

Keli's story: returning from weakness and pain

Keli Roberts had achieved everything she'd aimed for and more. She left the life of a model and actress in Australia and Europe to become a fitness instructor in this country. Her love of hard physical training and teaching were well received by some of Hollywood's most visible celebrities. Soon she was leading Nicole Kidman, Beverly Johnson, Lauren Hutton and Jennifer Gray in routines designed for strength and agility. Other celebrities, like Cher, Kirsty Alley, Jennifer Jason Lee, Susan Dey and Faye Dunaway, hired her as their personal trainer. She made a video with Cher and its success led to a series of videos on her own. It seemed like nothing could stop her from living the dream she'd had as a young athlete growing up in Australia.

She did notice an increasing array of aches and pains. "It seemed pretty normal, given my profession," Keli recalls. She'd been warned for years that her blood tests indicated a great deal of inflammation but, fueled by ambition, the sheer love of her chosen field and lots of Aleve, she worked through the pain. One day in 1999, she was no longer able to. "In fact, I could hardly move," she said. She agreed to the tests her doctor had been suggesting and, after a biopsy, was diagnosed with polymyositis. Her symptoms were very severe, including trouble breathing as well as moving.



Keli Roberts, DM patient

"By this time, I was working completely for myself," she said. "The thought of having no income was devastating. I didn't know how I was going to get through it." Keli's muscles responded well to prednisone and she dreamed of regaining a normal life. "All my clients except one were understanding and made temporary arrangements until I could heal," she said. Along with improving her strength, prednisone made her dizzy and sick, so she avoided the weight gain. The medication also spun her into a manic episode: "I was in a psych ward for several days," she said. "It may have been a blessing in disguise, as I had struggled with highs and lows all my life." Once released, shaken by all that had happened to her, she forced herself not to worry so much and to concentrate on small things she could do.

"It's amazing how accomplishing one practical thing can make you feel better when you're sick," Keli said. "In my case, finding a roommate, though it didn't solve all my problems, at least made me feel I was moving towards solutions." Keli spent several months recuperating, finding satisfaction in tiny bits of progress. "I moved as much as I could, in a gentle way," she said. A small balcony garden flourished under her attention. "I began to take great joy in my gardening efforts," she said. "At least I was outdoors and

moving a little bit. Even though I was just fussing over a bunch of potted plants, their growth encouraged me."

Keli had already adopted a healthy diet: "I was used to eating fresh fruit and vegetables, lean meat and fish, whole grains and low-fat dairy products," she said, "so I just kept that up." She took a great many warm baths, began exercising under water, and walked, slowly at first, then increasing the distance and speed. Finally, she began riding her bike. "I slowly came back," she said. "It was several months, and I didn't force anything, but I knew I had to make progress."

Keli's stature in her profession was such that she was hired by manufacturers of fitness equipment to train other trainers in the use of new products. This new career focus has sent her all over the world, and she's developed many programs to provide continuing education credits in step training, kickboxing, circuit training, sports conditioning, indoor cycling, dumbbell training, body bar training, core training, rubber resistance training and medicine ball training. She's written manuals on rubber resistance training and teaches people with rheumatoid arthritis and fibromyalgia how to use this type of training to relieve pain and avoid stress on joints and muscles.

She's had to teach herself how to avoid flares. "I still have them," she said. "Each time I make a new kickboxing video, it seems to trigger a flare." Then there's her new sport,

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THE MYOSITIS ASSOCIATION

1233 20th Street, NW, Suite 402
Washington, DC 20036

P: 202-887-0088

P: 800-821-7356

F: 202-466-8940

Email: tma@myositis.org

Web: www.myositis.org

Executive Director: Bob Goldberg

Editors: Theresa Reynolds Curry,
Kathryn Spooner

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TMA advocates for IVIg reimbursement, patient registry

Advocacy is a term often used but little understood. It means being an advocate for your cause and trying to persuade others to your point of view. The crisis that has developed for those needing IVIg therapy to treat myositis and other autoimmune diseases has created a great many advocates as this crisis has worsened over the past 18 months.

TMA, along with other autoimmune disease organizations, is currently having a letter circulated in Congress that would request the Secretary of the U. S. Department of Health and Human Services to declare a public health emergency with regard to IVIg reimbursement through the Medicare and Medicaid programs. This would restore previous rates of reimbursement until there was a determination made as to the impact of the reimbursement changes that took place in 2005 and the effects they have had on the availability and distribution of immune globulin products. TMA has asked its members to urge their Member of Congress to sign onto the IVIg "Dear Colleague" letter. For further information, contact TMA at 1-800-821-7356 or tma@myositis.org.

TMA is also advocating for funding from Congress to provide for a myositis patient registry and surveillance survey. These will help establish a more accurate picture of the number of those who have myositis, their demographics, and treatments being used.

TMA, like many organizations that represent rare diseases, faces the challenge of getting Congress and the public to focus on their disease. Referencing this challenge, Bob Goldberg, TMA's Executive Director, was quoted in *IG Living!*, a new publication for those who use IVIg, saying that the more common and better

represented diseases get a disproportionate share of federal research funding and as for those who have myositis "we just want help for people who desperately need it In the end, it's about justice and fairness."

Through our advocacy efforts and the assistance of persons such as Fabio who can garner media attention, we are working to secure federal funding and create greater awareness of myositis.

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Fabio to speak at Capitol Hill event

On September 21, Myositis Awareness Day, TMA will be hosting an event on Capitol Hill in Washington, DC, to celebrate Myositis Awareness Day and recognize the efforts of those who are working to increase public knowledge and awareness of the myositis at the federal level. A proclamation, introduced in Congress by

See TMA advocates on page 3

ASK THE DOCTOR

Rash differs according to skin color

TMA often hears from people wanting to know why their rash doesn't look like the photos in the doctor's office or the rash of another dermatomyositis patient in their support group. Some members have told us they didn't even know they had a rash until their doctor found it. Often, these are patients with darker skin pigments that make the rash less visible. We asked Dr. Richard Sontheimer, dermatologist, TMA medical advisor and professor at the University of Oklahoma, what the typical rash would look like on an African-American DM patient.

DR. SONTHEIMER:

This seemingly straightforward question has a complex answer. First of all, the rash of dermatomyositis results from changes that come from damage to the tiny blood vessels in the underlying dermal layer of the skin. An example of these blood vessel changes can be seen in individuals having a light complexion by observing the small blood vessel abnormalities that are often visible to the naked eye in the nailfold skin immediately surrounding the fingernails. The skin color caused by the degree of ethnically or racially determined melanin pigment obviously affects the visibility of the blood vessel changes in other areas of skin commonly affected by dermatomyositis.

The degree of darkness of normal healthy skin is due to the amount and distribution of melanin pigment in the overlying epidermal layer of the skin. In individuals having racially- or ethnically- determined lightly pigmented skin, the rash of the dermatomyositis resulting from blood vessel changes in the underlying dermis appears as a

red-purple or lilac color similar to that of the red-purple heliotrope flower (a dermatomyositis rash affecting the eyelids is often referred to as the "heliotrope rash").

In individuals having racially or ethnically determined more heavily pigmented skin such as Blacks/African Americans and Hispanics/Latinos, the red-purple skin

color of dermatomyositis skin inflammation can be absent altogether or difficult to see by both the patient and the doctor. This occurs as a result of the masking effect on red color produced by blood vessel changes in the underlying dermis by the higher level of brown

melanin pigment in the overlying epidermis. When visible, the color change of dermatomyositis in more darkly pigmented individuals is often perceived as a dull red or red-brown color.

Skin rash in an Hispanic woman: a case study

In the October 2005 edition of *The Journal of Family Practice*, Jamie Goodall, MS, and Richard P. Usatine, MD, of the Health Science Center at San Antonio, describe a 48-year-old Hispanic woman who came to their clinic as a new patient with a rash that appeared on her face three months before and had recently spread to her chest and hands. It itched occasionally and seemed to worsen after exposure to the sun. The woman also had been feeling very weak, with difficulty brushing her hair, rising from a seated position and climbing up stairs, and was diagnosed with dermatomyositis. The authors publish photographs of the rash as it

appears on the face, chest and hands of the Hispanic woman, available free of charge at www.jfponline.com.

Sun intensity influences disease type

Dermatomyositis is more common in latitudes with high UV intensity. A study led by TMA Medical Advisor Fred Miller, MD, PhD, analyzed clinical data and, where possible, blood samples from 919 DM and PM patients. Statistical analyses of weather and patient data spanning more than 10 years revealed a very strong positive correlation between UV intensity and the proportion of DM patients at a given referral center. In fact, the results reveal the strongest correlation ever shown between UV light and any human disease. Among the 15 locales studied, the lowest proportion of myositis patients with DM was found in Glasgow, Scotland (26.7%), and the highest was found in Guatemala City (83.3%).

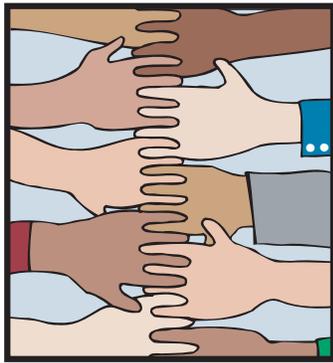


TMA advocates,

continued from page 2

Representative Steve Israel, to declare September 21 National Myositis Awareness Day is expected to be passed this summer. The Capitol Hill event will honor those in Congress who have assisted with this proclamation and the other TMA legislative efforts focused on IVIg reimbursement and increased funding for research related to myositis. Fabio, renowned male model and actor, will be speaking on this occasion to thank those who are helping and to encourage the media to provide more coverage of rare diseases such as myositis.

Further information about this event will be available in August.



How does your doctor diagnose inflammatory myopathy?

By Lawrence H. Phillips, II, MD
T.R. Johns Professor and Vice-Chair
of Neurology, University of Virginia

If you have read any of the Sherlock Holmes mysteries, you have had a glimpse into the way physicians make diagnoses. Dr. Watson, the narrator of the stories, often expresses awe at the seeming brilliance of Holmes' observations, but the great detective explains frequently that his conclusions are based on simple observations and deductive reasoning.

Medical diagnoses are made by this same process, and it is no coincidence that Sherlock Holmes employed this method. Sir Arthur Conan Doyle, Holmes' creator, was a physician, and he modeled the detective's character after that of one of his medical school professors who was noted for his ability to make brilliant diagnoses based on simple observations in his patients.

Physicians who care for patients with myositis use the process of deductive reasoning to arrive at their diagnoses as well.

Although very few of us are as consistently brilliant as Sherlock Holmes, the process of making a diagnosis most often begins with the collection of clues from the history of the illness and observations from the physical examination. Although our muscles make up a substantial part of our body mass, there are only a limited number of ways in which they can produce symptoms when they malfunction. The neuromuscular physi-

cian is trained to recognize the signs and symptoms of muscle malfunction.

The main symptom of muscle disease is, of course, weakness. In patients with myositis, we have learned that not all muscles in the body are affected equally. For example, certain groups of muscles, such as the ones that we use to bend our fingers to make a fist, seem to be disproportionately weak in inclusion-body myositis (IBM). Observation of weakness in finger flexor muscles is thus an important clue to the possibility that a patient may have IBM. The neuromuscular physician assembles such observations ("findings" in medical speak, "clues" in

Holmes' terms) to make a tentative preliminary diagnosis.

Once the preliminary diagnosis is made, a search for supporting evidence

begins.

Such evidence can come from the results of a number of tests. Blood tests, in particular "muscle enzymes," provide important clues. The muscle enzymes consist of proteins that exist in high concentrations in muscles. The main one is creatine kinase, or CK. When muscle is damaged or degenerates, muscles leak CK into the blood stream. In someone with myositis, the CK level in the blood may be elevated, thus when an elevated CK level is

found, it is an important clue that something is wrong with muscle. A number of other blood tests may be done to determine whether or not other diseases that may produce secondary damage to muscles are present.

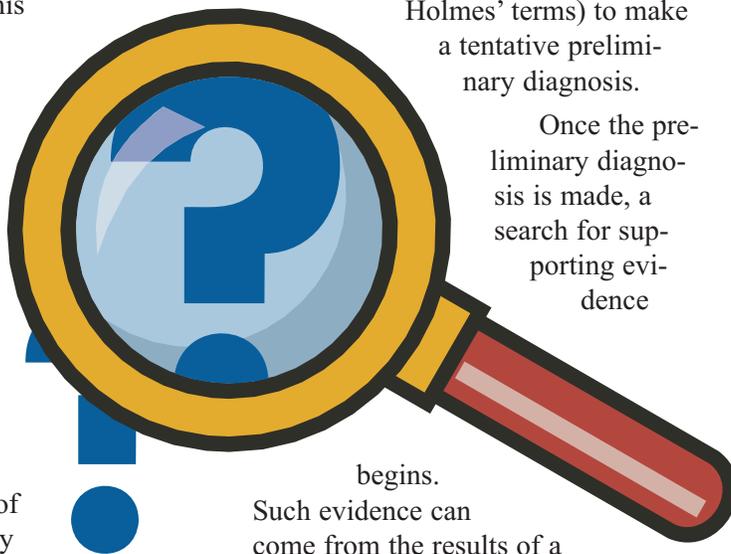
Although few remember it fondly, the electromyogram (EMG) study can provide par-

ticularly helpful information. This study consists of two parts. The first is the nerve conduction study (NCS), where recordings are made from nerves and muscles while small electrical shocks are applied to various points along a nerve. The NCS is then followed by the EMG study, where a fine needle electrode is inserted into various muscles. Those who have had this test (myself included) will recall hearing a sound like static on a radio receiver during this test. There are patterns of electrical abnormalities in nerves and muscles that can indicate the presence of an inflammatory disease, and the physician who does the test is trained to interpret them.

In recent years, physicians have learned that the appearance of the muscles on magnetic resonance imaging (MRI) scans of a limb can provide evidence about muscle disease. Increasingly, neuromuscular physicians are performing MRI scans on patients who are suspected to have myositis. This study, too, can provide evidence about selective involvement of muscles.

Ultimately, a biopsy of one of the muscles is usually needed to make a confident diagnosis. The information obtained from physical examination, blood tests, EMG, and MRI scans can suggest that the most likely diagnosis

If you have read any of the Sherlock Holmes mysteries, you have had a glimpse into the way physicians make diagnoses.



is a muscle disease, but there are other diseases of the nervous system that might produce similar abnormalities. Since decisions about treatment hinge on having an accurate diagnosis, the neuromuscular physician will usually feel most confident when the evidence from a muscle biopsy is available.

Although the biopsy procedure requires removal of a piece of muscle, it is really a rather minimal procedure. A small piece of muscle is obtained by one of two methods. The most common one is done through a small incision (usually an inch or so) in the skin over a muscle in the arm or leg. This is done through a patch of skin that has been numbed by local anesthetic, so there is little or no discomfort. As an alternative to the "open" procedure, some physicians will use a needle to obtain muscle tissue. This has the advantage of only requiring a small nick in the skin, but the disadvantage is that the amount of muscle obtained is sometimes insuffi-

cient to allow a confident diagnosis.

However the muscle sample is obtained, it is examined by a physician who has special training in interpretation of muscle biopsies. The muscle sample must be processed and stained with various chemical compounds before it can be interpreted under the microscope. The processing can take a week or more, so the final diagnosis from a muscle biopsy can be delayed. Occasionally, the information obtained on the biopsy is inconclusive, and a second biopsy is sometimes necessary.

The neuromuscular physician will make the most accurate diagnosis possible based on information from all of the sources described above. The process I have described is used by neuromuscular physicians to make diagnoses in other muscle diseases as well, but it is particularly important in the evaluation of a patient who may have some form of myositis.



Keli's story, continued from cover

something she truly loves, competitive cycling. "When I get myself in shape for the season, it seems I can do it as long as I build myself up very gradually," she said. "I am very, very careful." Keli does cyclocross, a combination of running, jumping and biking, won the California-Nevada state championship for women over 40, and competes at the national level. This sport, which is held in the rain, mud and snow, satisfies her competitive spirit as well as her desire to keep learning about herself. She finds the challenges of the rugged courses entertaining and fun. "I may not pace myself on the course, but I do afterwards," she said. "I make sure I get plenty of rest."

Keli Roberts will be at the Annual Conference in Orlando. For more about Keli's work, visit her web site at www.keliroberts.com.



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Gardens are therapy for mind and body

There's a story about a young Tibetan student complaining to his Buddhist teacher. No matter how he tried, the young man couldn't focus his thoughts enough to find the mix of concentration and detachment necessary for meditation. "Forget sitting on the floor and chanting," the older monk said: "Tend a garden."

That's good advice for everyone. Attention to minute detail, working with nature, and seeing tangible results from physical labor is a combination that frees the mind and lifts the spirit now just as it has for centuries. When space, energy, or physical limitations interfere with traditional gardening, experts suggest container gardening, an occupation that Keli Roberts (see page 1) found soothing as well as just enough movement to keep her flexible during a flare.

"July is a great time to start a container garden," says Andre Viette, host of the popular radio show, "In the Garden." "People worry about the heat – but many of our annuals and vegetables originally came from places that are extremely hot. You just have to make sure your plants get enough water, which is much easier to do if they are in containers."

With new varieties of plants available at nurseries, gardening has become an all-season hobby, said Meg Shelton of Shelton Herb Farm in North Carolina. She has ideas for carrying your fall garden over through the winter. She encourages people to grow their own supply of fresh salad greens for cutting all winter and well into spring. The trick is knowing what to plant, Shelton said. She chooses a lightweight bowl-style plastic pot to plant in early winter, keeping the containers small enough so they're easily moved if the temperature plummets into the 20s. At her home near Wilmington, she simply sets the bowls under a table or hides them from the frost beneath a sheet. Where

it gets a little colder, she advises moving the bowls to a porch if you expect a night in the mid-20s.

Stori Snyder, assistant director of the Hilltop Garden and Nature Center at Indiana University Bloomington, gives us some guidelines for getting started.

■ **Prepare the containers:** Punch holes at the bottom for drainage and put in some rocks for the plant roots to wrap around. "The roots don't want to have wet feet, so to speak," Snyder said. Containers should be at least one size larger than the purchased pot size.

■ **Feed the soil:** Grow more plants in a small space by enriching your soil with manure, compost or humus. Buy a kit to test the composition of the soil to see if it needs more nitrogen, phosphorus or potassium, which are important nutrients for plants. Snyder said it's practically "a given" that soil will

need compost or manure after subsequent plantings because plants always remove nitrogen from dirt. One way to improve the soil is to add a scoop of compost to the hole where you cover a plant. Feed the plants again at least once during the growing season with a sprinkling of compost or compost tea, which is compost steeped in water.

■ **Buy local:** Consider planting native varieties because they handle your region's climate better. Local nurseries and county extension services can offer guidance. Some herbs, such as mints, sage and thyme, are hardier than others and grow back in the spring.

"Native varieties won't be as stressed and will require a little less maintenance," Snyder said.

■ **Reap an edible harvest:** A tomato plant can grow well in a 5-gallon bucket. They come in many varieties, although compact varieties grow better in containers and require less staking. Snyder said cherry and pear tomatoes look delightful in hanging baskets. Tomatoes mature at different rates, so gardeners might want to select varieties that ripen at different times or varieties that are indeterminate, which means they ripen repeatedly until it becomes too cold.

■ **Choose companions:** Snyder said gardeners should consider researching "companion plants," which grow well together because one plant provides the soil with a nutrient the other plant needs and vice versa. Carrots and tomatoes are companion plants, Snyder said, as are roses and garlic. Basil and tomatoes are a dynamic duo with considerable aesthetic appeal. Snyder noted that "they smell fantastic" and the variety of colors is interesting – yellow tomatoes and purple basil, for example.

■ **Grow your own seasoning:** Herbs are good for container gardening because compact herbs, such as rosemary, lavender and thyme, can grow in small spaces. Sage needs a lot of space and should be in a container by itself. Mints, including lemon balm, are invasive and should be planted in the ground or in their own container.

■ **Get blooms from your bulbs:** Bulbs planted in containers should be brought inside after the green leaves die back and the nutrients



are stored in the bulb. They should be dried and stored in a cool place until next spring. Spring-blooming bulbs planted in yards should be planted in the fall, while bulbs that bloom in the summer can be planted in the spring.

- **Cultivate some climbers:** Vines, clematis and morning glories make interesting container plantings and require trellises or something else to climb.

Whatever you plant, you'll need to be aware of the plant's requirements. Plants in containers need to be watered daily during much of the summer. Watering during the middle of the day should be avoided, but whether watering in the morning or evening is better is much debated. Watering in the evening will avoid scorching the leaves, while watering in the morning will avoid potential growth of unwanted fungus on damp leaves, said Snyder, who chooses morning waterings.

People recently disabled who have never gardened can find a new and rewarding hobby, says Diane Relf, PhD, HTM, veteran Horticulture professor at Virginia Tech. And with some modifications, gardeners who have lost physical ability can continue this valuable activity. Planters, pots and raised beds make gardening easier for disabled and elderly gardeners. Relf says she's been a consultant to gardeners who work in a small backyard, a third floor apartment patio, on top of a hospital, and on the grounds of a retirement home.

She believes the garden area should be as small as possible, so the fun of gardening doesn't change to drudgery. All of the raised beds or planters should be easily accessible and arranged in a fashion to fit together as an attractive landscape unit. "Avoid the tendency to line up little garden plots in rows," she says. She suggests some dimensions for planning placement of heavy pots or raised beds:

	Wheelchair	Semi-Ambulatory	Ground
<i>Height</i>	2-2.5 feet	2.5-3 feet	.5-1 feet
<i>Width (one-sided)</i>	2 feet	2 feet	2 feet
<i>Width (two-sided)</i>	3-4 feet	4 feet	4 feet
<i>Diameter (circle)</i>	3-4 feet	4 feet	4 feet

Raised beds are generally 3-4 feet wide and as long as the landscape design allows, but depending on your strength and endurance, Relf recommends limiting the length of the bed to 10 or 20 feet. There's a wide choice of plants that can be used in planters, Relf said. Planters can be built to be mobile to adjust to available sun or move out of the way.

Your containers will need full sun, or at least six hours of sun a day. That requirement goes up to 8-10 hours of sun if you're growing vegetables. If full sun is not available, choose shade-tolerant plants such as begonias and impatiens. A water source should be nearby and the hose should be light and accessible. It may be worth the investment to install automatic or trickle irrigation systems in permanent planters. Attachments that are an advantage for any gardener are an on/off valve at the hose end, extension nozzles, water breakers, and easy-to-use lever-controlled water faucets.

Try mulching in larger raised planters to slow the evaporation of water from the bed, discourage weeds, and keep the soil cool for the roots. Weed-free organic material is the best mulching because it enriches the soil as it decays, Relf said. Most pest control should be done by hand and without chemicals to avoid the danger presented by working with toxic substances. Relf suggests hand-picking pests and quickly removing any parts of plants that seem to be disfigured to prevent the spread of disease.

With a little ingenuity, many TMA members stay in the garden and find it gives them much comfort. To find their suggestions, check out TMA's

"Products Extras" in the "My TMA" section of www.myositis.org.

Fall planting

Late summer is a perfect time to try out some annuals in your new containers. Because you can control the shade and water conditions of your planters better than you can in your landscape border, you can benefit from lower prices on the droopy, leggy plants now on sale at nurseries. Stock up on reduced-price annuals and perennials, giving them a little extra care in planters, and then making the decision whether they will thrive under regular garden conditions.

Everyone wants to plant in the spring, when nurseries are bulging with fresh annuals and perennials. But in many places, fall is the longest, most benign season for flower planting. Much of the country won't have a frost until October, so even tender annuals like marigolds will have many weeks of peak beauty. And perennials put in the ground in the fall will be the size of second-year plants next growing season. Another plus: growing fall flowers will add to the landscaping that shows off the spectacular color of hardwood trees and fall decorations, like pumpkins and cornstalks.

Make sure to check the overcrowded roots of your bargain flowers for insects and damage, plant carefully in well-drained rich soil in a clean container, and monitor very carefully for the next couple of weeks, trimming, watering and examining for bugs. By mid-August, you'll have a spectacular display, ready to admire in their container or to transplant to a permanent home.



New edition of Living with Myositis on sale

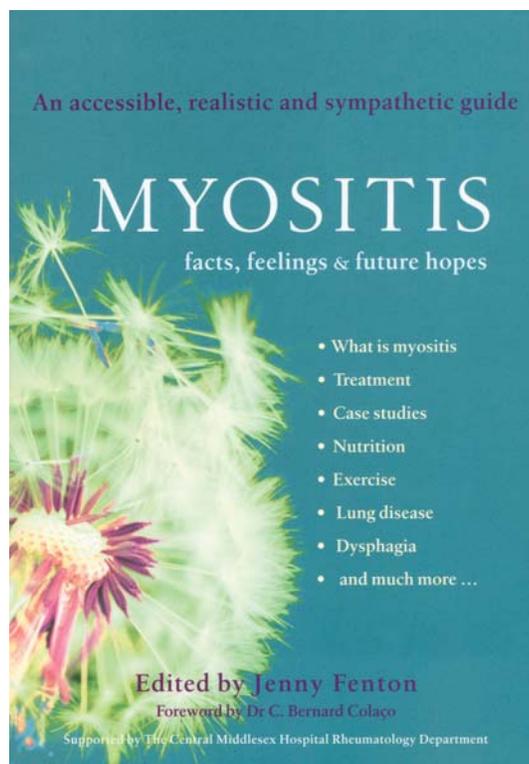
“Living with Myositis” by Jenny Fenton has been reprinted and updated, with many new chapters and case studies added. The new book is called “Myositis: *facts feelings and future hopes.*” All the case studies tell the reader how the real people with myositis introduced in Fenton’s first book are managing three years since we first met them in her original book

The book includes chapters on diagnosis, treatment, nutrition, exercise, occupational therapy, feelings, coping, dysphagia, lung disease and many others, all written by experts in their fields. Many new chapters, also professionally written, have been added, including: *The Genetics of*

Myositis, Myositis in Children, Remission Case Studies, Coping with Relationships, Stress, Holidays, and A Laboratory Perspective when Diagnosing Myositis.

Support for the book comes from The Central Middlesex Hospital Rheumatology Department and the *Foreword* was written by consultant rheumatologist Dr C. Bernard Colaco.

Jenny was diagnosed with dermatomyositis in 1998. After six years of treatment with steroids she is now drug free and in remission.



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