

One of the most enigmatic diseases, lupus affects Asian American women more often than white women. But with no known causes or cures, the almost always fatal disease has doctors and scientists stumped.

# Living with Lupus

STORY Lisa Wong Macabasco



In the 12th century, an Italian physician named Rogerius looked upon his patients' faces, pocked with a red rash. He called the disease lupus, Latin for wolf, for the facial lesions that resembled a wolf's bite.

Eight hundred years later, Karen Ng crawled toward a Manhattan hospital elevator, dragging herself on her hands and knees. After weeks of dismissing her persistent fatigue, swollen

limbs and feverish state, she had just gotten off the phone with her doctor. Go to the emergency room, her doctor said. *Go now.*

Normal women have a hemoglobin level of around 13; level six is considered a dire warning. Hers was at three. She got to the emergency room just in time to collapse and have immediate blood transfusions. "I ignored my own body," says Ng,

now 31. "I saw all these signs, these clues, but I chose not to act."

Other Asian women must not make the same mistake. Lupus has disproportionately ravaged the Asian community and other communities of color — like African American, Latino and Native American — affecting Asian American women two to three times more often than white women. But it remains one of the most mysterious, complex and overlooked diseases.

Lupus is a chronic disease where the body attacks its healthy tissues, resulting in redness or swelling, pain and organ damage. It affects each person differently and can be very mild or excruciatingly severe. A panoply of symptoms may come and go without warning. One can have some, but not necessarily all, symptoms: a red rash or color change on the face, often across the nose and cheeks; sun-sensitive skin; painful or swollen joints, especially after waking up; mouth and nose sores; sharp chest pains; seizures or psychosis; and blood or kidney problems. Other symptoms include fatigue, fever, hair loss, swollen lymph nodes, dry eyes and mouth, and muscle weakness.

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The causes and cures are yet unknown, but researchers speculate that genes are involved, as nearly half of lupus patients have a relative with the disease. Adding to the mystery is that no numbers exist detailing how many Asians have the disease, how many new cases are diagnosed or how many die from it each year. Lupus is estimated to affect 1 million to 1.5 million Americans, 90 percent of whom are women, mostly teenaged and young. Famous patients affected by lupus include former Philippine president Ferdinand Marcos, musician Seal, CBS anchor Charles Kuralt, and hip hop producer J Dilla.

The data on lupus in the Asian American community is woefully scarce, but anecdotal evidence is enough to make doctors and advocates worried. There has been an increase in the prevalence of lupus among Asian Americans, according to Duane Peters of the Lupus Foundation of America. Sharon Chung, a University of California, San Francisco

rheumatologist, adds that Asians have been found to have more aggressive cases of lupus. But extremely low awareness levels among Asian Americans coupled with the community's fear and stigma of having any chronic illness means that the disease is being forced underground, pushing diagnosis further away while intensifying the disease's effects on the body and isolating patients. "You don't talk about illness at the dinner table," Ng says. "Asian people don't talk about their own health."

What's more, the disease's name in Mandarin (*hóngban*

*lángchuang*) contains the words red, rash, wolf and sore. "When people see the name of our program at health fairs, they shrink back and say 'Oh my god,'" says Ng, founder of the Hospital for Special Surgery's LANtern (Lupus Asian Network) Program. "They think it's contagious, that it's an STD, that it's always deadly. People basically don't know what it is."

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It was 1999, and 24-year-old Ng was feeling sluggish. But she figured that was to be expected from being such an active high achiever. A biology graduate student at New York University on the pre-med track, she attributed her fatigue to stress from her fervent studying. She had also joined a new gym and thought, I'm working out more. It's natural.

At Thanksgiving dinner with her family in Palm Springs, Calif., the warm desert air pushed temperatures into the 60s and 70s, but Ng was freezing. Her joints were so painful and swollen she couldn't hold a toothbrush. "I thought, 'oh, I'm getting older,'" she laughs now. "I just brushed it off."

Ng's health continued to deteriorate, but she still found excuses for her health problems. "I thought it was my thyroid medication," she says, referring her longstanding thyroid condition. "I thought my doctor would adjust my medication and it would be fine." By then, Ng was so tired that she couldn't take a shower without having to bend over and hyperventilate.

Eventually a doctor tested her blood and sent her straight to the emergency room. She had type 4 lupus kidney disease, the most serious type. Two leading causes of mortality from lupus are kidney disease and heart disease, and Asians with lupus have a higher incidence of kidney involvement. Asians are also more likely to have nephritis, a kidney disease that is one of the most acute manifestations of lupus, according to UCSF's Chung.

Ng's kidney disease was so severe she had to enter chemotherapy. "It hit all at once," Ng says. "It was a real crisis within a small amount of time."

Like a good Chinese student, her first thought was: "This can't be happening — I'm missing finals!" It was a major disruption," she now laughs. Soon the terrifying seriousness of chemotherapy set in, but Ng handled it with the calm, studied assertiveness of someone from the medical world. "I was straightforward: this is what we have to do, and let's get this done. I bought all the lupus books. I read everything. It was a coping mechanism. My emotions shut down," she remembers.

Besides dealing with high doses of steroids and the ordeal of chemotherapy, Ng faced serious decisions about fertility treatments and harvesting to preserve her eggs since chemotherapy can affect fertility. She had been in a long-term relationship and was on the road to marriage and children. "The most traumatic aspect of it was the fact that I might not have children," Ng says. "I've wanted kids since I was 14. That threatened my identity."

Ng moved back in with her parents in California to undergo chemotherapy, and only then was she blindsided with the emotional ramifications. She had been forced to leave grad school and her medical school dreams. She had left her boyfriend behind in their New York apartment for an indefinite period of time to go through chemo alone. "My life turned upside down within a month," she says. "The emotional impact of that was something I could not avoid."

Ng stresses that the emotional impact of lupus is equally as devastating as the physical aspects, which is something Asian communities tend to overlook. "Mental health is not valued as a priority in Asian communities," she says. "It's hard for us to think we can get emotional support, we can get through this by talking to other people, and it actually might help. We internalize a lot of emotions and feelings."

This is where LANtern comes in. Ng started the New York-based program in 2001, and today it remains the only group in the country dedicated to Asian Americans with lupus. Its main service is a toll-free nationwide bilingual English and Chinese support line where people can talk to peer health educators who are lupus patients themselves. "There's such turmoil involved with having lupus," she says. "It's the most mysterious, confusing, complex disease you can possibly dream up. Not knowing what's going to happen, not knowing how it's going to affect you — it's very debilitating."

Part of the reason there is so little known about lupus among Asian Americans is because they are not represented well in lupus studies. Chung, who has done genetic studies on different populations with lupus, says she is very interested in enrolling Asian patients with lupus, but it remains difficult. "I don't think participation in research studies is something really thought about in the general Asian culture," Chung says. Duane Peters agrees that the epidemiological data is limited for all ethnic groups. "There's so much we just don't know right now," he says.

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Ng was lucky to be diagnosed with lupus so quickly. Her thyroid condition served as a signpost that she was at risk for another autoimmune disease (one in three people with lupus have another autoimmune disease), but many lupus patients go for years bouncing from doctor to doctor without a definitive diagnosis, which is typically achieved through a combination of doctors' examinations, lab tests and patient medical history. One survey found that more than half of those with lupus suffered for at least four years and saw three or more doctors before being diagnosed correctly. "One of the biggest complaints patients have is that doctors can't figure out what's wrong," says Ng.

## What are the symptoms of lupus?

Lupus can have many different signs and symptoms. There is no single test to tell whether you have lupus or not. Usually the disease will be diagnosed by a combination of your medical history, a physical examination and laboratory tests. If you have lupus, you will have some, but not necessarily all, of these symptoms. Without these symptoms, you probably do not have lupus. Always check with your doctor.

- A red rash or color change on the face, often across the nose and cheeks (known as a butterfly patch in Chinese)
- Very sun-sensitive skin
- Painful or swollen joints (especially when you wake up)
- Sores in the mouth and nose
- Sharp chest pains
- Seizures or psychosis
- Problems you can't see without lab tests, such as blood or kidney problems

You may also have many other symptoms such as: fever, fatigue, hair loss, swollen lymph nodes, dry eyes and mouth, muscle weakness, color changes in the hands due to cold, blood clots and recurrent miscarriages. When you have many active symptoms, this is sometimes called a lupus "flare."

— LWM

Source: LANtern (Lupus Asian Network) Program

Part of the problem is that lupus symptoms can be subtle and easily overlooked: a little joint pain, fatigue, hair loss. "We can all brush that away and keep going," Ng says. "It's not life threatening. There's no sharp pain. It's not going to kill me tomorrow. But the internal organ damage can occur without you even realizing it. There would be no outward symptoms and no way you would know unless your doctor did the right tests." Even getting to the doctor can be a difficult task for Asian Americans. "Complaining about one's health or speaking frankly to a physician about particular symptoms, that's not necessarily encouraged [in the Asian community]," adds Chung.

Exacerbating the issue is that Asian women tend to hold back from complaining about feeling tired. Lupus can cause overwhelming fatigue: Ng can sleep for 12 hours, wake up for two hours, and then have to go back to sleep for another 10 hours. This exhaustion can go on indefinitely, incapacitating students from going to classes, employees from going to work and mothers from taking care of their families. "Lupus patients get a lot of grief because people think they are faking it or being lazy, particularly in Asian communities who value strength and not complaining," Ng says.

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Annabelle Villarreal will never forget the first piece of information she learned about lupus after she was diagnosed in 1986. She had gone directly to look up the disease in an outdated medical book and blinked in shock and horror at the three words that she found under the lupus entry: "Almost always fatal." Oh my god, she thought. This is really it for me. She was 22.

One of the biggest misconceptions about lupus in the Asian American com-

munity is that it's an automatic death sentence. While this may have been more true decades ago, and it can still be potentially deadly, today people

**"The teacher said [my son] Gabriel was picking up on it [my symptoms], and it was like he was grieving for me."**

— Annabelle Villarreal, who was diagnosed with lupus in 1986

with lupus can and do have healthy, normal lives with the proper treatment and lifestyle.

But for Villarreal, then and for the next year, there was no dissuading her that her life was over. She fell into a depression, partially due to the corticosteroid she was taking for lupus, but also because the former Filipino community beauty pageant competitor was now unrecognizable. "I was pretty vain at that time," remembers Villarreal, now 45. "I was experiencing weight gain, my face was bloated. I didn't look like me anymore."

Lupus patients watch their bodies go through tremendous changes. High dosages of steroids, which are the most common medication that lupus patients are prescribed, can cause unusual weight gain, most noticeably in the face (called "moon face") and lower back (called "buffalo's hump"). "When I was on intense doses of steroids, my feet were so swollen, I couldn't fit into any normal shoes," Ng says. "I had to buy some size 10 slippers — I normally wear size 7.5 — and hobble in them because my feet were literally tree trunks."

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Combine this with immunosuppressive (chemotherapy) treatments, which can cause severe hair loss, nausea and vomiting. "You just feel fat, ugly and bald," Ng says. Since many lupus patients are young women, the intense changes in their bodies can send self-esteem plummeting.

Like Ng, Villarreal first knew something was wrong while in graduate school, studying public administration at Columbia University. Also like Ng, she blamed stress for her symptoms — thinning hair, aching joints, a slight rash on the face — which came and went during the school year. But while back home in San Diego during summer break, her symptoms escalated to severe skin conditions and scabs on her hands from inflammation. She saw an internist, who identified it as lupus immediately.

Haunted by those three words from the medical book and so depressed she was considering dropping out of school, Villarreal began attending lupus support groups. But the gatherings only heightened her fear. "There was no one like me," she says. She was the youngest one and the only Asian American. The other members were not only much older, but also

looked terrible. "I thought, 'Is that gonna be me?'" She stopped going to the support group after a few times and eventually found help from her family and friends.

Villarreal has now lived for more than 20 years with this supposedly "almost always fatal" disease. She even had a son, overcoming the odds against high-risk lupus pregnancies. While more than half of all lupus pregnancies go off without a hitch, 25 percent produce normal babies prematurely and less than 20 percent end in either miscarriage or fetal death (Ng has had two miscarriages). Villarreal admits she felt "terrible" throughout her pregnancy, with skyrocketing blood pressure and her body "blowing up like a balloon." She was almost completely bedridden for the final five months before the birth. A few years after her son was born, she went through chemotherapy, which induced menopause at 33. "I was lucky to have my one child," she says.

Gabriel is now 14 and mature beyond his years, she says proudly. She remembers going through a lupus "flare" when he was 3. One day she and her husband were called to Gabriel's preschool. A teacher said her son would not stop crying, that he was inconsolable, and asked if something was wrong at home. Villarreal explained that she was in a "flare," a time when she experiences many active symptoms at the same time, which made her tired all the time. "The teacher said Gabriel was picking up on it, and it was like he was grieving for me," Villarreal says, her voice breaking. That night, they asked him how he was doing. "I'm worried," he said. Imagine he's 3 years old and using those words! He said, "I don't want mommy to go to heaven."

Villarreal experienced flares every few years until 2001 when, after a second round of chemotherapy, she became determined to take control of her lupus with a strict medication regimen and a lifestyle that doesn't leave her overworked. She strives to be a good worker and mother, but not at the expense of her

health. She still works (less than full time) for the State of California's Employment Development Department in Chula Vista, but has less ambition now. "My job isn't the all-important thing," she says. "I don't have to be 'supermom' all the time. I decided I'm not going to try to be promoted. It's less important to me now. I'm focusing on family, having a healthy lifestyle and keeping lupus at bay." And she hasn't had a flare since 2001. "Knock on wood," she laughs.

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Lupus is life changing, particularly in relationships with family, friends, spouses and employers. There may be feelings of guilt and not wanting to be a burden on or worrying the family that prevents an Asian lupus patient from asking for help and support.

While much about lupus is unknown, researchers are certain it's not contagious, and LANtern emphasizes that there is nothing patients can do to prevent or cause lupus.

What is important, Ng says, is to listen to your body and don't dismiss symptoms. Today, Ng is maintaining her health, and looks as healthy as the next person. She has run half-marathons, skied, snowboarded, snorkeled and remained active when feeling well. She still hopes for a family. She urges Asian American women to be proactive about treatment and care, learn as much as possible and ask questions. "Ask for help because being proud and independent can also make you a fool. I collapsed in the emergency room because I waited until the last minute to seek help," she says.

Villarreal is pushing for more awareness about the disease as well. "If I'd known more about it before I was diagnosed, it wouldn't have been so scary," she says. "If my family and friends had known about it, I wouldn't have felt so alone, like I was the only one in the world who had it." ❀

## Lupus resources: where to find out more

### ■ LANtern (Lupus Asian Network) Program

212-774-2508

866-505-2253 toll-free

[www.hss.edu/conditions\\_14347.asp](http://www.hss.edu/conditions_14347.asp)

Bilingual English/Chinese lupus support line.

Speak with a peer health educator with lupus or volunteer.

### ■ DxLupus

[www.DxLupus.org](http://www.DxLupus.org)

A website serving people with lupus and those who care for them.

### ■ Lupus Foundation of America

800-558-0121 toll-free

[www.lupus.org](http://www.lupus.org)

A national organization with tons of information and resources, as well as local chapters.

### ■ UCSF Lupus Genetic Research Project

888-223-3067 ext. 1 toll-free

<http://medicine.ucsf.edu/lupus>

Call to participate.

— LWM