

Changed forever: Senior talks about college years with myositis

It's been a long journey and a hard one for Lynne Messinger, a college senior who's spent her college years battling polymyositis. But she's learned some things, too - lessons that have nothing to do with arts and sciences. Lynne is beginning her supervised teaching at the middle school level, and she knows a thing or two about pain, courage and compassion. When her struggles began, she was not much older than the students she faces in her practice teaching. "I can't help but think how awful it would be to be 12 or 13 and have to go through this," she said.

It was hard enough for her. One day she was a beautiful, normal teenager at her senior prom; months later, she was weak, in pain and worried about what was wrong. "It was almost a relief when I was diagnosed," Lynne said. "I thought I was going insane, that



Lynne and Donald Duck

it was all in my mind. I was confused, exhausted, completely terrified." All this happened in her first and second years of college. Along with the tests came the needles: "I'd always been afraid of them," Lynne said. "In fact, I still am - but it was something I just had to live through." Lynne had her EMG and biopsy while she was on winter break during her sophomore year.

Once diagnosed, Lynne was treated with prednisone, starting at 60 mgs. "Boy, was I not prepared for that," she said.



Lynne and Scott

Lynne, who'd always been slim without watching what she ate, gained 40 pounds in two weeks. "I ate all the time," she said. "I was so hungry, it hurt. I couldn't imagine not eating; I was that hungry." After two weeks, she looked in the mirror and saw someone she didn't recognize. "My face changed completely, I was covered with zits and I had facial hair. I looked like a fat 13-year-old boy."

Lynne used what energy she had to study: "That was one good thing - since I couldn't go out, I had more time to read. And I quickly learned who my real friends were." The real friends were those who went out of their way to check on her, to let her talk about her illness, to learn how to help her. "Even today, when someone opens a bottle or a can for me without me asking, I just appreciate it so much." Lynne recently wrote a term paper about the kinds of community support she found when struggling with polymyositis.

Her boyfriend amazed her:

"There I was, fat and miserable, hairy and with zits and he continued to tell me I was beautiful," she said. "Of course, I didn't believe him, but it was great for him to try." He told her later that he was confused about how to help her. Other people came out of nowhere when she was sick, then disappeared when she felt better. "What's up with that?" Lynne asked. "It's like they only liked me when I was in rough shape." The response of family members was mixed: "My parents felt guilty, like it was their fault," she said. "But they came through for me again and again." Her little sisters didn't know how to react. One minute they accused her of dodging household chores; the next minute they'd catch a glimpse of her stretch marks (from prednisone) and feel sorry for what she'd been through.

Lynne's much better now, although there are remnants of the disease. She's lost most of the weight and regained some of her strength. She's



Lynne with friends Scott and Katie

recently had a flare and is starting on methotrexate (more needles!). Her skin dries out, especially when she takes hot showers, and her hands are often the rough "mechanic's hands" that are typical of polymyositis. And, she says, she's forever changed inside. "I have more compassion, more understanding,"

Ask the Doctor with Dr. Ann M. Reed

Ann M. Reed, MD, is a pediatric rheumatologist with special interest in juvenile myositis, childhood immune diseases and osteoporosis. She is the head of pediatric rheumatology and associate professor of pediatrics at the Mayo Clinic in Rochester, MN. Dr. Reed is a founding physician member of TMA and serves on TMA's Medical Advisory Board. She participated in the Annual Conference Medical Panel, and her presentation and question-and-answer session will be a part of the treatment issue of *OutLook Extra*, this winter.

We thank Dr. Reed for taking the time to answer these questions commonly asked by families.

Q: Many parents have told us their children have stomach problems when on prednisone. How common is this? How can you treat or prevent this side effect?

A: Prednisone can affect the stomach in a number of ways, including being directly absorbed by the stomach. Doctors often try to prevent this before it happens. They recommend that children eat and drink well in the mornings when taking the prednisone to reduce any irritation the medicine may cause. If stomach problems become worse, doctors can give patients medicines that coat the stomach.

Some patients may experience more problems even after these first steps are taken, but there are more options, including systemic H₂ receptor inhibitors and proton pump inhibitors, both to prevent stomach discomfort.

As with other JM symptoms, this stomach irritation is not seen in a majority of patients, so no prospective studies have looked into this problem and how often it may occur.

In most medical practices, it probably occurs in about 20 to 40 percent of the patients. Some doctors routinely prescribe treatments for children to reduce this side effect.

Q: Is there any new information on effective treatment of calcinosis for JM patients?

A: Finding the answer for treating calcinosis has been a frustrating challenge for families and physicians. Calcinosis tends to be difficult to treat, and no therapy is known to be effective. Since only a small percentage of JM children have calcinosis, there have been no large studies looking at effective treatments.

The most important aspect of treatment is to manage the underlying disease, generally by first using steroids like prednisone. As the disease is controlled, doctors believe patients are less likely to develop calcinosis, which typically occurs one to three years after the onset of JM. (Calcinosis occurs most often over the knee and elbow joints and hip prosthesis.)

Since it is not known what causes calcinosis, it is difficult to determine the best treatment. A recent report shows that using etanercept (Enbrel) to treat children with chronic juvenile dermatomyositis (JDM) improves calcinosis as well as the muscle weakness and other symptoms. Other commonly used therapies include aluminum phosphate and magnesium oxylate. Doctors continue to test out newer treatments like diltiazem (Procardia), probenecid (Benemid or Probalan), and biphosphonates, including alendronate (Fosamax) and etidronate (Didronel or EHDP).

Calcinosis study

Calcinosis specimens which have been surgically removed or biopsied from patients with myositis are need-

ed (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

What is Calcinosis?

Calcinosis (*kal sin OH sis*) occurs more often in childhood dermatomyositis (JDM) than in adult dermatomyositis (DM). These are hard, sometimes painful lumps of calcium under the skin that typically appear on the fingers, hands, elbows and knees. Painful sores can appear if these lumps break the skin. For these sores, vitamins and other supplements may help.

Calcinosis is usually not one of the first signs or symptoms of JM but occurs later in the illness.

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she said. "I don't make fun of people who are different or who struggle. I appreciate friendship and kindness so much more." She hopes someday to use her experience to help the young teenagers she teaches. And she has some advice for young people with myositis: "Keep your chin up. If people are mean, pay them no attention - they're not worth it. You are who you are no matter what you look like or what the disease does."

Lynne, who has an adult form of polymyositis, would be glad to talk to any teens with JM. You can reach her through TMA at tma@myositis.org.

Planning a party: JM families enjoy time together

A major hurdle for any support group, especially for a group so spread out, is to get people together face to face. Shari Hume took on that challenge, and she and husband Tom, whose son Parker has juvenile myositis, hosted a JM Summer Party in California.

They sent out invitations to all TMA JM support group families as well as to social workers at nearby Children's Hospitals. They gave invitations to Parker's doctors and nurses to distribute. (You can also send invitations by email to save money.) They mailed letters to local attractions explaining JM and requesting tickets. Legoland, Six Flags, San Diego Zoo, Universal Studios-Hollywood, and Wild Animal Park all replied by sending complimentary tickets. Each JM patient received two tickets to the park of their choice when they arrived at the party.



Other entertainment included a magician; an arts-and-crafts table for creating unique wooden treasure and jewelry boxes with paint, stickers and beads; and a number of games, including water balloon toss, horseshoes, and beanbag toss.

Winners chose magic kits, travel games, jewelry, and other gifts Shari found at Oriental Trading Company.

"I think that all the kids had lots of fun," says Shari. Over 40 people came, including six JM children, and some traveled up to 200 miles to take part in this special event.

Every family brought a dish to share with the others, and the Humes provided a carnival-size popcorn machine, too. "No one wanted to leave," says Shari. "The party started at 2 and was supposed to end at 5. But some people stayed until 10."

For more information on hosting a similar party, contact Shari Hume at 760-487-1078 or sharihume@cox.net, or Kathryn Spooner at kathryn@myositis.org.

"We all went to the party as strangers," adds Shari. "But by the time it was over, we felt like best friends."

Benefits of exercise in JDM

Exercise has been thought to increase muscle inflammation and even contribute to calcinosis forming, but little research has been done on this.

To study the possible benefits of exercise, researchers at the Institute of Child Health and Great Ormond Street Hospital in London measured muscle inflammation before and after moderate exercise in 20 juvenile dermatomyositis children and 20 healthy children. Of the JDM children, 10 were in active stages of the disease, 10 inactive. Only the test of relaxation time was significantly higher in JDM children versus healthy children.

The researchers conclude there is no evidence that moderate exercise leads to an increase in muscle inflammation. "Other research indicates that muscle damage may be due to hypoxia (oxygen doesn't reach the muscle tissues) and that exercise may have a positive effect especially during the active phase of disease," say the study's authors. They suggest that exercise is an important part of recovering weak muscles. This and other studies recommend different types of exercises (strength, flexibility, and aerobic) to help achieve the best recovery.

Have you visited the Bulletin Board recently? In the Community section, there's a Board just for those dealing with juvenile myositis. Here are some of the posts you'll find:

"As I am beginning another flare after two years I was thinking of the children and the difficulty they must have trying to express themselves and the frustration their parents must endure. How are all the children doing? How about you parents posting on the progress of all of them?" (Franklin/PM)

"Sorry to hear of the struggle for diagnosis. Your son should check out the kids' section under community. Parts of it are still under construction but it will let him know he's not alone. You will find a wealth of information and support from all here." (Jennifer/JM mother)

"My 11-year-old daughter (JDM) has had many stomachaches since starting treatment with high dose steroids and Methotrexate a year ago. They improved after her Zantac was changed to Prilosec. It seems that whenever she is hungry she will get a stomachache. She has less stomach problems when she eats six smaller meals per day instead of three large ones." (Karen/JM mother)

We want to serve you the best we can, but we need your help!

Share your story: Write down your own experiences with juvenile myositis for the upcoming book on juvenile forms of myositis. Find out more in the Juvenile Programs section of www.myositis.org.

Give us your ideas: Tell us what you want to see on the special JM pages of the web site - with separate areas for kids, teens and parents. Share your ideas with us.

Help others: Whether you have a question or just want to check in with others, use the JM Bulletin Board or the email listserv for JM families. Something that may seem trivial to you may be a big comfort to someone else.

Join the e-pal program: Want to email other JM children? Send your email address to kathryn@myositis.org. Tell us your age, when you were diagnosed, and some of your interests or hobbies so we can match you best.

If you have any questions or suggestions, or if you want to be a part of these programs, please email Kathryn Spooner at kathryn@myositis.org. We love to hear from you!



THE MYOSITIS ASSOCIATION

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When I Am Weak, I Am Strong

Mary found out she had juvenile dermatomyositis when she was 5. She sent us her story for the JM book we're publishing. Here is part of her story:

"Most five-year-olds know how to tie their shoes, say the alphabet and maybe even spell their full name," says Mary. "Some have trouble coping with sharing their toys, but how many have to learn to cope with a life-long disease?"

Mary loved to have fun with all of her friends, but started to have trouble running and playing games. Soon, she couldn't tie her shoes or get up off the ground. She went to the doctor, and he told her she had juvenile dermatomyositis. "What in the world is juvenile dermatomyositis?" thought Mary. "What a day that was, being told that I had a disease and I needed to go see a specialist." She was a little scared about going to the specialist, a doctor who knows a lot about juvenile myositis.

"The first thing he did was

explain to me in very simple terms what this disease was," she says. "He explained that my immune system, which was supposed to keep me healthy by fighting germs, was working too hard. My immune system thought I was sick and tried to fight off an infection, but there was no infection for it to fight, so instead it attacked my muscles.

That was why I felt so weak and stiff. The redness on my knees, knuckles, elbows and eyelids was caused by my swelled blood vessels."

She was poked and stuck as doctors and nurses tested her to find out how to help her. She had an IV in her arm to give her medicine

through the needle. But even through this, she kept smiling: "I learned many valuable lessons: crying doesn't make it stop hurting, I was still better off than most of the kids in the hospital, and if I wanted to do something physical, I had to work harder than the other kids and never let myself give up. My life had changed."

Her parents and her doctors have told her to do the things she likes to do. She ran track in

school, coming in last in every race. Her motto is "Last place is better than no place." Then she tried riding horses. She keeps riding horses, and she is on her high school's JV field hockey team. She still takes medicines and wears guards on her hands to rest her fingers and wrists.

She feels lucky to have done the things she loves to do, but she has worked very hard to do them. She has never given up. "In a strange twist," she says. "My muscle 'weakness' has actually made me stronger."

Mary's story is only one of many. We want to hear from every one of you - and also your friends, brothers or sisters, nurses, therapists, teachers, grandparents, or anyone else important to you. Help other children and teens by telling them about when you found out you had JM, what or who helped you the most, or how the different medicines made you feel. If you've gone to summer camp, tell us about that, too.

Visit the juvenile programs section of www.myositis.org or email kathryn@myositis.org for more information about TMA's book on juvenile myositis.



Back to school fashion tips

Back to school means shopping for new pens and pencils, notebooks, backpacks - and clothes.

If you're taking prednisone or other steroids for your myositis, you may have gained some weight. You'll most likely return to your normal size once you start taking less of the medicine and return to being as active as you were. In the meantime, your clothes may not fit quite right. So what can you wear? You don't want to go out and buy a whole new wardrobe. Here's some advice from others who have been there:

Lauren's experience

Lauren, a 12-year-old JM patient, says to dress simply. She avoided form-fitting clothes and bought a larger size than normal. (Don't buy them too big, though, since this can actually make you look bigger.) She didn't buy too many clothes at once since her weight changed pretty quickly.

"I had more luck with cute short skirts than pants that were cut tighter through the thighs," she says. "An over-blouse did not emphasize my bigger tummy as much and was more comfortable." Try dresses with an empire waist rather than a fitted waist, she adds.

The most important thing for everyone, she says, is not to worry what others think. This will just bring you down.

General tips

Many of the same ideas apply to boys and girls alike. Find clothes with materials that have more "give" in them - the denim in jeans won't give as much as khaki pants, for example.

Choose darker colors and patterns that work best for your size and shape - avoid horizontal stripes or busy patterns and colors. A single color can work best so you're not changing the color or pattern at the wrong part of your body.

Buy pants with a flat front rather than pleated. V-neck shirts can make your neck look longer, which can help you look slimmer.

Baseball or wider brimmed hats are important additions, especially if you're taking medicine that increases your sensitivity to the sun.

Have fun with your clothes

You can be creative in what you wear, especially with accessories. Since she was also taking methotrexate, Lauren was highly sensitive to the sun.

She chose hats in different colors and styles to match her flip-flops, which had flowers, beads and other extras. She also kept her fingernails and toenails painted in bright colors with different designs. She had been a dancer when she was younger. "Since I couldn't dance for now," she says, "Mom said my feet could still have fun!"

Satisfy your after-school hunger

Need something to eat when you get home from school?

Healthy snacks can also be tasty snacks, so don't just grab a soda and a bag of chips. Here are some ideas:

■ *Mix dried fruits (raisins, cranberries, and apricots) with cereals and nuts. If you're on a gluten-free diet because of celiac disease, make sure the cereal is gluten-free. Almonds are usually a safe choice for those with celiac, too.*

■ *Put different toppings on rice cakes - peanut butter and bananas or low-fat cheese and salsa.*

■ *Top celery with peanut butter or cream cheese and raisins.*

■ *Grab your favorite flavor of yogurt and stir in granola, fresh or dried fruit, or nuts.*

■ *Dip fresh vegetables, like carrot sticks or celery, in bean dips, salsa or a low-fat vegetable dip.*

■ *Make pizza bagels by heating pizza sauce and cheese on a plain bagel.*

There are lots of healthy choices for snacking. Use your imagination to create new and different snacks each day.

It's important to eat foods that will make you feel better. Learn what foods and ingredients you need to stay away from, especially when you're taking certain medicines. When you're on prednisone, for example, you may need to eat less salt or sugar. If you also have celiac, you can't eat foods with wheat, rye or barley.

Give us your best snack recipes to share with others!