

Lupus: Why Doctors Often Miss It

BY JAN YAGER

When Sallie Sperling's first son was born 23 years ago, she found little of the joy she had expected. Hit by incapacitating fatigue, she wasn't even able to take care of him at times.

"I was a basket case for six months," she says. Her doctor's comment? "You're a new mother. What do you expect?"

Sallie tried to persuade herself that he was right. But her strange bouts of fatigue continued, so she consulted other physicians too. One said she had low blood sugar and put her on the then-fashionable diet for it. Another suggested removing her gallbladder, a recommendation she refused.

After about a year and a half, her symptoms gradually disappeared. Sallie became the mother of two more sons, experiencing none of the problems she'd had before. All was fine—until five years ago. Two weeks before leaving with her husband on a six-week bicycle trip through Europe, Sallie caught the flu—or so she thought. She felt better by the time she left, then nearly collapsed at Heathrow Airport. "I slept for thirty-six hours. We thought it was jet lag." Two weeks later, cycling through Scotland, she couldn't go on. The Sperlings rushed home.

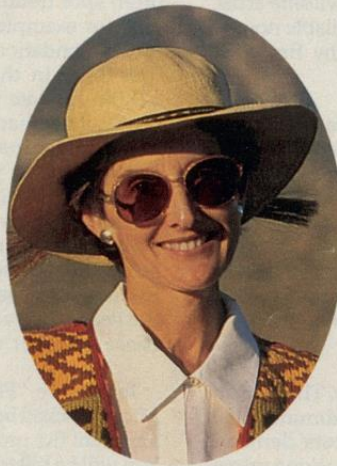
Flu was quickly ruled out, but her doctors had no idea what else might be wrong. By then, she had a wide range of symptoms: rashes, terrible arthritis-type aches, chest pains. She temporarily lost her sight and—most frightening of all to her—couldn't think straight.

"It was not a good year," she says in a tone of obvious understatement. "Such an incredible amount of worry. We were constantly trying to hide our fears from the children. My husband became so protective of me that I finally blew up, very gently, and said, 'Whatever I can do for myself, you've got to let me do.'"

"You're just stressed out."

"It's all in your head."

Women with lupus know they're sick, but doctors don't always believe them.



Sun is a no-no. Lupus patient Sallie Sperling always wears a hat and sunblock.

One day, Sallie read an article about Lyme disease and noticed that she had many of the symptoms listed. Excited, she consulted an expert on the disease. As she learned, she had the wrong disease but the right doctor. After a number of tests, he gave her the news: lupus. Eighteen years and umpteen doctors later, Sallie Sperling had finally been correctly diagnosed.

This Strange Disease

Half a million Americans—the vast majority of them women—have a systemic lupus erythematosus, as lupus is commonly known. The immune system goes haywire, producing large numbers of antibodies that attack cells and tissues. In turn, this can injure or inflame

just about any part of the body: the skin, joints, kidneys, lungs, blood, central nervous system, tissue linings and other organs.

The disease usually shows up between the ages of 15 and 45. Symptoms come and go, and flare-ups are typically followed by periods of remission that can last for years. Cases can be mild, as Sallie's eventually proved to be, or life-threatening.

Diagnosis today is better than ever, cutting the once-high death rate by allowing treatment before significant damage is done. But many women still must go from doctor to doctor before finding out what's wrong with them.

A big problem is that there's no simple test. Though a couple of blood tests can be very helpful in making the diagnosis, doctors still must suspect lupus to order them. And because symptoms usually are vague and variable, doctors frequently are thrown off the track.

The only definitive sign is a butterfly rash, so named because of the shape it forms across the nose and cheeks of some women. Other symptoms can include fatigue, joint pains, fever, weight loss, poor appetite, anemia, mouth sores, sensitivity to sunlight, nausea and chest pains, among others.

Many of these problems easily can be attributed to other problems. Anemia, for example, can seem to be the result of heavy periods. Nausea can be chalked up to a nervous stomach.

Very frequently, a woman is told either that her symptoms are all in her head or that she is suffering from stress or some other emotional ailment. Marie McDonald, 43, of Bridgeport, Connecticut, actually was told that getting married would cure her.

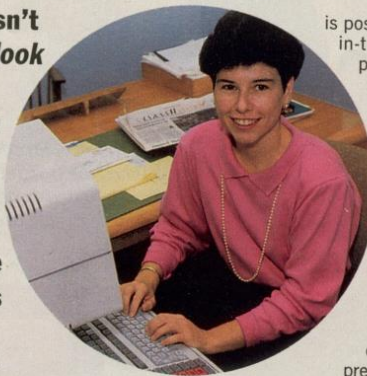
Fighting Lupus

If you suspect you have lupus, consult either your family physician or an ar-

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Lupus
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Lupus doesn't make you look sick, even though you are. "You pray for a symptom that can be seen," says newspaper copy editor Vicki Croke.



thritus specialist. (Because almost all patients have joint pains, these doctors tend to be the best informed about lupus.) The physician should rule out other possibilities for your symptoms and give you an ANA blood test, says noted lupus researcher Dr. Peter Schur, professor of medicine at Harvard University. A negative result means you almost certainly don't have lupus, he says. But if the test

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is positive, there's a one-in-three chance of lupus, and you should have further, more sophisticated testing.

Treatment depends on the extent of the disease and the specific problems it is causing. When major organs such as the kidneys are being attacked, doctors generally prescribe very powerful corticosteroids. For fever, aspirin may be all that's necessary; for joint pains, a non-steroidal anti-inflammatory such as Naprosyn often is used.

Sallie Sperling was relatively lucky: She didn't need steroids, which often cause debilitating side effects. For two years she took an anti-inflammatory drug to combat joint pains; since going into remission three years ago, she's been medication-free.

Flare-ups can't always be prevented,

but making certain lifestyle changes can be helpful. Absolutely critical is to stay out of the sun. Lupus patients don't go out without a hat and religiously put on sunscreen with an SPF of 15 or greater. (In a different, very mild form of the disease called discoid lupus, which causes only skin rashes, these precautions are the only treatment required.)

Another necessity: getting enough rest. Early on, Sallie says, she had a real problem with that. "The moment I felt OK, I exhausted myself doing a million things. So then I would relapse. I had to pace myself. The fatigue lupus patients feel is a deep, interior exhaustion that is hard to describe. Now, the moment I feel it coming on, I just stop."

Lupus patients also are advised to eat nutritiously, exercise regularly, drink moderately and not smoke. As Vicki Croke, 32, of Cambridge, Massachusetts, puts it: "I do the things everyone should do, except that I'm stricter."

Adapting to Lupus

The changes lupus makes in most people's lives go beyond health ones. Sometimes there are work problems. Employers aren't always sympathetic about an illness that comes and goes. Someone

with a severe case, like Marie McDonald, may find herself unable to work at all, even though she used to routinely put in 12- to 14-hour days.

In addition, people often misunderstand the illness. Marie once was cruelly asked if she had AIDS, a vastly different disease of the immune system. (Lupus is not contagious.) And if a person doesn't look sick, as is often the case, people have a hard time believing she is. "Is she really that tired, or is she just making excuses?" they wonder.

"You pray for a symptom that can be seen," explains Vicki. "Once I had a stomachache on Monday and a headache on Tuesday. My parents were very supportive, but I knew they were thinking that I just didn't want to go to school. So when I woke up the next day with a swollen eye, I thought, Ah ha! Now they have to believe me."

The changes lupus brings can be for the better, however. Vicki, in remission for 16 years, credits lupus with her burning desire to lead an extraordinary life. A copy editor for the *Boston Globe*, she has reported in Moscow, gone skydiving and just recently returned from an expedition to northern Canada to see polar bears.

Says Sallie: "After watching two friends who were my age die of lupus, I began to realize that I might not live to

see my kids grow up. So I took a hard look at my life, and we made changes." The Sperlings moved to Tucson from Connecticut. They took the children to Europe. Sallie dropped all notions of being a superwoman. Out went old friends who wanted to talk about "me, me, me"; in came new ones who give as well as take.

"It's a paradox, but it has been very rewarding," she says. "I've learned

things that would have taken me years and years to figure out if I'd been healthy. For now, lupus seems to have receded into the shadows. But if I get it again, I think I will cope better." **WD**

Dr. Jan Yager, Ph.D., is a sociologist and author of 11 books, including Business Protocol: How to Survive and Succeed in Business (Wiley, 1991).

FOR MORE INFORMATION

Support groups for lupus patients are available in many communities. Check with your doctor, local hospital or other community health agency to find out about them. The following organizations can provide a variety of information about lupus. Enclose a self-addressed, stamped business-size envelope.

Lupus Research

National Institutes of Health (NIH)
National Institute of Arthritis and
Musculoskeletal & Skin Diseases
(NIAMS)
Box AMS
Bethesda, MD 20892

The American Lupus Society

3914 Del Amo Boulevard
Suite 992
Torrance, CA 90503
800-331-1802

Lupus Network

230 Ranch Drive
Bridgeport, CT 06606
203-372-5795
(Needs \$.45 postage on SASE)

The Lupus Foundation of America, Inc.

1717 Massachusetts Avenue, N.W.
Suite 203
Washington, DC 20036
800-558-0121