

# TRACKING A MEDICAL MYSTERY

Since it was first described hundreds of years ago, lupus has defied physicians and disrupted the lives of patients. Here are three views of this disease: from a patient, a physician, and the president of the Lupus Foundation of Southern Arizona.

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**I**“It’s never lupus,” is the reoccurring line delivered by Dr. Gregory House, the main character on the television show *House*. However, according to the Lupus Foundation of America, five million people worldwide have a form of the disease.

Lupus was first described during the Middle Ages by an Italian physician, and it is believed the name is derived from the appearance of rashes that resembled a wolf’s bite (lupus is Latin for “wolf.”)

It is a disease that some say is a cruel mystery.

“It attacked me in the prime of my life,” says Jodi Norton, the president and co-founder of the Lupus Inspiration Foundation for Excellence (L.I.F.E). “Before the age of eighteen, I had never been sick, not one cold and suddenly, everything changed.”

Norton recalls the sunny day in 1991 as she and other nationally ranked student athletes from the Orlando, Florida, diving team began their practice. Wanting to cool off, Norton shared water bottles with fellow divers. What happened next was months of flulike symptoms, followed by multiple doctor visits, before finding out



she had mononucleosis. Several years later, she was diagnosed with Systemic Lupus Erythematosus, or SLE.

“I think ‘mono’ was the catalyst for my illness. When I first started feeling ill, I didn’t listen to my body and rest. After all, I was a busy teenager and an overachiever — so many aspects of my life were changing, which created stress.”

Ernest Vina, M.D., a board certified rheumatologist and assistant professor of medicine at the University of Arizona College of Medicine, says a variety of factors come into play in a patient developing lupus, including: genetic predisposition, hormonal components and environmental triggers.

“Lupus is a chronic inflammatory disease where the immune system attacks the body’s tissues and organs,” explains Dr. Vina. “The cause of lupus is a bit controversial because it tends to be multi-factorial — meaning there are many factors that all work in different ways that lead to the immune system being dysfunctional in these patients.”

Early symptoms associated with lupus are joint pain and stiffness, ulcers in the mouth, and a facial rash resembling butterfly wings. ▶



Jodi Norton, co-founder of the Lupus Inspiration Foundation for Excellence

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“Lupus is a disease that can affect any organ in the body,” states Dr. Vina. “Typically, it is not immediately diagnosed because a lot of the symptoms can mimic other diseases.”

For Jodi Norton, her diagnosis was not immediate. While in college, she saw more than six physicians before transferring from the University of Arizona to Columbia College in New York in 1993. She continued to experience symptoms of fatigue, swelling and hives before she was admitted into the ER and was officially diagnosed with SLE.

“Because I looked healthy and athletic, many of the doctors I saw early on dismissed my fatigue as overtraining,” she says. “If I had to give anyone experiencing chronic illness advice, I would say, be your own advocate.”

Rebecca Shields, president of the Lupus Foundation of Southern Arizona, says it is important for the public to have access to information regarding the disease. LFSA offers support, resources, and referrals to patients diagnosed with lupus.

“It is not just a physical disease,” says Shields. “It is important to get the family involved to understand what the patient is going through even if he or she may not show physical signs of lupus.”

According to Norton, it also is important for patients to remain positive. Initially, she was advised to stop diving, yet she persisted. In 1999 she graduated with a bachelor’s degree in neuroscience from Columbia College, maintaining a 3.7 GPA while competing on the NCAA Division I diving team.

“Diving was my passion — my refuge — and I wasn’t about to give it up.”

Although she pursued an active lifestyle despite her diagnosis, she has battled other autoimmune diseases over the years. The former diver says lupus has affected every tissue and organ system in her body, with the exception of her kidneys.

“It’s not uncommon to see a lupus patient who has other autoimmune diseases,” explains Dr. Vina. “There are no specific cures for lupus, but there are some treatments to help control it.”

Depending on the severity of lupus, treatment may consist of non-pharmacologic approaches, such as advising patients to avoid smoking and excess sun exposure, along with intravenous suppressant therapies.

“A primary care physician can be the initial doctor to screen for lupus and other diseases, but eventually it would be a rheumatologist who could confirm the diagnosis and recommend treatment,” he notes.

Drugs sometimes used to manage SLE include Methotrexate and Plaquenil (hydroxychloroquine), both of which can be taken in pill form. In 2011, the FDA approved Benlysta (belimumab), which is administered intravenously by infusion.

“Treatment ultimately depends on the patient’s needs, preferences, and what other diseases they may have,” Dr. Vina says.

Along with treatment, local organizations are hoping to encourage public awareness and support for those diagnosed with lupus.

“It is extremely important for patients, either newly diagnosed or those having lupus for some time, to know they are not alone and there is help, support, guidance and empathy,” adds Shields.

One of Norton’s goals is to educate others with her upcoming book titled, *Taming the Wolf Within: Tales of Inspiration*, along with helping those living with lupus through her foundation L.I.F.E. Currently, the foundation has provided more than 100 merit-based scholarships to college-level students diagnosed with lupus.

“Lupus has changed my life in many ways,” she reflects. “It has forced me to face my own mortality. More importantly, it has taught me to laugh more, love stronger, and to face challenges head on.”

After 24 years of fighting her “wolf,” Norton says she sets boundaries; making it clear that lupus is not in control of her life.

“I’m Jodi and I have lupus, but that doesn’t define me,” she declares. “Adversity comes in many forms, but the one commonality is that we get to decide how we react to the various hurdles we face in life. Never be afraid to follow your dreams and passions, for they will lead you to success. Anything is possible if you believe.” **TL**



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