

**Jeremy Margolis:**

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# Lupus and Your Heart

Two’s a crowd when it comes to lupus and cardiovascular problems.

BY STEPHANIE STEPHENS

**W**hether he’s the perfect example of compassion and self-awareness or the kind of guy who cuts people off in traffic, Jeremy Margolis figures he’ll still have it.

Lupus, that is. And he’s right.

Margolis, who has a Ph.D. in psychology, is a manager of behavioral research for CVS/Caremark. Generous with his time and easy to laugh, he is dedicated to educating others about their health.

“I mix psychology with health care in my job so that people take better care of themselves,” Dr. Margolis says. His sense of humor re-

mains intact even though he has been diagnosed with a potentially fatal disease. He suffered a minor heart attack in December 2008: His circumflex artery, which curves to the left around the heart, was blocked. Surgeons inserted stents to open the artery.

“It wasn’t a cardiac problem that caused my heart attack. It was a lupus-related problem,” Dr. Margolis says. Patients with lupus are at increased risk for cardiovascular disease, including hardening of the arteries, heart attack, and stroke.

Late last year, Dr. Margolis was diagnosed with vascular dementia, the most common type of dementia after Alzheimer’s disease.

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It develops when impaired blood flow to parts of the brain deprives cells of food and oxygen, resulting in a progressive loss of memory and other cognitive functions. His vascular dementia was confirmed by brain biopsy late last year, a painful reminder that lupus is an enemy of not just the heart, but also the head.

The term “neuropsychiatric lupus” applies to the group of 19 neurological and psychiatric symptoms that can occur in people with lupus. These symptoms are thought to be caused by nervous system damage due to the disease, according to Robin L. Brey, M.D., editor-in-chief of *Neurology Now*, fellow of the American Academy of Neurology, and professor and chair of the Department of Neurology at University of Texas Health Science Center at San Antonio. “The most common of these is memory loss, which can occur in as many as 80 percent of people with lupus at some time in the course of their disease,” she says.

Lupus patients may also consult a neurologist for symptoms such as seizures, stroke, depression, anxiety, and headache. Currently, no optimal therapy is available for lupus-associated cognitive dysfunction, which may come and go on its own.

Dr. Margolis can't help but wonder why he involuntarily drew straws for this bewildering illness usually labeled a “woman's disease.” When the 41-year-old living in Detroit, MI, was diagnosed in 2006, he knew next-to-nothing about lupus.

Most people have heard of the disease. You might even know someone who has it—1.5 million Americans do, according to the Lupus Foundation of America, Inc. ([lupus.org](http://lupus.org)). But few people know what lupus is or how profoundly it can affect the heart.

### WHAT IS LUPUS?

Lupus is a chronic or ongoing inflammatory disease that can affect various parts of the body, especially the skin, joints, blood, and kidneys, according to the Lupus Foundation. Four types of lupus are recognized, each as individual as those they affect: systemic lupus erythematosus, which is the most common form of

the disease; cutaneous lupus erythematosus, which is limited to the skin; drug-induced lupus, which is caused by certain prescription drugs and rarely affects major organs; and rare neonatal lupus, which affects infants of women who have lupus.

The immune system normally protects the body against viruses, bacteria, and other foreign substances. But in an autoimmune disease like lupus, the immune system loses its ability to tell the difference between foreign substances and its own cells and tissue. The immune system then makes antibodies that target the body's own tissue or “self.”

Symptoms of lupus often mimic other less serious illnesses, can range from mild to life-threatening, and may go into periods when they're not present, called remission. Lupus can affect any part of the body, but most people experience symptoms in only a few organs.

The heart, lung, kidney, joints, blood, pancreas, and brain can be inflamed by lupus, says Dr. Brey. Lupus primarily affects young women and women of color—African Americans, Hispanics, Asians—but anyone can get it.

“We're learning more about important predisposing genetic factors that, in conjunction with certain gender-related and environmental factors, trigger this complex disease process,” Dr. Brey says.

Women, it seems, have a much higher prevalence of almost all autoimmune diseases. For example, systemic lupus erythematosus has a 12:1 female-to-male ratio during the ages of 15 to 44 years. Overall, only 10 percent of individuals diagnosed with lupus are men.

Men in the general population have higher rates of heart disease than women, but more women die from heart disease. Heart disease is the leading cause of death in women.

“We don't know how rates of heart disease in men with lupus compare to those without lupus,” says Susan Manzi, M.D., M.P.H., and chair of the Department of Medicine at West Penn Allegheny Health System in Pittsburgh, PA. Dr. Manzi also co-founded the Lupus Center of Excellence in Pittsburgh. “It's hard

#### LUPUS:

### The Basics

#### Lupus is:

- A disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better).
- Not contagious.
- Not like or related to cancer or HIV/AIDS.
- A disease whose symptoms resemble those of rheumatoid arthritis, blood disorders, fibromyalgia, diabetes, thyroid problems, Lyme disease, and a number of heart, lung, muscle, and bone diseases.

#### The goals of any lupus treatment plan are to:

- Reduce inflammation caused by lupus.
- Suppress the overactive immune system.
- Prevent flares and treat them when they occur.
- Control symptoms such as joint pain and fatigue.
- Minimize damage to organs.

Source: Lupus Foundation of America.

“I tell my patients with lupus to behave as though they’ve already had a **heart attack.**”

—ROBIN L. BREY, M.D.

to do studies since so few men have lupus,” she says.

Dr. Margolis understands why so many men with the disease ask him questions. “They think they’re the only one out there. They feel so isolated. I know.”

### A DIFFICULT DIAGNOSIS

Lupus is not a lone stranger to the body. Rather, it is accompanied by a number of other unwelcome visitors that target bodily systems besides the cardiopulmonary, including nervous, gastrointestinal, musculoskeletal, renal (kidney), and the skin. It is also a very difficult condition to diagnose, says Dr. Brey, since symptoms can change, overlap, come and go—even when paired with straightforward clinical and laboratory factors.

“There’s no gold standard diagnostic test for lupus,” she admits.

In fact, patients usually spend four years with three different physicians before obtaining a diagnosis. The American College of Rheumatology ([rheumatology.org](http://rheumatology.org)) includes the following criteria as factors in lupus diagnosis:

- ▶ three types of skin rashes
- ▶ mouth sores
- ▶ two or more joints being painful and swollen
- ▶ swelling of linings around the lungs or heart, as in pleuritis or pericarditis
- ▶ kidney disease
- ▶ a neurological disorder, such as seizures or psychosis
- ▶ low blood counts
- ▶ immunologic disorder
- ▶ positive antinuclear antibody: a positive test result may indicate lupus

The Lupus Foundation’s “Could You Have Lupus” interactive symptoms checklist ([lupus.org/newsite/pages/lupusChecklist.aspx](http://lupus.org/newsite/pages/lupusChecklist.aspx)) is an excellent place to start recognizing signs and symptoms.

“Only four symptoms are required for a lupus diagnosis. And one person with lupus can have a very different illness from another,” Dr. Brey says. “It can be very confusing for doctors and patients alike.”

“Information isolation” occurs, Dr. Margolis believes, because specialists are inclined to view his complex condition “in terms of their particular organ. It seems difficult for doctors to talk about how everything works overall.”

Those who do see the whole picture respect the seriousness of the disease. “Lupus is underappreciated and potentially fatal. People are often astounded by that,” says Dr. Manzi. She and Dr. Brey—both considered experts on lupus—are on a mission to propel awareness and research of the condition from the back burner to the front. “Many doctors just don’t see enough of lupus to feel expert about it,” Dr. Manzi asserts.

Dr. Manzi authored what Dr. Brey terms “a pivotal paper” in

2000 that found women with lupus in their 20s and 30s had a 50-fold increased risk for heart attack compared with similar aged women without lupus. The overall risk of coronary disease is about 10 times more likely in women with lupus at all ages.

Research into lupus is shedding light on vascular disease in general. “Lupus may be an ideal model for premature atherosclerotic vascular disease (AVD), because AVD in everyone is related to inflammation in the vessel walls,” Dr. Brey says. Chronic inflammation may spur on heart disease, leading to plaque damage, clotting, and deadly blockages.

Women with lupus have significant inflammation at an early age, Dr. Brey explains. Inflammation is a non-specific immune response that may include increased blood supply to an area of the body.

With lupus, inflammation and overactive immune system abnormalities may combine with traditional risk factors for coronary heart disease, says Dr. Manzi. These include high blood pressure, high cholesterol, and obesity—all of which seem to occur more frequently in patients with lupus, but which can’t bear all the blame for the increased risk.

She cites research showing that many patients with lupus may have metabolic syndrome, high blood pressure, and kidney disease. However, even after adjusting for these risk factors, patients with lupus still have about a 7 to 10 times higher risk of nonfatal coronary heart disease and a 17 times higher risk of fatal coronary heart disease.

Bottom line: Patients at any age with lupus, especially systemic lupus erythematosus, should have their modifiable cardiovascular risk factors aggressively monitored and managed. On the bright side, many factors are potentially reversible, just as in the “regular” population.

“I tell my patients with lupus to behave as though they’ve already had a heart attack,” Dr. Brey says.

Tough love, but this is one tough disease, requiring consistent medical care. An additional conundrum is that drugs used to treat lupus can exacerbate cardiovascular problems such as stroke risk. Corticosteroids, for example, may increase triglycerides—a type of fat or lipid in the blood—plus high blood pressure and weight gain.

### TREATING LUPUS

When it comes to outsmarting lupus, less intervention is not more. Dr. Manzi poignantly recounts the story of a 27-year-old female with lupus who had arrived at her hospital’s emer-



**Ana Solorzano-Leonard:**  
“I won’t quit or give up.  
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ins-and-outs of the emergency room.

What began as a cough snowballed into pericarditis, inflammation of the sac around the heart, recalls Solorzano-Leonard. The latter is the most frequent problem lupus causes the heart. Diagnosed with lupus in 2002, she has also experienced migraines, joint pain, fevers, numbness, and fatigue. And then there was the cough in summer 2008.

She was prescribed methotrexate, an antimetabolite, to control symptoms by suppressing the immune system. Precautions often read that “methotrexate may cause very serious side effects. Tell your doctor if you have or have ever had excess fluid in your stomach area or in the space around your lungs...”

Initially on the medication, Solorzano-Leonard says she felt “great” but then began to get congested, finally coughing repeatedly and feeling fluid moving in her chest “right on top of the bone.” Then she developed chest pain but was told by doctors that her

gency room complaining of shortness of breath.

“A chest x-ray and EKG were both fine,” the doctor recalls, but Dr. Manzi told the staff the woman shouldn’t go home. “Admit her and watch her.”

The patient suffered a fatal heart attack that evening caused by severe coronary heart disease.

Patients with lupus, like the rest of us, really have to be their own best advocate, counsels Dr. Manzi. They must stay informed and insist on preventative cardiac care. “Be very tuned into your body and try to minimize traditional risk factors. Also eat wisely and engage in physical activity.”

Walk, don’t run, to your emergency room if you have angina, chest pain or pressure, jaw pain, left arm pain, or shortness of breath, she says. Make some noise, too, if you encounter resistance. Ask questions, and then ask again.

That’s also the advice of 46-year-old Ana Solorzano-Leonard of Bakersfield, CA. Her unwillingness to accept the status quo saved her life. This respiratory therapist works on the Code Blue team—they spring into action when a patient is unresponsive—for a local acute-care hospital. She knows the

lungs were clear, even as she became shorter of breath each day. She complained that she “didn’t understand” and knew something was terribly wrong.

One day, after five months of increasing discomfort and anxiety, Solorzano-Leonard was sure she was having a heart attack: sweating, jaw and chest pain, and rapid heart rate—“yet I was oxygenating perfectly.” She stood her ground and demanded further diagnostics, which revealed fluid was crushing her heart. After surgery, she was informed her heart’s lining has thickened and won’t expand. She’ll need more surgery, later.

“I will eventually die from these heart issues,” confesses this determined, once-athletic tomboy who can also no longer bask in the sun due to resulting lupus-related joint pain. She’s been told methotrexate may have exacerbated possible lupus-induced pericarditis. “It was a double-whammy,” she says.

Like Dr. Margolis, she readily shares her experience and knowledge with other inquisitive lupus patients. “So many women ask me questions. I have moments I get really angry, but not at anybody in particular. I won’t quit or give up,” she avows. “I won’t let lupus take over.” NN