

# After

# The

By Gerri Miller

# Diagn

Three people with lupus share their personal stories of disbelief, pain, and hope

One newly diagnosed patient and two veterans discuss the impact lupus has had on their lives—and how they have learned to live with it.

Because lupus is a mysterious, invisible disease with no cure, a diagnosis can be quite scary for someone facing it for the first time. Naturally, there are a lot of questions, especially for those who have never heard of lupus.

But there's also a measure of relief in being able to put a name to what may be years of debilitating symptoms and misdiagnoses, as our trio discovered.



*Gwen Sayer*

# Tony Jackson

AT 6'6" AND 220 POUNDS, Tony Jackson was a college athlete working his way toward a professional basketball career when he became one of the 10 percent of lupus patients who are men.

Two years before, he'd experienced shoulder soreness that he attributed to the sport. Then, shortly after transferring to Maine's Husson College, he had surgery for a patellar tendon rupture, and the stiffness he'd begun to experience in his joints became progressively worse. He attributed this to a lifestyle that crammed drinking, partying, sports, and classes into days that left little time for sleep. Then he lost 20 pounds and had to stand in a hot shower for an hour to loosen up enough to function. Doctors gave him painkillers, but they didn't help. Angry and frustrated, Jackson went to the emergency room in November 1990 and demanded some answers.

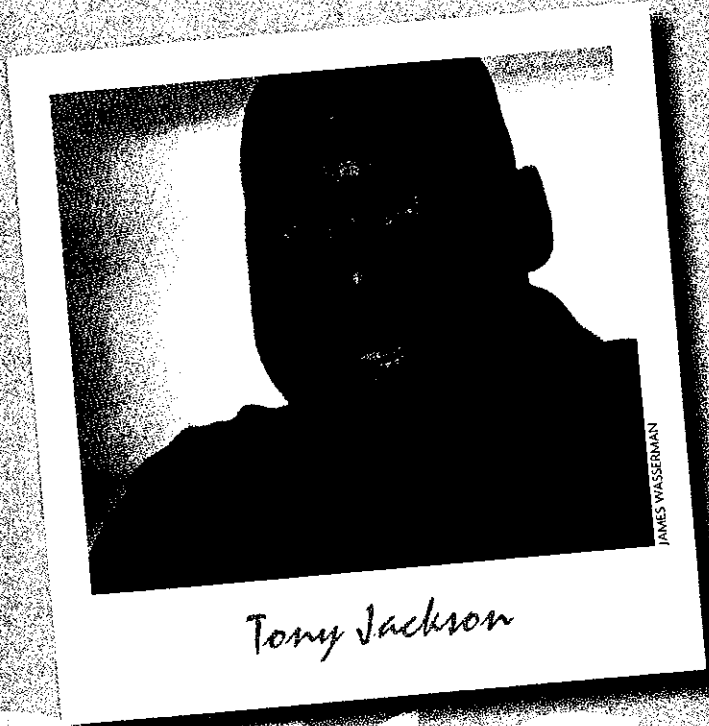
"They ran a battery of tests and eventually I was diagnosed with lupus," Jackson says, who had never heard of the disease.

He focused immediately on a treatment strategy. Doctors prescribed a short-term aggressive treatment of 80-milligram daily doses of prednisone, and Jackson became virtually pain-free. But he still could not return to his old life.

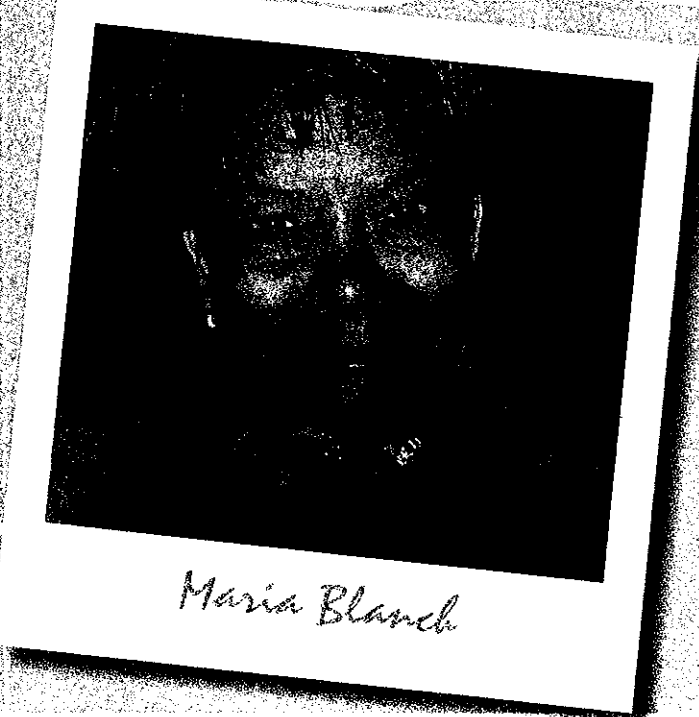
"I'd gone from being an athlete at a very competitive level to having a reduced quality of life," says Jackson, who became very depressed when his athletic dreams were dashed.

"I was not the model for how to effectively cope with a lupus diagnosis. I became pretty withdrawn and never reached out for counseling or support."

Eventually, Jackson put his energy into academics, earning an undergraduate degree in communications and a master's degree in public administration. Then, against the advice of family members concerned about his stress level, he enrolled in law school at Washington University in



## OSIS



*"I'm not as physically fit as I once was, but maybe I placed too great a value on outward appearance in the past."* —TONY JACKSON

St. Louis. Indeed, he had several flares while there, but understanding professors allowed him extra time on assignments, and he graduated in 2002.

Jackson, now 36, lives in Philadelphia with his family—wife Cassandra and daughters Sydney, 4, and Taylor, 2—where he works with a legal services firm. He hopes to take the Pennsylvania and New Jersey bar exams soon.

Currently on 10 milligrams of prednisone, 400 milligrams of Plaquenil, plus medication for hypertension and hypothyroid, Jackson is under the care of a nephrologist for his kidney-involved lupus. He is scheduled for a kidney transplant in early summer. Three family members—his mother, sister, and uncle—offered to become donors, and all proved suitable matches.

In the meantime, Jackson wishes he had more energy for work and play, and at 240 pounds, he misses his pre-prednisone body and face.

"I'm not as physically fit as I once was,

but maybe I placed too great a value on outward appearance in the past," says Jackson, who doesn't smoke or drink.

"My wife pushes me to exercise and makes sure I get sufficient rest by allowing me some quiet time without interruptions."

Meanwhile, experience has taught Jackson the importance of early and diligent treatment, communicating openly with his physician, asking questions and doing research, and finding ways to improve his quality of life. He had a three-month remission 10 years ago, and it made him appreciate how precious good health can be.

Jackson soared in college basketball until his diagnosis in 1990.

These days, Jackson finds joy in cooking, reading, listening to jazz, and in his spirituality. "In a way, I thank God for the lupus because it transformed my life. I'm somewhat limited in what I can do, but I pace myself. I have a good life."

He hopes to reach out and help others with the illness, especially young men, and he can be reached via e-mail at [Aljackson@wulaw.wustl.edu](mailto:Aljackson@wulaw.wustl.edu). ■



# Do's & Don'ts

FOR THE NEWLY DIAGNOSED

People new to lupus have a lot of questions, and Daniel Wallace, M.D., noted rheumatologist and author of *The Lupus Book*, has heard them all. Once he determines what type of lupus a patient has and what areas are affected, Wallace discusses courses of treatment, coping mechanisms for handling stress and fatigue, and changes in lifestyle, including diet and sun avoidance. Here are some of his recommendations:

# Maria Blanch

IN FALL OF 2003, MARIA Blanch, a 47-year-old hospital personnel administrator, began feeling ill. Her joints ached, her extremities swelled, and she felt extremely fatigued. A friend who happens to be a doctor advised her to see a specialist, but she didn't, and her symptoms worsened. Finally, in March 2004, she made an appointment with a rheumatologist, and test results confirmed she had lupus.

"It was very surreal, like I heard it, but didn't hear it," she remembers about getting the news. "I was shocked."

When Blanch shared the news with her husband, Stanley, he was very comforting and promised to do whatever was needed to support her. Then they went out to dinner and avoided the subject of lupus altogether.

"I was completely in denial," Blanch says. "But my doctor, Jessica R. Berman, M.D., a rheumatologist at the Hospital for Special Surgery in New York City, had recommended that I go online to get more information. So the following day I came to work, closed the door to my office, and started researching." (See sidebar "Learn More About Lupus.")

The information she found on lupus offered Blanch many answers, but she still had plenty of concerns. Would her medications—200 milligrams of Plaquenil twice a day and 15 milligrams of the anti-inflammatory Mobic—affect her lifestyle? She was



Swimming helps Blanch manage her weight and build muscles.

relieved to find out that with modera-

tion, they would not. Did her eating habits have to change? The doctor assured her that her diet high in fruits and vegetables and plenty of water was generally good, although to date there is no recommended lupus diet.

But there would be adjustments. She loved going on vacation to sunny places. "I have to be careful now. We had already scheduled a trip to Malta in the summer, so I bought a slew of hats, sun block, and long-sleeved cotton blouses," she says.

With her gym visits diminished

■ **DO BE PROACTIVE.** "Insist on being treated by doctors who are knowledgeable about lupus."

■ **DO AVOID STRESS.** It's one of the leading causes of lupus flares.

■ **DO AVOID THE SUN.** Use sunblock every day and wear protective clothing and hats.

■ **DO AVOID OVERWORKING YOURSELF.** Eliminate activities that inflame the joints.

■ **DO CONSIDER HORMONE THERAPY** for menopause. But note that flares might occur. Although most experts agree that lupus patients should use the lowest possible dose of estrogen for no more than a year or two, have your gynecologist work with your rheumatologist to coordinate care.

■ **DO BE HOPEFUL.** Promising new lupus medications are being tested, and ongoing research on the immune system is providing important clues to how and why lupus impacts the body.

■ **DON'T ASSUME YOU CANNOT PLAN A FAMILY.** If you are a woman whose lupus is not highly active, you can likely get pregnant. But find an obstetrician who has experience with lupus and high-risk pregnancy.

■ **DON'T ISOLATE YOURSELF.** Get support from friends and family.

■ **DON'T SMOKE.** Smoking makes lupus disease activity worse—not surprising, considering all the chemicals found in cigarette smoke that have a negative effect on cell health.

because of fatigue, Blanch worried about weight gain. "I'd started throwing up to compensate," she confides, adding that she is no longer doing that. She has taken up swimming, an impact-free exercise that helps strengthen her muscles.

Blanch also gets great support at home from her husband, his grown children, and friends, many of whom are doctors and social workers. At work, she is fortunate to have an understanding boss and co-workers.

And, although she often finds herself exhausted by her hour-plus commute to Manhattan from her home in New Jersey, she says, "I am able to relax for a while when I get there. Co-workers give me space when I'm tired, and I'm free to leave if I'm not feeling well."

Not having to worry much about her work schedule helps Blanch keep her stress level in check—which is very important, since stress can cause flares. She also relaxes and rests more on the home front and reports less swelling and pain in her joints. But the fatigue often persists.

"Some days are better than others," she says. "I allow myself to get angry or cry if I'm a little overwhelmed. But I've been lucky," she adds, citing her supportive home and work environments. "I never said 'Why me?' I said, 'God, help me cope with this illness and allow me to make it through every day.' I have been lucky in finding a physician whom I trust and have a good relationship with, and my husband who has been so understanding and so supportive. I try to focus on the positive things in my life." ■

# Gwenn Sayer

WHEN GWENN SAYER STARTED FEELING SYMPTOMS of lupus, she was an active and athletic Los Angeles career woman in a high-pressure information technology job. Frequent travel, long hours, and stress were par for the course. At first she attributed the muscle aches to heavy weight training. When red marks appeared on her skin, one doctor told her to stop drinking red wine. But the symptoms continued to get worse. Another doctor told her she had undifferentiated connective tissue disease, which was hardly the definitive answer she was looking for.

"I was in a lot of pain and I had severe fatigue," Sayer remembers. "I could hardly get out of bed."

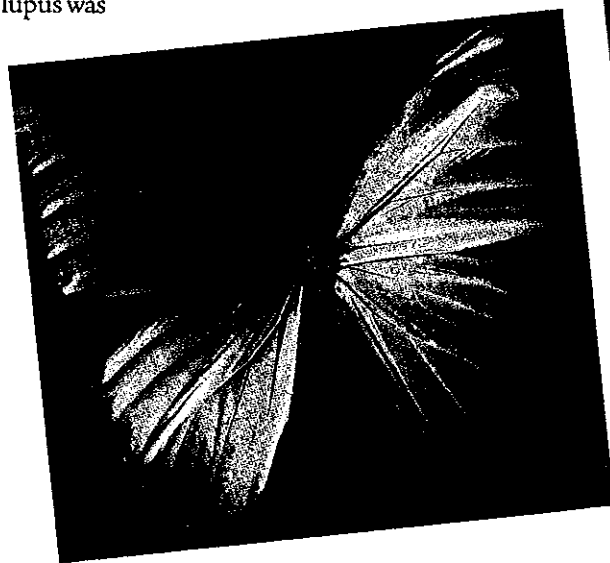
Desperate, she contacted Daniel J. Wallace, M.D., after reading an article about lupus on the Internet. Six weeks later, in May 2000, she received her diagnosis. Sayer, who has a family history of autoimmune disease on her mother's side, had lupus.

Her first reaction? "I cried." Her second reaction? "Wondering if I was I going to die."

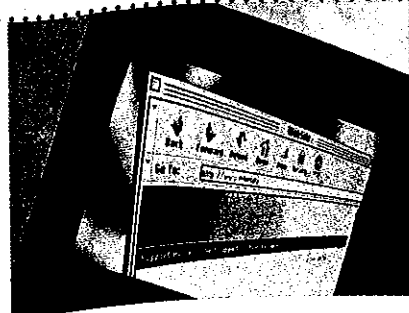
Wallace reassured Sayer that lupus was not a death sentence. She nevertheless "freaked out about the news... and immediately went into denial." This was especially easy when high doses of prednisone made her feel better. She started a new job at a dotcom company and went on with her life.

Not long afterward, she began having migraines,

Sayer started a company called Mariposa Bella, which means "beautiful butterfly."




JIM MCGUIRE/PICTURE QUEST



## Learn More About Lupus

LFA recommends the following websites for helpful information about lupus:

 Lupus Foundation of America, Inc.  
[www.lupus.org](http://www.lupus.org)

*"Having lupus caused me to look at my value system and redefine what success is... Now I focus more on my relationships and accumulating experiences."* —GWENN SAYER

and in September 2001 she was hospitalized with a flare. She underwent six months of chemotherapy and continues to take high blood pressure medication in addition to 400 milligrams of Plaquenil daily.

Indeed, lupus was a major lifestyle change for Sayer, 39, who had thrown herself into her career years before when premature ovarian failure prevented her having children.

"I had totally defined myself through my career, and I lost that," she says. "I went through a depression where I drew the curtains and didn't answer the phone. I withdrew, which is a big mistake. It's hard to do when you're down, but you need to reach out."

To help get out of this funk, Sayer became an adult literacy tutor through the L.A. Public Library and started leading a support group for young adults with lupus. "This took the focus off me and helped me appreciate what I do have," says Sayer. She also made new lupus friends when other friends "didn't get

it." And she started making jewelry. Her company, Mariposa Bella ([www.mariposabella.com](http://www.mariposabella.com)), means beautiful butterfly—and she donates some of the proceeds to lupus research.

Sayer regularly struggles with her weight. She's had trouble losing pounds since she was on prednisone—an effort that is compounded by an underactive thyroid and the fact that she's an "emotional eater." Most days she tries to follow a diet of lean meats, fresh vegetables, salad, water, and green tea. She also takes a multivitamin, calcium, and Omega 3 supplements and is considering a visit to a nutritionist.

"I'm not 100 percent, but when I eat right, get my sleep and exercise, I feel really good," says Sayer. "I don't get to the gym every day, but I may walk the dog or do a yoga tape. And I always stretch before I get out of bed.

"Having lupus caused me to look at my value system and redefine what success is," says the formerly driven Type-A personality. "Now I focus more

on my relationships and accumulating experiences."

For example, Sayer was on TV's "Trading Spaces" in Spring 2004 ("I was wiped out for three weeks after!") and went on a trip to Mexico with her husband Andrew, first treating her clothing with Rit® Sun Guard (a laundry additive that helps block the sun's harmful UV rays) before she left. She also finds something fun to do every day—even if it's just "getting my toenails painted a crazy color" or reading a great book.

"People who are newly diagnosed need to know that it may be overwhelming at first, but you will get better at handling it," Sayer assures. "We can't control what life brings us, but we can choose the way we react to it. Are you getting enough sleep, eating healthy food, taking your medication, and going to your doctor appointments?"

"It can be empowering to take control that way. And if you're not satisfied with your medical care, get a second opinion. Get answers." ■

● MEDLINEplus  
(offers information in both  
English and Spanish)  
[www.medlineplus.gov](http://www.medlineplus.gov)

● National Institute of Arthritis  
and Musculoskeletal and  
Skin Diseases  
[www.niams.nih.gov](http://www.niams.nih.gov)

● National Library of Medicine  
[www.nlm.nih.gov](http://www.nlm.nih.gov)  
● WebMD  
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