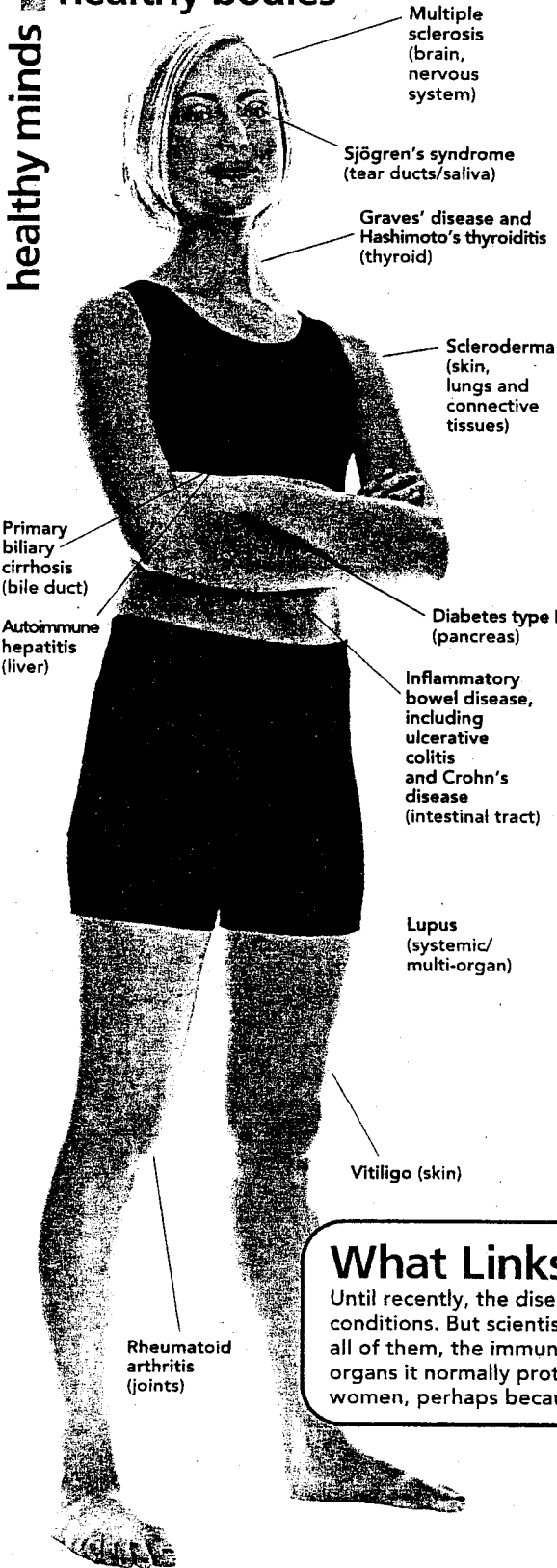


healthy minds ■ healthy bodies



Autoimmune disorders, which strike about three times as many women as men, have common symptoms. That may be the key to treating them.

When The Body Attacks Itself

IN THE SUMMER OF 2002, CORINNA Vigil, 21, of Denver lay dying. Six years before, she had been diagnosed with systemic lupus erythematosus, a disease in which misguided immune cells attack the body's DNA. At age 18, her kidneys failed. Medications damaged her heart. A rare complication gouged huge gaping sores into her legs. "I didn't want to go on living, because it hurt so bad," she says. "My family and I were planning my funeral."

Today, Corinna describes herself as "a walking miracle." Her wounds are healed, her energy is restored and her lupus is in complete remission. The experimental treatment that saved her life—a stem-cell transplant at Northwestern Memorial Hospital in Chicago in September 2002—represents one of several advances that are offering new hope to the 14 million to 22 million Americans, mostly women, with autoimmune disorders.

"We are thinking outside the boundaries," says Dr. John Varga, a rheumatologist at the University of Illinois in Chicago. "Rather than seeing the 80 autoimmune disorders as separate diseases, we've

really protects. One individual may be susceptible to various autoimmune disorders. Similarly, therapies developed for one of those diseases, including new "biological" agents made from living cells, may make other diseases easier to manage—and perhaps overcome.

For the first time, medical science may be able to offer patients such as Corinna Vigil the possibility of a cure. The complex, risky procedure she underwent still is considered experimental, says Dr. Richard Burt, an immunologist at Northwestern who has performed more stem-cell transplants than anyone in the world. "We reset the immune response, like rebooting a computer," he explains. "We give enough chemotherapy to knock down the malfunctioning immune system and then regenerate it, like a newborn baby's, with stem cells extracted from the patient's own bone marrow or from a donor's." He reports "dramatic" results in his 80 stem-cell recipients.

By Dianne Hales

What Links These Illnesses?

Until recently, the diseases at left were treated as separate conditions. But scientists have come to see them as related. In all of them, the immune system attacks the cells, tissues or organs it normally protects. Most also are predominant among women, perhaps because of the effects of female hormones.

realized that they are similar in many ways." These illnesses, which rank among the top 10 killers and top four disablers of women under 65, result from a common biological "error": The immune system declares war on the cells, tissues or organs it nor-

Finding Therapies That Work

The risks and benefits of stem-cell transplants for lupus and other autoimmune disorders—including rheumatoid arthritis, multiple sclerosis, scleroderma and myasthenia gravis—are being evaluated in studies in the U.S. and Europe. But because of potentially fatal complications, this therapy is generally reserved for life-or-death cases when all other treatments fail.

Autoimmune disorders strike about three times as many women as men, possibly because of the effects of female hormones on the immune system. Women are most vulnerable in the prime of life, during their reproductive years.

A month after her wedding in 1977 at 22, Susan Caritey of Pittsfield, Mass., was diagnosed with rheumatoid arthritis, which inflames the lining of

Photos for PARADE by Jeffrey Murnaghan (Vigil, El Qubus (Caritey) and Allison Leach) (Blackstone), Blackstone's hair and makeup by Tomasz Kruski and styling by Elyse Lenkin. Book for Mark Edward Inc. Prints and heady by Allen Allen and top by Sutton Studio, hair at Blackstone.

the joints. "My hands, wrists and feet would swell and ache so much that I couldn't button a blouse. I took 18 aspirins a day until I developed ringing in my ears." Caritey, who has two children (now ages 18 and 23), says she struggled "to give my kids as normal a mother as I could." As her disease progressed, she says, "I had to calculate whether I'd be able to walk across a parking lot." Cortisone injections into inflamed joints provided only temporary relief.

In 2000, Caritey enrolled in a clinical trial of a promising new therapy: Humira, a molecular "smart bomb" called a monoclonal antibody, which blocks inflammation. Within 18 hours of her first injection, she felt a difference. Three years later, with biweekly injections, she works as a labor-and-delivery nurse and goes hiking. "There's no inflammation and no pain," declares Caritey, now 48. "This medication has given me back the life I'd lost 25 years ago."

Humira, which won FDA approval earlier this year, is the latest in a new group of treatments that target specific proteins involved in inflammation, reducing pain and swelling and helping to prevent further damage. "They've revolutionized the way we treat rheumatoid arthritis," says Dr. Jill P. Buyon, a lupus specialist at New York University and co-author of *The Autoimmune Connection*. "The impact is unbelievable. Patients can go back to work, take care of their kids. Given early enough, these medications may actually stop the disease process in its tracks."

Unexpectedly, medicines developed for one autoimmune disorder have proved effective in treating others. And the pace of discoveries is accelerating.



Corinna Vigil with nurse Cathy Jones at Kaiser Permanente Skyline clinic in Denver, where she goes for post-transplant treatment. Her lupus is in complete remission.

Unexpectedly, some biologicals developed for one autoimmune disorder have proved effective in treating others. Enbrel, another rheumatoid arthritis biological, is now used to treat Crohn's disease (which affects the bowel) and vasculitis (which attacks blood vessels). Remicade, initially approved for Crohn's, helps treat

rheumatoid arthritis. In trials, Antegren, the first in a new class of biologicals called SAM (selective adhesion molecule) inhibitors, has reduced relapses and improved the quality of life for patients with MS and Crohn's.

"Every therapy that helps in one disease sheds light on another," says Dr. Joseph Craft, an immunologist at Yale University and a medical adviser to the Alliance for Lupus Research. "The good news for patients is that the pace of discoveries is accelerating, and so is the pace of applying these discoveries at the bedside."

Getting An Accurate Diagnosis

For many with autoimmune disorders, the biggest challenge is finding out what's wrong. "If you had to pick one feature of these diseases that stands above the crowd, it's patient frustration," says Dr. Buyon. Early symptoms, such as low-grade fever or achiness, often wax and wane and are dismissed or misdiagnosed by doctors. Half of the people with lupus consult three or more doctors over four or more years before getting an accurate diagnosis.

"It took 14 months to find out what was wrong," says Michelle Mayer, 34, a health-care researcher at the University of North Carolina. Seven years ago, Mayer's hands became red and swollen. Doctors concluded that the problem was Raynaud's syndrome, an extreme sensitivity to cold. More than a year passed

continued

Living Well With A Chronic Illness

By Margaret Blackstone

have multiple sclerosis. You may also have MS, or you may be coping with another autoimmune condition. One thing we will have in common is the disorientation we feel while doctors are trying to make the right diagnosis. For most of us, the process is a slow one. It may take months, even years, to be diagnosed correctly. During this time, we need to ask questions, but the questions often have no direct answers and may even be impossible to formulate adequately at first.

If you are going through this frustrating period now, the best things you can do for yourself are to rely on those you trust, get plenty of rest and keep yourself occupied with positive activities, including meditation or other means of relaxation that allow you to keep your mind free of fear or panic.

After You're Diagnosed

Try to think of this as a door being opened, not closed. Of course, you'll



"The only real invalid is the person who thinks she or he is one," says the author.

have periods of grief for the "old you," but sad is not bad. Sad is what you go through as you grieve that some things in your life will change, and you may not have a lot of control over how they change. For your sake and your health's sake, try to approach this new chapter in life as a challenge, not as a defeat.

Sharing Your "News"

Tell who you need to tell, but don't tell everyone.

After I had endured a long diagnostic process and calmed myself down, I wondered whom to tell and when to tell them. It is not as simple as saying, "Tell your family first." You need to tell your spouse or partner and very close friends for unwavering support. If your children are young, tell them the facts calmly and simply. If they are older, share information during the diagnostic process, because they'll know that something is up.

As for your job, choose what you want to say and when. Above all, if you suspect that there will be repercussions at work, remember: You are not legally bound to tell your boss.

Getting The Best Care

Whatever your treatment regimen, it helps immeasurably if you put together a helpful health-care team. I have found that working together with my internist and my MS specialist has vastly improved my care and cut down on the

time I spend in doctors' offices. For example, my blood must be tested periodically. My internist draws the blood and sends the results to my specialist; as a result, the blood work does not have to be repeated. It's easier on my arm, my mind and my time.

Living Well

The only real invalid is the person who thinks she or he is one. I take nothing away from anyone's real suffering by saying this. I simply mean, if you can't completely put mind over matter, you can at least tend your mind.

Respond to your own needs; do not postpone them. To that end, remind your family that you love them but that, for now, your health is the top priority.

Above all else, you need to remind yourself that you are still you, as good and as important an individual as you were before your diagnosis.

Margaret Blackstone is the author of The First Year—Multiple Sclerosis: An Essential Guide for the Newly Diagnosed (Marlowe).

healthy bodies AUTOIMMUNE ILLNESS/continued

before Mayer developed the facial reddening and thickening that are hallmarks of scleroderma. "By the time I was diagnosed, the disease was progressing so rapidly that I thought I would be dead in five years," she says.

While new blood tests for lupus and multiple sclerosis are promising faster, more accurate diagnoses, there are no conclusive laboratory tests for many autoimmune disorders. "Sometimes it's not until every piece of the puzzle is in place that a physician realizes what it is," says Dr. Bu-yon. Anyone troubled by undiagnosed symptoms, she suggests, should put together a complete family history. "Genetics accounts for about half of the vulnerability to autoimmune disorders, and these diseases tend to cluster in families. Make sure your doctor knows if close relatives have similar symptoms or a diagnosed autoimmune disorder."

Environmental factors—chemicals, drugs, bacteria and viruses—also may play a role in triggering disorders. The American Autoimmune Related Diseases Association recommends keeping a detailed record of when symptoms start, recur, flare or subside. Then seek a specialist—a rheumatologist, dermatologist, immunologist or gastroenterologist, depending on the symptoms—who has expertise in autoimmune disorders.

Once diagnosed, many women face a wrenching decision: whether to have children. While diseases such as multiple sclerosis may improve during pregnancy, others worsen before or after childbirth. And some autoimmune disorders, such as rheumatoid arthritis and thyroid disorders, increase the risk of infertility.

Initially advised against pregnancy, Michelle Mayer consulted a rheumatologist who asked what she wanted most. Her answer: a baby. With high-risk care, she has since had two healthy children. "Getting pregnant gave me something to live and fight for," she says. "My condition now is pretty good. I worry that I may not know my children as adults, but maybe I would not have lived so fully if I hadn't re-



Susan Caritey at her home in Pittsfield, Mass. "I got back the life I'd lost 25 years ago," she says.

Given early enough, the new treatments may stop the disease process in its tracks.

alized at 27 that life is a short ride."

This year, the Department of Health and Human Services issued a comprehensive research plan to fight autoimmune disorders—a big step toward making the "ride" longer for the 5 percent to 8 percent of the population with these conditions. "I've never been more optimistic," says Yale's Dr. Craft. "We can offer patients better tests, better therapies, better lives—and the promise of much more progress to come."

Visit www.parafe.com for more information on autoimmune disorders and to find links to other women's health topics featured in this issue.

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