

Meet Our Members: Kadie Maher shares her story

JM student has fun, stays focused

At 18, Kadie Maher has had juvenile dermatomyositis for so long that she relies on family stories rather than her own memory to recall the beginning of her disease. "I know there were a few things that happened then that let my parents know something was just not right," she said.

Kadie was playing soccer when her father (also her coach) noticed something strange about her running. "I couldn't really run," she said. "He said I was running without bending my knees, like a giraffe." Kadie was six and a dancer and swimmer as well as a soccer player.

Shortly afterwards, Kadie's mother looked down at her daughter's hands in church and noticed they were bright red.

A third incident really made everyone take notice. When Kadie ran up the steps to greet a friend's mother, the exertion made her short of breath and also made the rash on her face stand out.

Kadie was diagnosed immediately by her family physician, but nobody seemed to know how to treat the disease, which by now was making her weaker and weaker. Her parents finally found a pediatric rheumatologist who confirmed the diagnosis and began treating Kadie with prednisone.

"I'm sure the prednisone affected my appearance," Kadie said, "but at

six years old I didn't pay much attention." What caught her attention were the alarming mood swings caused by the drug. "It was especially bad before I understood it. I couldn't even watch a Disney movie without getting terribly upset." Her emotions were very much on the surface, she said, and crying spells were common.

There were other challenges over the early years. Kadie dropped out of her swimming class. "I guess I had expected to be a competitive swimmer, like my sister," she said. "When I couldn't even keep up with the others, I gave it up."

Kadie knew she wanted to keep active, though, and stuck with dance, attending class and practicing four or five times a week. Even as a middle school student she was driven. "Probably more so after I was sick," she said. Kadie also was diagnosed with arthritis, which meant she couldn't continue en pointe in ballet, but she did other classical, modern, jazz and hip-hop routines all through her school years.

Dance was great, she said, because she could modify her practices to accommodate her disease. The movements gave her flexibility, balance, strength and an aerobic workout. She worked at it even when she felt weak.

Her parents encouraged her, she said. "They supported me in my wish to keep going. They did remind me all the time to get enough sleep, though." Kadie's high school classmates knew

she was struggling with a chronic disease. "I didn't go out of the way to let new people know about it," she said, "although I kind of preferred that the other dance students know so they wouldn't think I wasn't trying."

Driven and persistent, Kadie said she needed the sleep reminders, especially as a high school student. "I was definitely in a kind of life where I had so much going on that sleep could have suffered." She became the president of Ridgefield High School, which cut into her dancing schedule. "My senior year, I had to stop dancing," she said. "I began to run, just to make sure I got some exercise."

Kadie's parents worked with her so she could continue her busy schedule at school. "When I began IVIG, I would have migraine headaches afterwards," she said. "We scheduled them for weekends so I would have time to recover." The family's goal was for her to miss school as infrequently as possible.

Kadie thrived on huge goals and a busy schedule. "I knew being school president would take a lot of time," she said. "I started getting involved in student government as a junior." She said the position turned out to be fun and also led to a new interest. She's now a political science major at Boston College: "I liked dealing with the administration and with the other students, getting things done."

Continued on page 2.

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Kadie, cont'd from cover

One thing her disease taught her, Kadie said: "I just had to be organized if I was going to spend time at doctor's appointments and getting (IVIG) infusions. I couldn't let anything slide and I couldn't procrastinate. She said she always felt supported by her friends, many of whom had been with her since the beginning of her long bout with JM. She found further support when she became involved with other JM patients and families who were fundraising for JM research.

Kadie chose Boston College after visiting there a couple of times. "I felt the energy of all these committed, energetic young people," she said. She did worry a little about going to a big football school, since she'd never had any particular interest in the sport. "I enjoy it now," she said. As she comes to the end of her freshmen year, she's found that it helps her to achieve her goals if she seeks out other students who are ambitious and hard-working, like her.

Kadie is still in treatment for JDM to control her rash. When she looks back over her childhood, she sees that she learned a lot from her long battle with chronic illness. "I found out how important it is to be focused, to work hard," she said. "I learned to look at the big picture, rather than momentary disappointments. It's really true that when the life you expect changes, you can discover a new life that's just as rewarding."

Read Kadie's tips for college students, page 6.



Consider summer camp

TMA has a long-standing summer camp program designed to encourage children with JM to take advantage of camps that help them pursue special interests, meet other children with chronic disease, and continue to be as active as they can.

Applying for TMA's camp program is easy, as you'll see below.

Child Eligibility: The child must be a current, full member of TMA. Joining is easy and gives you the valuable additional benefits of membership. If you aren't current TMA members, request membership materials or join online. Upon completion of camp, TMA asks parents to send a short "camp report" to let TMA know how the camp experience was for their child. Children are also encouraged to write to us about their time at camp.

Camp Eligibility: Any camp that can handle the individual needs of your child is eligible for the program. If you

would like a list of accessible camps, contact TMA.

Approval of Campers: TMA will approve scholarship requests in the order they are received, so long as there are sufficient camp funds available.

Complete the Application: Once your child is accepted for a camp, ask the camp director or other camp administrator to mail or fax the completed application to the TMA office. All applications must include the name of the camper's primary physician.

Payments: TMA will pay up to \$100 toward the camp fees that the parent must pay, either directly to the camp or to reimburse the parent.

Refunds: Parents must notify TMA in advance if their child will not be able to attend camp. TMA will contact the camp to request a refund.



Current research of interest

Comparison of clinical features and drug therapies among European and Latin American patients with JDM

An article in “Clinical Experiences in Rheumatology” published online in February, described the differences in treatment of juvenile dermatomyositis on two continents. Researchers, many of whom are doctors treating JDM, compared the demographic features, initial symptoms, diagnostic investigations, disease course, and drug therapies of children with juvenile dermatomyositis followed in Europe and Latin America.

They reviewed patients seen between 1980 and 2004 in 27 pediatric rheumatology centers. They reviewed patient charts for information about sex; age at disease onset; date of disease onset and diagnosis; onset type; presenting clinical features; diagnostic investigations; course type; and medications received during disease course.

The European and Latin American experiences are similar to the characteristics of North American experiences with JM: four hundred and ninety patients (65.5%) were females. The mean age at which children first came to the clinical setting was 7 years, and the mean length of time until remission was 7.7 years.

Disease presentation was acute or gradual in 57.1% and 42.9% of the patients, respectively. Researchers reported that 41.3% of patients had only one bout with the disease, while 58.6% either had several phases or became chronic.

The usual symptoms were muscle weakness (84.9%), Gottron's papules (72.9%), heliotrope rash (62%), and malar rash (56.7%). Overall, the demographic and clinical features of patients from the two continents were

comparable. One exception was a difference in the type of drugs chosen for treatment: European patients more frequently received high-dose intravenous methylprednisolone, cyclosporine, cyclophosphamide, and azathioprine, while methotrexate and anti-malarial medications were used more commonly by Latin American physicians.



Twin study: exercise helps young JM patient and healthy twin

In a study that appeared in the November Issue of “Musculoskeletal Disorders,” Brazilian researchers examined the impact of an exercise program on a young JM patient. Since exercise has been shown to benefit adult myositis patients, physicians proposed that the same would be true in JM. “Responsiveness to exercise training in juvenile dermatomyositis: a twin case study,” was conducted with Sao Paulo twins, which added another dimension to the research.

Both the patient who was diagnosed with JDM and her healthy twin underwent a 16-week exercise training program with both aerobic and strengthening exercises. Researchers assessed one repetition-maximum leg-press and bench-press strength, balance, mobility and muscle function, blood markers

of inflammation and muscle enzymes, aerobic conditioning, and disease activity scores.

As might be expected, the healthy child had an overall greater absolute strength, muscle function and aerobic conditioning compared to her JDM twin, both at the start and after the trial. However, the twins presented comparable relative improvements in the bench press, leg press, lung function, and time-to-exhaustion. The healthy child had greater relative increments in low-back strength and handgrip, whereas the child with JDM presented a higher relative increase in lung and heart endurance.

Researchers believe this to be the first report to describe the training response of a patient with non-active JDM following an exercise training regimen. The child with JDM exhibited improved strength, muscle function and aerobic conditioning without any increase in disease activity.



Check out the Outlook

Find articles of interest in the Outlook, TMA's newsletter for adult myositis patients. In this issue, we introduce new members of TMA's board of directors, (page 2); meet John Kollar, an amazing architect who now designs miniature homes for birds, (cover); find out about the influence of exercise on disease activity; and learn about high-tech, low-tech and common-sense tools that compensate for weakness from Mike Shirk, a San Diego artist.

Families feel financial strain of chronic illness

When your child was first diagnosed with juvenile myositis, your immediate concerns were for his or her health and the well-being of your whole family.

But if the illness has lasted a while, you've probably found that it also has caused a great deal of financial as well as physical and emotional stress. Some suggestions, from "Kids Health" and the Social Security Administration, provide resources as well as some ideas for coping with unforeseen expenses.

Costs of Health Care

The realities of long-term health care cost can be very different than families imagine. Costs can be staggering, and families experiencing the first shock of their disrupted life don't always realize the extent of the expense until the first bill or explanation of benefits arrives, plunging them into the mire of uncertainty. If you are using all your time and emotional energy dealing with a seriously ill child, it may be wise to ask a trusted family member, friend or professional to sort things out with physicians and insurance companies, keeping you informed as needed.

Often parents think that insurance will cover all or most of their child's medical expenses, that they'll be able to afford their child's health care. But each medical service comes with its own price tag. For instance, you'll find that hospital care, surgical procedures, doctor visits, and laboratory tests are separate services with separate bills. It's easy for the typical 10% co-pay to consume a family's entire financial reserves.

Other costs are indirect: missed time at work, child care for siblings, increased utility bills, custom transportation, and home renovations, such as ramps for wheelchair accessibility.

Educate yourself

The best way to make sense of bills and prevent financial problems is to be proactive. Whenever you have a period of waiting (and there will be lots of them) learn all you can about your insurance policy, and ask some questions:

Which doctors participate in your plan? What services are covered?

Learn the meaning of insurance language:

- **co-pay** is the part or percentage of the bill you must pay.
- **deductible** is the amount you must pay before your insurance company will pay for services.
- **referral** is when your insurance company requires the primary care doctor to be the one to refer your child to another doctor or specialist.
- **precertification** is when you must get approval from your insurance company in advance of medical tests or treatments the doctor has ordered. If you skip this step before receiving treatment, the procedure may not be paid for by the insurance company.
- **network provider** is any doctor, hospital, or other provider of medical services who has agreed to participate in your insurance company's network, and to offer their services at negotiated rates. These professionals are also called participating providers.
- **pre-existing condition** is an injury or illness that existed prior to the effective date of your current insurance policy and therefore may not be fully covered.
- **usual, customary, and reasonable** refers to the amount usually charged by health care providers for services and treatments in the area where you live.

To understand your health plan's design and its policies, which can ultimately save you thousands of dollars, it's important to get a written copy of your policy from the insurer or your employer. If your insurance company has a website, you should check it out for additional information.

Sometimes there are resources that parents don't know about; or overlook in the emotional turmoil of the illness. If your child is hospitalized, make sure you take advantage of onsite programs designed to help you:

- **Locate the resources** available within your child's hospital. Often there's a financial counselor in the hospital business office who can answer your questions about medical expenses.
- **Ask the hospital** to have a case manager assigned to your child. If the hospital has none on staff, ask your insurance company for the name of the person who will be working with you.
- **Make your child's health care providers aware** of your plan's benefits and limitations. They have learned to deal with insurance companies and are your partners in coordinating care with your health plan.
- **Negotiate individual fees** not covered by insurance with the doctors, clinics and hospital and set up realistic payment plans.
- **Keep a journal** and files to record doctor visits and any services performed (including lab work, X-rays, CT scans, etc.) and the fees for these services so that detailed information is easily accessible. This will be extremely helpful when dealing with your insurance company.
- **Contact your state's department of insurance** if you encounter problems with your health care coverage — especially if you've already

appealed denied or inadequate coverage. (See more on this below.)

■ **If your insurance company denies a drug** prescribed by your child's doctor, find out who makes the drug. Pharmaceutical companies often have programs that will either help you contest the denial or supply the drug at reduced or no cost.

If you have a case manager, don't forget to ask for help, particularly in deciphering bills and making sense of paperwork. Remember to update your case manager with new information and stay in frequent contact. If there's no specific case manager, find someone competent in the hospital business office to help you interpret bills, estimate costs, or help you deal with your insurance company.

Compare notes with other families who have dealt with catastrophic health issues. Their efforts may save you time and energy, and you'll also appreciate the support.

Short- and long-term financial assistance is also available from various sources, including private as well as government agencies. You may be surprised by the services available and the enthusiasm with which others embrace your needs.

Government organizations can assist in the medical and related care of your child. You don't need to be at poverty level to qualify, and may be eligible for programs you never knew existed. Two such programs that supplement the health insurance of a chronically or seriously ill child are Medicaid and Supplemental Security Income (SSI). As you research various avenues of assistance, ask your case manager about these and other options.

Take advantage of free financial advice and support offered by national agencies like the Consolidated Credit Counseling Service (CCCS). The CCCS provides certified financial counselors who help families examine their financial picture and overcome

debt. They can negotiate with creditors on your behalf for lower payments, reduced interest rates, and forgiveness of late charges or penalties. You may choose to enroll in their formal debt management program, in which case you would send one payment per month to the CCCS office, which then prorates and disburses your payments to creditors.

SSI benefits for children

Children applying for SSI benefits must have an impairment of comparable severity to that which would disable an adult. However, instead of evaluating ability to work, an individual functional assessment is made of how the children's impairment affects his or her ability to perform the same normal daily activities as other children.

The disability determination for each claimant is made by an agency in each state called Disability Determination Services (DDS). These offices are funded by the federal government and are responsible for developing medical evidence to determine whether a claimant is disabled under the law and when disability began or ended.

The DDS requests medical evidence (objective information about the claimant's impairment) from physicians, psychologists and hospitals identified by the claimant on the disability application. This evidence is the most important piece of the process because it provides an accurate history of the impairments. If that evidence is insufficient to make a determination, the DDS will pay for an additional examination from the physician or from an independent source. Remember to think in terms of disability that can be confirmed by medically acceptable clinical and laboratory diagnostic techniques, rather than symptoms.

Ask your doctor for a complete description of your child's condition and treatment. It is also helpful to record response to treatment, effects

of medications, and other factors that contribute to your child's disability. Because state agencies and field offices have high workloads, the benefit application process can take several months. In some states, the decision can be reached relatively quickly, within a couple of months; in other states, the process can take as long as six months; so it's wise to initiate your application as early in the process as possible.

For general questions or to apply for benefits, call your local Social Security office or call toll free 800-772-1213. To request a copy of SSA's listing of impairments or any other publications on the disability program, write to: SSA, Office of Disability, Professional Relations Branch, 3-A-10 Operations, 6401 Security Boulevard, Baltimore, Maryland 21235.

What if my claim is denied?

Whether your child is denied certain treatments by your insurer, or denied SSI benefits, it makes sense to appeal. Recent statistics from four of the six states examined for the outcomes of appeals filed with insurers showed that 39 to 59 percent of appeals resulted in the insurer reversing its original coverage denial. Data from a national study conducted by a trade association for insurance companies on the outcomes of appeals filed with states for an independent, external review indicated that coverage denials were reversed about 40 percent of the time.

SSI disability claims are denied about 19 percent of the time, but there is a formal appeal procedure offered within 65 days. The denials were found to be mostly because of lack of preparation by the applicant. A large number of these cases were approved when documentation was provided. Some families have found it worthwhile to get professional help in dealing with either insurance or SSI denials.



Volunteer this summer

If your JM is in an active stage, you may think that you have nothing to offer your community. Nothing could be farther from the truth. Even if you need some assistance yourself, there are plenty of opportunities for you to make a difference, meanwhile gaining valuable experience for school or work. We've collected some ideas to help you get started.

Love sports? Look into the Special Olympics, which always needs coaches, scorekeepers and managers, particularly if they have personal experience with disability. To get involved, call your local Special Olympics office. They'll help you find a volunteer role just right for you. Go to www.specialolympics.org to find information on your local opportunities, descriptions of what volunteers do, testimonials from former and present volunteers, and a video of some Special Olympics activities.

Want to help a child? Try your local Big Brothers, Big Sisters program or your local Boys and Girls Club. If you can play a board game, tutor a child after school or during the summer, or take a kid to the movies, you can make a difference. Go to the Big Brothers, Big Sisters web site at www.bbbs.org, or call (888) 412-BIGS to find a local agency. Find your local Boys and Girls Club at www.BGCA.org.

Love animals? Find your local animal shelter or SPCA and ask for volunteer opportunities. If you are not able to walk dogs or clean cages, there are still plenty of other ways to

help with fundraising. You could also spend time with cats or dogs at the shelter.

Love politics? Call or write to an elected official you admire and ask to work in his or her office for the summer. Politicians on every level are constantly short-staffed, especially in the summer when regular staff members are on vacation.

Want to help a kid with a chronic disease? As someone who has experience with JM, you are in a special position to help other chronically-ill children simply by talking with them and helping them adjust to life with a disability. To find a child to help, check with the nearest children's hospital, with your physician, or with your church.

Go online. There are many helpful services on the internet to help match you with a suitable volunteer position. Try volunteermatch.org; or the new serve.gov website, which will match you with opportunities according to your zip code.



Going to college? Tips for the transition

Kadie Maher (see page 1) has kept her strength up throughout her long battle with JM, but her rash is persistent, and she still takes medication and gets IVIG infusions every six weeks. Kadie is completing her freshman year at Boston College, and she has some tips for those contemplating college away from home:

■ Work with the health center at school. Kadie is able to get her IVIG

infusions right on campus. She scheduled the first one for parent's weekend, just in case there were any complications. She has infusions every six weeks. "I catch up a little on my sleep," she said, "because the initial dose of Benadryl makes me sleepy." Kadie said she has so few breaks that she tries to enjoy the 9-hour sessions. "My friends come and bring me food, and we visit," she said. "As long as I drink enough water and the infusion doesn't go too fast, I'm fine."

■ Sun exposure is not worth it. Kadie's learned this over and over again, she said. She goes to outdoor events, but always with sunscreen, sunglasses or a big hat.

■ Watch what you eat and how much you rest. Kadie agrees that it's hard for a college student to follow a good diet and get enough sleep, but she tries very hard, choosing lots of vegetables, fruits and lean meat. "Believe me, I can tell when I'm not eating well or getting enough rest," she said.

■ Organize your time. Kadie has such a busy week that she tries to get a little ahead on reading over the weekend. "It's great to have a break, but you've also got to be realistic about what's facing you in the coming week," she said. "If I can get a good start, it makes all the difference."

■ Keep moving. Kadie's found that walking up and down the hilly campus at Boston College gives her plenty of exercise. "I do a ton of walking every day," she said.





JUST FOR ME

Fun facts and news for children affected by JM

Have fun at camp!

Camps are fun for kids and are a great way to spend part of your long summer break. If you want to go to camp, it's easy to find one that fits you. Find a camp by going to www.mysummercamp.com.

Some things to think about:

- **Are you taking a lot of special medications, need help walking or climbing up and down stairs?** If so, you may want to look at camps for children with special needs on the website above. Many of these are offered free to children who have a disease like JM.
- **What are your interests?** There are tons of camps designed around a theme, whether it be horseback riding, swimming, baseball or soccer. Make sure you are strong enough to join in these activities, and check with your doctor.
- **Are you unable to be in the sun?** Kadie Maher (see page one) found that it was better for her to pick a camp that had activities inside, so she didn't always have to be putting on sunscreen and covering up. She went to a leadership camp and a writing camp, and found new friends and interests.



Get stronger this summer

Doctors are discovering that exercise makes children with JM get stronger, and it also helps them feel better. No one knows why, but exercise seems to help you control the illness. If you are feeling weak, but would like to stay active, ask your doctor about an exercise program. A good place to begin is with a physical therapist. Once you have an exercise program, you can follow it on your own.

Another way to stay active is to continue to do the things you liked to do before you had JM. You may not be able to run as far or as fast as you used to, but anything you do to stay active will help. Walk as much as you can, ride your bike and swim.



Have fun with silly cover-ups

Tired of putting sunscreen on your arms every time you go outside? Take a look at [sunnysleevez](http://sunnysleevez.com) (www.sunnysleevez.com) for removable sleeves with lots of bugs, butterflies, tie-dye, dinosaurs and more on them.



Word scramble

1. pmac
2. miminwgs
3. armshmlawos
4. otabs
5. enoac
6. seaabbl

1. Camp 2. Swimming 3. Marshmallows 4. Boats 5. Canoe 6. Baseball

Instant fun: Just add water!

This wet and wacky game is as refreshing as a dip in the pool. On a hot day, even if you drop the ball, you're still cool!



What You Need:

- Gallon-size milk jugs (one for each player)
- Tape
- Ribbons
- Water balloons

Instructions:

1. Create the catchers by cutting the bottom off a gallon-size milk jug (one for each player). Be sure to tape the cut edges, and decorate with ribbon.
2. Fill a bunch of water balloons to the size of a grapefruit.
3. See how many times you can toss the balloons without breaking them or how far you can catch and throw them.



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