



TMA poster features “Faces of Hope”

Creative and generous spirits were behind the first TMA poster, and it shows. Poster children Nicholas Brechtel and Kay Ann Gucciardo, both patients of Dr. Lauren Pachman, met in early winter to pose for the photo.

Amie Brechtel had scouted the Chicago area and found a gifted children’s photographer, Lori Allen of LA Photo Designs. Lori has a way with children and, if you visit her web site, www.laphotodesigns.com, you’ll see why Amie was so impressed. Lori offered to set up a photo session the next time Kay Ann was in town for her regular visit to Dr. Pachman.

Lori then offered to take and produce the photos free of charge, a considerable donation of time and talent. Lori later offered to design the poster, and we gratefully accepted.

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JM kids love summer camp, and you can’t beat the price!

Although there is still snow on the ground in many parts of the country, it’s not too early to think about summer, swimming and fun outdoors.

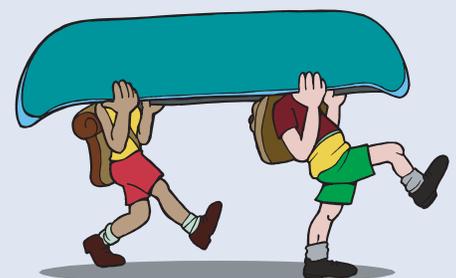
Children with juvenile myositis can enjoy the summer, despite their illness. Although TMA does not yet have its own camp program, we’ve found that camps, run by the Muscular Dystrophy Association and the Arthritis Foundation, provide wonderful experiences for children with chronic diseases. These camps have years of experience working with children with neuromuscular diseases and other chronic illnesses. We recommend camps for JM children even if they don’t need special accommodations. If they do, you’ll have a chance to discuss your child’s special needs in the application process. Camp may be the one time during the year that they can talk openly about their fears with other children who have similar experiences. Their time away from home will be a joyful period of growth and independence, supported by dedicated people.

To make sure every child with myositis has an opportunity to attend one of these camps, if they so desire, TMA will help pay for them to go to camp. You can find the camp nearest you by going to www.mdausa.org or www.arthritis.org or calling 800-572-1717 for MDA camps or 800-283-

7800 for AF camps. These organizations will pay all or part of the camp costs. Costs not paid by MDA or AF will be paid by TMA.

Simply find an MDA or AF camp appropriate for your child, pick up an application, and let us know the amount you need. The information you will need to apply for TMA funding can be requested from the camp directors or TMA at 540-433-7686. If you or the camp director have any questions, call TMA or send an email to tma@myositis.org. You must be a TMA member to be eligible for TMA funding — so if you are not already a member, you will want to join now. We will award the “camperships” as they come in, so don’t delay!

Funding for the TMA camp scholarship program is provided by the family of JM patient Amanda Felix. Amanda’s family, including TMA Board Member Harriet Bollar, has raised this money so that every child can have a valuable camp experience. So grab your child, find a camp, and stock up on sunscreen! We’d love to hear about your child’s experience at camp this summer!



A RACE TO THE FINISH – JEFF CAMPBELL'S STORY

By JEFF CAMPBELL

Sometimes your goals can't easily be measured by simply a time or place. Sometimes, just completing what you set out to do is reason enough to continue. In hindsight I can't even tell you how I finished the race...just that I finished. It was simply another step in my journey of coping with juvenile dermatomyositis and learning how to work with the gifts God left me.

My story is the same as the stories of many children with JDMS, with one slight twist. In 1972, when I was three, my pediatrician was able to diagnose my condition on the first visit and rush me to Chicago to start treatment. Prednisone was the treatment used and its side effects were many. Calcium deposits, arthritis, cataracts, and thinning skin all remind me of my condition every time I wake up; yet they don't stop me from getting dressed, going to work, and training for my next race. What made the biggest impact was how Dr. Lauren Pachman allowed and encouraged my parents to make sure I was involved with sports and exercise. The irony is that I may not have even seen Dr. Pachman had it not been for the advice of a visiting nurse during a trip for treatment.

The nurse had heard of Dr. Pachman and pulled my parents aside. She said if I were "her kid" she'd make sure I became one of Dr. Pachman's patients. One year later, I began seeing Dr. Pachman and saw her until I finished college in 1991.

There were countless trips from my Indiana home through rain and snow. During it all, she focused on my quality of life as I continued to improve. Baseball, swimming lessons, and physical therapy were all part of my routine until high school, when I took up tennis. Two years later I made varsity, and fell in love with the idea of pushing myself to each new level. It was then that I started my "things-to-do list". I still have the list today and continue to actively pursue new challenges.

College was an exciting time, not only because I was on my own for the first time but also because I learned more about what my body could and could not handle. I also learned about the value of money and pursued scholarships. Because I was a good student, I was able to get sizeable grants, scholarship money and loans.



Jeff Campbell, JM patient

Now, at age 34, I look for new challenges. My condition has stabilized over the last ten or so years and I am medication-free. I am actively employed at the J.C. Penney corporate office in Plano, TX and plan to attend

Every day brings a new opportunity and a chance to cross one more goal off my list, and I feel that new treatments and research have made the condition more bearable.

graduate school this year in pursuit of my MBA. While my muscle enzyme tests are still above "normal", they are very stable. My body has learned to

adapt and allowed me to complete the Chicago Marathon in 1998 and my first Sprint Triathlon in 2002. Every day brings a new opportunity and a chance to cross one more goal off my list, and I feel that new treatments and research have made the condition more bearable. While nobody knows what the future holds, I still go back to a fortune cookie I received last year which read: "It's not the destination, but the journey that counts."

Scholarships for JM patients

Jeff Campbell was kind enough to write about his experience getting help with paying college tuition. If any other JM patients have had similar experiences, we would love to hear from you.

One grant I received was from the State of Indiana through its vocational rehabilitation program. It provided a sum of money each semester plus an additional amount for books. The amount granted was based on the school and student need. My high school guidance counselor told our family about the program. I met with the representative each semester to discuss grades, make sure I was still on schedule with classes and not falling behind, and discuss career options.

There are a few things from my experience that I can offer as advice:

Each student must actively ask about potential scholarships for students with disabilities. As a student, I didn't like to think of myself as disabled. My doctor and counselor filled out forms, explaining the condition and how it affected my normal daily functioning. My parents' income had to meet the "student need" requirements as defined by the financial aid department of the university and the State of Indiana. Today, students can find out about these programs more

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easily by researching available scholarships through the Internet. Most states have a Vocational Rehabilitation Department, and you'll find the list at:
<http://www.parac.org/svrp.html>.

Colleges and universities now have scholarship information listed on their school Internet sites. One university in particular, The University of Tennessee, has an entire site devoted to students with disabilities and what it can offer. It also has scholarship information categorized by disability. The link to that site is:
<http://ods.utk.edu/scholarships.html>.

Students should discuss their situation with college or university financial aid offices. These offices can offer invaluable advice on what scholarships may be offered for incoming students and what services are available (wheelchair accessibility, note-taking services, etc.). College should be a rewarding experience where kids with myositis can both learn from and interact with diverse people. It helped me grow as a person and taught me life lessons I could never replace. Mostly, it taught me an independence that I believe everyone struggling with this condition strives for. ■

Calcinosis study

Calcinosis specimens which have been surgically removed or biopsied from patients with myositis are needed (paraffin or frozen tissue blocks, H&E slides). The goal is to study the composition of these lesions in order to develop a better understanding of the causes of calcinosis and improved ways of treating it.

To refer samples or for additional information, contact Lisa G. Rider, MD, or Frederick W. Miller, MD PhD, NIEHS, 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 or

MILLERF@mail.nih.gov. ■

Writing the book on JM

The Myositis Association plans to publish a book about juvenile forms of myositis. The book will include experiences from both patients and healthcare professionals, covering myositis from a clinical standpoint and from the patients' and families' personal perspectives.

If you are a patient with juvenile myositis, a family member, friend, teacher, nurse, therapist, or any person important in the life of a juvenile myositis patient, TMA will soon be asking you to submit materials for publication in the book. We are interested in your stories, letters, poetry, drawings, and other work, and we hope to hear from even the youngest myositis patients in their own words. Although stories can be general, we encourage you to also write on a topic of particular interest or with special meaning to you. You may submit more than one entry; in fact, we invite you to do so. We welcome materials from any age or country, and anyone affected by juvenile myositis in any way.

Keep checking TMA's web site at www.myositis.org for more information. If you have questions regarding this book, please contact Kathryn Spooner at kathryn@myositis.org or 540-433-7686 ext 15. ■

Membership challenge

An anonymous donor has generously offered to contribute \$100 to The Myositis Association for each new patient member, with an additional \$100 for JM research for each new juvenile myositis patient member. Not only does this help TMA to reduce its membership fee to \$35, but it helps fund new programs and services to benefit all of TMA's members. For those affected by juvenile forms of myositis, your membership will help even more by increasing funding for research to find a cure for juvenile myositis! As one TMA Board mem-

ber asked, how else can one turn \$35 into \$235 so quickly and for such a worthy cause? ■

Use our new JM listserv

TMA has established a listserv that will allow JM patients and parents to communicate whenever they want, and it's as easy as sending a single email. This listserv is only open to the JM patients and parents who are members of TMA. If you are not already a member, please join us now to take advantage of this terrific opportunity.

Listservs have proven beneficial to groups with a common interest. They make it easy to share information and ideas quickly. By sending a single email to the listserv, your question or comment is then sent out to the other JM patients and parents on the listserv for their response. All messages sent to the listserv on a particular day are delivered to those on the list in a single email so that you don't receive a flood of emails throughout the day.

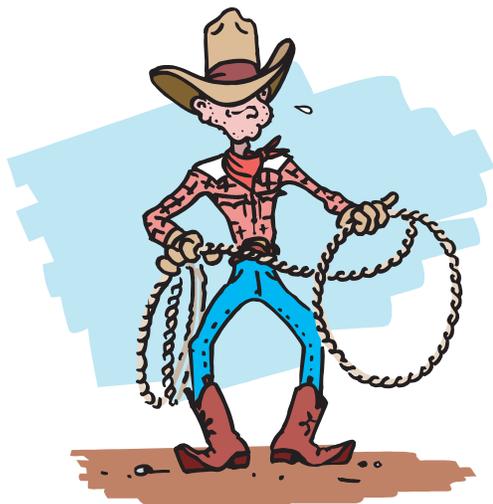
We hope you and your family will actively participate on the listserv. Please email us if you have not already received an introductory email to the listserv so that we can be sure we have your correct email address. We don't want anyone to miss out on this great new tool! ■

TMA poster, continued

The next step – producing the poster – took us from Chicago to Savannah, GA, where TMA member and master printer Jere Connan, owner of Printworks, donated the printing, also a considerable contribution.

We're providing the poster to pediatric rheumatologists and other physicians who care for juvenile myositis patients and their families. If you'd like your child's doctor to have a copy for his or her office, please call us at 540-433-7686 ext 12 or email tma@myositis.org. ■

Round up the family, and head to Houston!



This year's conference was scheduled over Columbus Day Weekend so more JM families and patients could attend. We hope you can plan to be there!

Why: TMA's 2003 Annual Conference in Houston

When: Columbus Day Weekend, October 10-13

Where: Inter-Continental Hotel
2222 West Loop South
Houston, TX 77027
713-627-7600 / 866-342-0831

How: Register on TMA's web site, www.myositis.org. Then reserve your hotel room by calling 866-342-0831; don't forget to mention The Myositis Association Conference to receive members discounted rates.

Who: The Myositis Association members, family, friends, supporters, and *YOU!*



THE MYOSITIS ASSOCIATION

755-C Cantrell Avenue
Harrisonburg, VA 22801

JM COMPANION

For patients, families and friends affected by juvenile myositis

ARE YOU WONDERING ABOUT JUVENILE MYOSITIS?

Do you feel like your friends treat you differently since you've been sick? We've written this article for you to share with teachers, friends and relatives.

You may know that I have a sickness called juvenile myositis (JM). I know you may wonder why I sometimes am absent or can't do things the rest of the class can do, so I hope this will answer some of your questions.

I didn't do or "catch" anything that made me sick. You won't catch it from me. Nobody knows what causes it. Most children with JM get better, and I can hope to be more like I used to be in a year or two.

My sickness makes my muscles weak, and I have trouble sometimes even walking or standing. Sometimes children have to spend time in a wheelchair. I have a type of myositis that makes my skin look red or puffy. Sometimes my skin itches or is very sore. I must stay out of the sun, or it will get worse. The sun can even make my muscles feel worse.

I have to go to the doctor a lot. The doctor tests my blood to see if my sickness



is getting better or worse, and to see if the medicine I take is working.

Sometimes medicine for myositis causes children to gain a lot of weight, and it makes their faces very fat. If I look different to you, that's why. When I am better, and can stop taking so much medicine, I will look like myself again. Other medicines may make me sick to my stomach or shaky or extra tired.

Sometimes I try to do too much, and the sickness or the medicine won't let me. That's why I sometimes suddenly need to rest, or stay home for a day or two.

I don't mind talking about my sickness. Please ask me if you have any questions. You won't embarrass me. ■

If you have brothers and sisters...

They might wonder: Is it okay to still tease her? Do I have to be careful around him? Can we run around and do the things we used to do?

Sometimes your brothers or sisters don't know if something they do might make you feel bad. Be sure to let them know what makes you feel too tired or causes you pain. Also let them know that you're still the same person you always have been, there just may be times when you need to slow down and rest.

Coming soon: Web site for JM kids

We're working on a special web page just for you! We'll let you know about all of the new things TMA has planned for you and your family. And we want to hear from you. What do you want to see on this web page? Ask your parents to email us, or send an email yourself to kathryn@myositis.org.

We want to make this a place to have fun and to learn. Even though we can't use every idea that we receive, we hope to use as many as we can to put together a great new page for you and your family to visit.

So start thinking about it today, and let us hear from you!

We want you..... for the TMA conference

Plans for the fall: shop for school, try out for the school play, work on your basketball moves, attend the TMA conference.

If a conference doesn't sound like your idea of fun, we want to change your mind! Young people who have come to our conferences have had a great time. We've scheduled it for early fall, when the weather in Houston is still warm and sunny. Houston has something for kids of any age - shopping, astronauts, rodeos and the special flavor that makes Texas the state that symbolizes the American west for all of the world.

If you're a new myositis patient, we invite you to meet others who have struggled with the same fears and questions you have. If you're older or are in remission, we also need you as teachers and friends for our younger, newer patients.

Questions? Feel free to email us at tma@myositis.org, and let us know what kinds of activities interest you. We want Juvenile Myositis to be a big part of the conference, and the more young people who attend, the more fun we will all have.

Brainteaser: Time to Tell

A sundial is said to be the timepiece with the fewest moving parts. What is the timepiece with the most moving parts?

Answer: An hourglass—filled with many grains of sand or other granular material.

Set off for summer camp

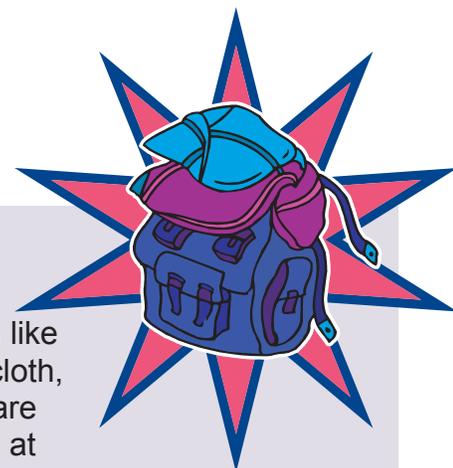
Do you ever feel like you're all alone? Being sick makes everyone feel that way. That's why we want children with juvenile myositis to meet other children like them this summer.

There are camps in every state for children who have special needs. You'll find great kids who have learned how to have friends and fun; and you'll be able to help kids who are just starting out.

Don't worry if you get tired easily, or need a lot of medication. These special

camps are set up for people like you. Some of the children will be in wheelchairs, some will have trouble eating, some will need to rest for part of the day. All of them will understand exactly what your life is like. You'll make friends and have fun.

If you want to help your parents find a camp for you, go to www.mdausa.org or www.arthritis.org.



Pack your bags

What should you take to summer camp? There are the obvious things like plenty of clothes, a towel and washcloth, and other personal items. But here are some other ideas to make your time at camp even more fun and unforgettable:

- Sunscreen
- Hat and sunglasses
- Small book with photos of family, friends, even pets
- Disposable camera or two
- Journal to keep track of all you do
- Address book to add new friends
- Paper, pen, envelopes and stamps to write home
- Cards and other small games to play inside
- Books to read during quiet times

There are a number of other things you may want to remember, so think about what you use every week that would make camp the best week it can be!

We hope you have a great time! Be sure to keep it all in your journal so you can tell us all about it when you get home.