

Putting the Pieces Together to Solve a Medical Mystery

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Kim Goranson knew something wasn't right. For more than 10 years, she endured exhaustion, pain, and bouts of confusion. But to her frustration, repeated medical evaluations revealed nothing. A high-energy real estate agent in Lincoln, Nebraska, Kim saw her successful career slip away as the symptoms took a heavy toll on her life.

"I had to quit working in 2010. I was only 50 years old," says Kim. "I thought I'd rest, get myself back together, and then get back to work. Instead, I got worse and worse. Many days, I didn't get out of bed."

Her outlook began to change, however, when Kim was referred to a clinic in Rochester, Minnesota. Although it took some time to arrive at a clear diagnosis, her team of medical practitioners was able to put the pieces of the puzzle together and determined that Kim had lupus.

Elusive answers

Systemic lupus erythematosus (SLE), also known as lupus, is a chronic inflammatory disease that occurs when the body's immune system attacks its own tissues and organs. Lupus is often difficult to diagnose because the inflammation it causes can affect many body systems—including the joints, skin, kidneys, blood cells, brain, heart and lungs. As in Kim's situation, symptoms are often vague, and they tend to mimic other medical conditions.

The most common signs and symptoms of lupus include:

- Fatigue
- Fever
- Headaches
- Confusion and memory loss
- Joint pain, stiffness and swelling
- Butterfly-shaped rash on the face that covers the cheeks and bridge of the nose
- Skin lesions that appear or worsen with sun exposure (photosensitivity)
- Fingers and toes that turn white or blue when exposed to cold or during stressful periods (Raynaud's phenomenon)
- Shortness of breath
- Chest pain
- Dry eyes

Inflammation caused by lupus can affect many areas of your body, including your:

- **Kidneys.** Lupus can cause serious kidney damage, and kidney failure is one of the leading causes of death among people with lupus. Signs and symptoms of kidney problems may include generalized itching, chest pain, nausea, vomiting and leg swelling (edema). People with lupus are also prone to urinary tract infections.
- **Brain and central nervous system.** If your brain is affected by lupus, you may experience headaches, dizziness, behavior changes, hallucinations, and even strokes or seizures. Many people with lupus experience memory problems and may have difficulty expressing their thoughts.
- **Blood and blood vessels.** Lupus may lead to blood problems, including anemia and increased risk of bleeding or blood clotting. It can also cause inflammation of the blood vessels (vasculitis).
- **Lungs.** Having lupus increases your chances of developing an inflammation of the chest cavity lining (pleurisy), which can make breathing painful. You may also be more susceptible to pneumonia.
- **Heart.** Lupus can cause inflammation of your heart muscle, your arteries or heart membrane (pericarditis). The risk of cardiovascular disease and heart attacks increases greatly as well.

Having lupus also increases your risk of:

- **Infection.** People with lupus are more vulnerable to infection because both the disease and its treatments weaken the immune system. Infections that most commonly affect people with lupus include urinary tract infections, respiratory infections, yeast infections, salmonella, herpes and shingles.
- **Cancer.** Having lupus appears to increase your risk of cancer.
- **Bone tissue death (avascular necrosis).** This occurs when the blood supply to a bone diminishes, often leading to tiny breaks in the bone and eventually to the bone's collapse. The hip joint is most commonly affected.
- **Pregnancy complications.** Women with lupus have an increased risk of miscarriage. Lupus increases the risk of high blood pressure during pregnancy (preeclampsia) and preterm birth. To reduce the risk of these complications, doctors often recommend delaying pregnancy until your disease has been under control for at least six months.

When Kim went to the clinic in 2012, doctors first suspected she had fibromyalgia. But the symptoms didn't quite fit. She was evaluated by specialists in Neurology, Sleep Medicine and Rheumatology. Her rheumatologist, Vaidehi Chowdhary, M.D., reviewed Kim's medical history, assessed her symptoms, conducted a physical exam and, based on that evaluation, ordered several specific tests. From her analysis, she determined Kim's lupus diagnosis.

Tests and Diagnosis

Diagnosing lupus is difficult because signs and symptoms vary considerably from person to person. Signs and symptoms of lupus may vary over time and overlap with those of many other disorders. No one test can diagnose lupus. The combination of blood and urine tests, signs and symptoms, and physical examination findings leads to the diagnosis.

"After 12 years of trying to explain to so many doctors all my vague, odd symptoms, Dr. Chowdhary was the first one ever who looked at me as if she understood," says Kim. "I almost wept when she told me I had lupus. It was such a relief. Until I was properly diagnosed, there was no way I was going to get better."

Blood and urine tests may include:

- **Complete blood count.** This test measures the number of red blood cells, white blood cells and

platelets as well as the amount of hemoglobin, a protein in red blood cells. Results may indicate you have anemia (a deficiency of hemoglobin), which commonly occurs in lupus. A low white blood cell or platelet count may occur in lupus as well.

- **Erythrocyte sedimentation rate.** This blood test determines the rate at which red blood cells settle to the bottom of a tube in an hour. A faster than normal rate may indicate a systemic disease, such as lupus. The sedimentation rate isn't specific for any one disease. It may be elevated if you have lupus, another inflammatory condition, cancer or an infection.
- **Kidney and liver assessment.** Blood tests can assess how well your kidneys and liver are functioning. Lupus can affect these organs.
- **Urinalysis.** An examination of a sample of your urine may show an increased protein level or red blood cells in the urine, which may occur if lupus has affected your kidneys.
- **Antinuclear antibody (ANA) test.** A positive test for the presence of these antibodies — produced by your immune system — indicates a stimulated immune system. While most people with lupus have a positive ANA test, most people with a positive ANA do not have lupus. If you test positive for ANA, your doctor may advise more-specific antibody testing.

Steps to wellness

Although there's currently no cure for lupus, Kim was able to begin rebuilding her life after she learned she had the disease. Dr. Chowdhary helped Kim create a treatment plan that included working with pain management specialists, physical therapists, a dietitian and an acupuncturist to find ways to successfully manage Kim's symptoms. Those steps made a big difference. With treatment, Kim was no longer confined to bed. Her pain lessened substantially, her energy increased, and her thinking became clearer.

"Dr. Chowdhary told me progress would be slow, and it has been. But I'm learning how to deal with the disease. I'm on a trajectory toward health and wellness," says Kim.