and a rehabilitation specialist. Since it was designed as an informal, multi-disciplinary session, presenters did not present formal lectures or slides, and a great deal is summarized in the winter *Companion*.

It is hard to capture the informal give-and-take of parents and their children and the experts assembled. Those who attended enjoyed the informal format. Because there were several small children, the room was set up to accommodate both parents and children. The children were pleasantly occupied with games and crafts provided by Ann Robertson, Seattle KIT Leader, and her group.

One of the families who came to the Seattle suburb of Bellevue last year was new to TMA, new to myositis, and still wondering what was ahead. Sissy and Brett Taylor drove up from Texas, with JM patient Kory, then six and Kacy, then 9. Sissy managed to put her finger on the one most important reason for newly-diagnosed families to attend a Conference. “We felt so alone,” she said. “In fact, I didn’t fully realize how lonely and confused we felt until we actually got there and saw other people just like us.” The same was true of Kory, who had seemed fairly unconcerned about her illness, but “Just like us, she felt alone and different,” Sissy said. Sissy, Brett and their girls quickly became favorites of the adult myositis patients at the Conference. Patients, staff, caregivers, presenters and vendors were inspired and cheered by the younger contingent.

Sissy mentioned another point that’s brought up quite often by parents. “Sometimes, I just don’t know what to ask, or I don’t know whether something my daughter is doing or experiencing is related to her disease or not. So having the time to take everything in and hear other questions and experiences really helped me.” Sissy mentioned that she learned from the other parents as well as the professional experts: “I found that another parent was having exactly the same confusion as I was,” she said. Like many of the families, Sissy and Brett attended the general sessions, and found a great deal of that information helpful, too. “I would definitely do it again,” Sissy said, “and I’d advise anyone with a newly-diagnosed child to attend.”

Tracey and Brenda Sykes have a different story. They’re veterans of TMA Conferences, and have attended several. They’ve had a long battle: their son, Brandon, was diagnosed as a toddler and has had flares off and on. He was 15 when the family attended the Seattle Conference. The Sykes had also gone to the previous Conference in Orlando in 2006.

“He wasn’t interested in going, then,” Brenda said. “But last year, we let him know that he was about to become an adult and would soon be managing his own illness.” Brandon attended the sessions as an adult member and was included in asking and answering questions. Like the Taylors, the Sykes were also warmly received by the adult myositis community, and many expressed their admiration for the way the family worked together. When Brandon had the opportunity to be interviewed on camera for a promotional video, he expressed his appreciation for the information he gathered at the sessions. “It dawned on me that it was my responsibility to know these things now,” he said.

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Solving the daycare di

Every working parent has similar problems. You've set up an intricate system of care, transportation, supervision, doctor's visits and homework. Then something goes wrong: your child has a flare, snow shuts the school, there's a teacher's work day. Then, of course, the whole summer lies ahead with new worries for busy families trying to juggle work, fun, and the increased demands caused by a sick child.

The National Association for Sick Child Daycare tells us that each day more than 350,000 children younger than 14 years of age with both parents working are too sick to attend school or child care. Working mothers are absent from their jobs from 5 to 29 days per year caring for ill children. This costs employers between $2 and $12 billion annually.

Although there are no easy answers, there are a number of suggestions that will make it easier for you to make good decisions. Our thanks to the network of pediatric rheumatology nurses, who provided much of this information.

■ **Start with the pros.** Amy Sharples, a pediatric rheumatology nurse with the University of Massachusetts Medical Center in Worcester, says the first place to turn is the state agency that governs daycare. "See if they know of any daycare providers in your area who care for children with medical issues," Sharples said. "Then take the names closest to you and set up interviews." Sharples noted that it would be very unlikely to find a daycare center that already had a child with juvenile myositis, but many of the issues: fatigue, the effects of medication, mood swings with drugs, are common to children with many kinds of chronic disease. Sharples recommends that parents look online for the information they need, a process that will save you a great deal of time on the phone as you make your way through the bureaucracy. "You'll find a link to the agency that does daycare licensing," she said. "You'll either be able to find appropriate places online, or you can call that office and ask for a list of people qualified to take children with special needs."

■ **Inform yourself.** There is a mountain of information about community-based childcare, and national programs designed to support parents who can't afford child care or who have hard-to-fill needs, such as a chronically ill child. One good place to start is The National Child Care Information Center (http://www.nccic.org/index.html), which provides links to dozens of other sources of information about day care in your state. The Center offers a helpful checklist of questions to ask when visiting child-care centers. Carefinder and Child Care Aware (800-424-2246) can help you find a local preschool or child-care center, which at least gives you a place to start in your search. The site also encourages parents to comment on their experience with specific child-care providers.

■ **Enlist the family.** Betty Bishop, a pediatric rheumatology nurse with the University of Minnesota Children's Hospital, said most of the JM families she sees have patched together after-school, holiday, and summer care with grandparents and extended family. "Naturally, parents feel more comfortable with a relative," she said.

■ **Provide training.** "That's where we come in," said Sharples. "Make an appointment at the hospital where your child is being seen. We do training all the time for inexperienced daycare providers. We will be glad to educate any competent provider or relative in how to work with a JM child. And we'll be glad to give them materials to take home."

■ **Check with your local hospital.** Some hospitals have "sick child day care centers" as a community service, where sick children stay. Be aware that, although hospital day care providers are trained to prevent infection from spreading, your child will be exposed to colds and flu. Check with your pediatrician or nurse. Many hospitals now have such facilities, or visit Child Care in Health Care http://www.childcareinhealthcare.org for valuable information related to hospital-based child care programs throughout the nation.

■ **Have a backup plan.** All parents would like to be home when their child is in a flare, but prepare ahead of time for when you just can't be there, or when you know there will be an extended period of illness. Explore every resource. You're not alone in your search for safety and reassurance for you chronically ill child, whether after school or for days when he or she just can't go to school.

To find out more about daycare in your area, go to www.daycare.com. You can also find more links on the TMA website at www.myositis.org.

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Children needed for rituximab trial

Many sites are participating in the pediatric portion of clinical trials for rituximab, a drug that has shown promise in children with JM. The study is about half-way through its recruitment phase, and is seeking children older than 5. All trial participants will receive the drug during the course of the trial. To determine if there is a trial center near you, contact Sherrie L. Pryber at the University of Pittsburgh: 412-647-3241 or at pryber@dom.pitt.edu.

If no trial is near you, you may be referred to the National Institutes of Health in Bethesda, Maryland. NIH is still seeking children for the trial based there, and offers reimbursement for some travel and other expenses.

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Chalk Talk for Parents

Know your tools

Even if your child has been able to keep up in school despite juvenile myositis, be aware that changing circumstances can alter the situation in ways you might not expect. Brenda Sykes, mother of 15-year-old Brandon, gives a couple of instances where apparently subtle changes affected her son's educational life.

"We weren't expecting how things would change when he entered middle school and went from classroom to classroom," she said. Brandon could handle the increased movement, but the closeness of the enclosed classroom was gone. "All of a sudden, he wasn't with a teacher who was familiar with him and his disease, and he was encountering other students who hadn't grown up with him." Brenda believes that facing difficult situations has always made her son stronger, but she advises other parents to prepare for the consequences of each new phase of educational growth.

Later, when Brandon returned after a summer's absence to begin high school at a different school, he was with students who, for the most part, hadn't ever seen him before. The JM flare and huge maintenance and intravenous doses of steroids had changed his appearance drastically.

"People who knew him before didn't recognize him," Brenda said. "And those who did just thought he'd always looked like this." Brandon, with his doctors and family's blessing, stays as active in school activities and sports as he can, so it's easy for teachers to just discount his disease, Brenda said. "I wanted them to be aware of changes or problems, so one day I brought pictures of how he looked before the flare, and showed them to his teachers. That one simple act showed them how dramatic the disease activity – and the medications – can be. I was very glad I had done it."

Even if you have already negotiated an individual education plan (IEP) for your child, it's wise to revisit it at every significant change. Kathy Gaither, the mother of a child with juvenile scleroderma (like JM, a chronic autoimmune disease) advises parents that they are a crucial part of their child's educational team.

"A meeting with teachers and school administrators is useful for educating school personnel about a child's diagnosis and potential ways in which the child's school performance might be impaired, even if school services are not requested," she said. An example might be if your child needs to move around to avoid cramped and painful muscles. No special formal educational service is needed, just some understanding on the school's part.

Gaither divides the IEP process into eight steps:

- **Referral**. That's when the parent requests an evaluation for special educational needs. This stage involves parents, the teacher, and any school staff who will be involved. The school is required to set up the evaluation within ten days of receiving a request.

- **Evaluation**. Teachers, counselors, health professionals and parents look together at the abilities and disabilities of your child to set the basis for his or her educational plan. The school has 30 days to complete this evaluation.

- **Eligibility**. The team then determines if your child has special needs making them eligible for special services. This determination comes at the end of the 30-day period or before.

- **IEP committee**. The school administrator, your child's teacher, a special education representative, you, and your child (if of an appropriate age) then develop the plan. Again, the team has 30 days after the evaluation concludes to come up with a viable plan.

- **Services**. The staff, teacher and parents set the logistical and practical details of how the services will be delivered. They should begin as soon as possible after a course is charted.

- **Instructional plan**. The team then sets long-range goals and short-term objectives. The team also collaborates on a time line for meeting these goals over a number of years.

- **IEP review**. The team, including the student where appropriate, continues to adapt the plan to the changing needs of the student. "Changes" can be changes in the health of the student, or simply the expected and unexpected changes that come from moving forward in the educational system.

- **Complaint process**. Whenever there's a disagreement that can't be resolved informally, parents, school staff, a mediator or hearing officer meet and search for a resolution. It's up to the team to set guidelines for resolving disagreements in advance.

There are resources available as you go through the IEP process. Kathy Gaither recommends:

National Information Center for Children and Youth with Disabilities
1-800-695-0285
http://www.nichcy.org

Protection and Advocacy
1-800-200-6270

The Pacesetter
1-888-200-6270
www.pacer.org

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Look ahead to a rewarding career

If you're presently a high school student, you may think you have plenty of time to decide on your career path and find the skills to market yourself successfully. You may also believe that completing an academic program will guarantee you a job.

Unfortunately, this is not always true. Now is the time to start exploring your career interests and developing your job skills. In today's competitive job market it is essential that you possess the very skills that are employable, and that will set you apart from everyone else. Many high schools make work-based learning activities available, and that's a good way to find out what jobs are possible and appropriate for you. Learn about informational interviews, job shadowing, internships and service learning at a special web site maintained for young people in transition at www.universityofwashington.edu/doit/ This web site is developed for students of high school age who have some degree of disability; however, it has a great deal of information for students who have no obvious disability but need occasional accommodation.

The nation's community college administrators are experts at knowing what skills will be needed in the work force next year, the year after, and in the next 10 years. Even if you plan to go on to a four-year college, you might want to talk to representatives from your community college for advice in developing skills that will actually have a market.

The following summary is based on recommendations from the "Do It" program at the University of Washington and successful JM adults who have made the transition. For detailed information on preparing yourself for your local workforce, visit www.universityofwashington.edu/doit.

Use school resources

- Visit your counseling office to find work-based learning opportunities.
- If you have an Individualized Education Plan (see related story, page 4), make sure mainstream career preparation activities are included.
- Work with your counselor for suggestions for disclosing your illness and identifying assistive technology resources.

Know your community

- Contact your local social security office and request an appointment with a benefits counselor, or visit the SSA Web site at http://www.ssa.gov/.
- Network with friends and families about the work experiences that interest you.
- Find a vocational rehabilitation agency in your area to help you prepare for employment and find community rehabilitation programs.

Know your rights

The School-to-Work Opportunities Act provides programs that help students apply what they learn to real work situations, including school-based training for jobs in the community and on-the-job training. More information on The School-to-Work Opportunities Act of 1994 can be found at www.ncrel.org/sdrs/areas/issues/envrnmnt/stw/sw3swopp.htm.

Contact your state Governor's "Committee on Employment of People with Disabilities" to find out if there are programs in your area that might help you. One of these national programs, High School/High Tech, is sponsored by the Office of Disability Employment Policy in the U.S. Department of Labor. Contact 202-376-6200 (voice), 202-376-6205 (TTY), or http://www.dol.gov/odep/programs/high.htm for more information.

View it, then DO IT

A short video, "Learn and Earn: Tips for Teens," may be freely viewed online along with a publication with the same title. It can also be purchased in DVD format from DO-IT: www.universityofwashington.edu/doit.

Be resourceful

Use the following websites to continue gathering information about work-based learning opportunities, job-search skills, employers, accommodations, legal issues, and career planning. The resources are out there. You just have to use them.

ADA and Disability Information
www.usdoj.gov/crt/ada/adahom1.htm

Career Magazine
www.careermag.com

Continued on next page.

Career from page 5

Career Planning
www.bgsu.edu/offices/sa/career/students/planning_process.html

Transition from School to Work and Community Life
http://thearc.org/faqs/qa-idea-transition.html

High School/High Tech
www.dol.gov/odep/programs/high.htm

Job Accommodation Network
http://janweb.icdi.wvu.edu

Mapping Your Future
http://mapping-your-future.org

Marriott Foundation
www.marriottfoundation.org

National Transition Alliance for Youth with Disabilities
www.ncset.org/publications/nta

One-Stop Career Center
www.wa.gov/esd/1stop/

Monster.com
www.monster.com

Parents and the STW Transition of Special Needs Youth
/www.kidsource.com/kidsource/content4/special.needs.trans.html

School-to-Work Fact Sheets
www.montana.edu/wochesw/ fact-sheets.htm

State and Local School-to-Work Links
www.aea10.k12.ia.us/curr/stw/generallinks.html

The DO IT program at Washington University compiled these resources.

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How to have a better summer

Make a wish...

Lauren Adelman did, and during a dark period of life it gave her a ray of hope. In the spring of 2006, she was 14 years old and facing her third flare, a flare that would be the worst yet. Frustrated at dealing with her JM for four years without remission, she was growing more and more discouraged.

"While some of the treatments seemed to work for a while, my myositis was never far from the surface," Lauren writes. "With each flare, the treatment clock would restart again for at least another year. This time, the side effects of the medication and the JDM symptoms were particularly difficult to handle." In fact, Lauren questioned if she had the strength to make it to the other side of another flare.

Feeling hopeless, she confided in her doctor, Maria Perez, a rheumatologist at Texas Children's Hospital. Dr. Perez told her about the Make-A-Wish Foundation, the national organization for children with serious illnesses.

"I was so surprised when I found I was eligible for a wish," Lauren said. "Between infusions, I spent hours on the computer and brainstormed with my family about where I would like to travel and what I might like to do. Since Lauren was an athlete and loved outdoor sports before her experience with JM, she chose New Zealand, a world center for extreme sports like zorbing, jet-boating, and luging.

A little less than a year ago, she boarded a plane for the 12-hour flight to Auckland. Every step of the way, she said, Adelman family members were treated like VIPs.

What about the extreme sports? Lauren tried them all. She jet-boated on Lake Rotorua at 65 miles an hour, flooded by adrenaline and lake water. She luged down a mountainside, just barely avoiding the fate of her dad, whose cart left its track.

She explains zorbing, an extreme sport that originated in New Zealand. With her cousin, she got inside a giant ball and rolled down hill. "The ball is about 10 feet in diameter and has about six inches of water inside. It's impossible to stand up, although we tried very hard. We sloshed back and forth inside the ball as we tumbled down the hill. What a blast! We zorbed three times because we couldn't get enough of this fun activity."

Lauren's trip wasn't all crazy sports, though. She toured the country, met sheep and sheep dogs, went to a Maori dinner and show, and rode horseback through a ranch. She saw unbelievable sights like the famous "glow worm cave" lit completely by mysterious New Zealand worms. She drank lots of hot chocolate (a New Zealand specialty – who knew?).

"The trip was amazing and is something I will never forget," she said. Her favorite New Zealand T-shirt: "I came, I zorbed, I conquered."

Attend a camp…

TMA offers $100 scholarships for juvenile myositis patients to attend a camp of their choice. Any camp is eligible, whether it serves children with special needs, or is a camp that includes all children, so long as it is appropriate for your ability level.

Getting a TMA "campership" is as simple as 1, 2, 3:

1. Be a TMA member.

2. Email TMA at tma@myositis.org for our complete instructions.

3. Attend camp and have your counselor document your attendance. Those eligible will receive a $100 reimbursement for camp expenses after completing the camp.

JUST FOR ME

Fun facts and news for children affected by JM

Jump right in!

Swimming is a great way to cool off when it's hot. It also makes your whole body strong.

If you don't know how to swim, you can learn! Check to see if there are lessons near your home. There are some easy things you can learn right now.

Floating

We were made to float easily. Make believe you are falling back on your bed. Lie back with your arms stretched out to the side. Turn your hands up and keep the backs of your hands in the water. Make your back tight and stretch out your legs. Take short breaths. Floating is a good way to rest if you get tired swimming.

Treading water

Get into the water and pretend you are slowly riding a bicycle. Keep your back straight and your arms straight out in front of you. Pull your arms together with your palms facing down and in. Pull them back out with your palms facing down and away from each other. See how long you can keep your head dry this way.

Going under

Breathe in as much air as you can and then let it all out. Take one more breath and hold it.

Slide under the water. Stretch out your body with your legs together and your arms straight out a little bit above your head. Pull your legs up then kick them apart. Bring your legs together and kick to move around.

It's fun to find out more about gravity. Gravity means that what goes up must come down. When you're in the water, the higher you try to lift yourself , the more gravity will try to push you down. So, if you want to float, try to keep yourself underwater and you will naturally float at the surface. But if you lift your head, arms, or legs out of the water, you'll sink right back down.

Fun Facts

- Elephants can swim up to 20 miles a day! They stick their trunks above the water like snorkels.
- At the 2000 Summer Olympics in Sydney, Australia, the USA won 33 swimming medals, including 14 gold medals.
- It takes about 800,000 gallons of water to fill up an Olympic-size pool.

Swimming checklist:

- Make sure to wear sunscreen
- Never swim alone
- Listen to the lifeguard

To find out more about summer fun, google BAM! CDC.

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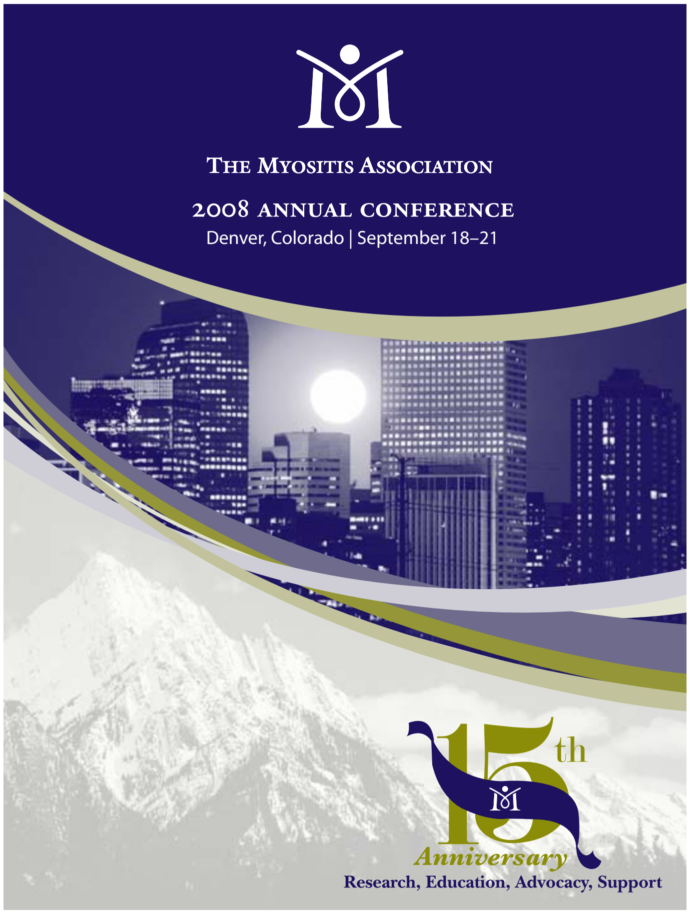
The Myositis Association

2008 ANNUAL CONFERENCE

Denver, Colorado | September 18–21

15th Anniversary

Research, Education, Advocacy, Support

You don’t want to miss this!

In celebration of TMA’s 15th Anniversary, we want as many TMA members to attend the Annual Conference as possible. For that reason, this year, TMA is offering a $15 conference registration fee for those who would not be able to afford the Annual Conference otherwise. And, the regular registration fee is only $150 if you register before June 15th.

Join us in Denver, Colorado, from **September 18-21**. It is going to be the best and biggest Annual Conference yet. And, it just so happens, the final day of the Conference is National Myositis Awareness Day! This will be a truly memorable event you will not want to miss!

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