



HEALTH

The great imitator

By CLAUDIA GIBSON

Autoimmune disease lupus is hard to treat, and a big enemy is the life threatening difficulty in diagnosis

MELISSA Correa of The Bronx had only vaguely heard of lupus when she was first diagnosed at age 17.

"I knew what it was because a girl at my school had it," said Melissa, now aged 33. "When the doctor told me I had lupus, I thought, OK, since the girl I knew seemed all right."

What Melissa did not know then, but has since learned, is that systemic lupus erythematosus (SLE), or lupus, is a serious, chronic disease, for which there is no known cause or cure, and only a few treatments.

Lupus can affect the joints, skin, kidneys, lungs, heart or brain, causing rashes, inflammation, and severe pain and swelling, among other symptoms.

Lupus is an autoimmune disease, where the body's own immune system stops protecting the body and begins to attack healthy tissues and organs.

Over 1.5 million people in the US suffer from lupus, with 90 percent of them women, often of childbearing age. For reasons not yet known, African American, Hispanic and Asian women are more often affected than Caucasian women.

Early symptoms include facial rash, joint aches, fever, sensitivity to sunlight and severe fatigue. Advanced symptoms may include convulsions and kidney failure.

There is no known cure for lupus, and the drugs used to treat it — steroids and Cytoxan, a chemotherapy drug — can have devastating side effects.

Diagnosing lupus can be difficult, because it presents itself in many different ways.

"They call lupus the great imitator, because it imitates so many illnesses," said Melissa Correa, whose own

THE 11 WARNING SIGNS OF LUPUS

- "Butterfly rash" across the nose and cheeks
- Mouth ulcers
- Hair loss
- Extreme fatigue
- Pain, redness and/or swelling in the joints
- A Reaction to sunlight that results in a skin rash
- Persistent fever
- Anemia
- Protein in the urine
- Fingers turning white or blue if cold
- Seizures

diagnosis took six years.

Starting at age 11, Melissa suffered through an array of baffling symptoms, including painful foot blisters, abnormal blood work, tightness and swelling of the legs, nausea, loss of appetite, severe headaches, fever, fatigue and convulsions.

She was misdiagnosed with everything from meningitis to a sexually

transmitted disease (she was not even sexually active) before blood tests helped confirm lupus at age 17.

According to Peggy Dowd, Executive Director of The SLE Lupus Foundation and President of the Lupus Research Institute (LRI), misdiagnosis of lupus is a serious issue, causing delay of treatment and worsening of symptoms.

She urges women and physicians, "Consider the symptoms and ask: could it be lupus?" Dowd recommends consulting a rheumatologist if lupus is suspected.

Melissa's symptoms subsided after two years, and she remained asymptomatic for eight years. But in 2001, Melissa's lupus returned with a vengeance. She developed kidney nephritis and eventual kidney failure, necessitating dialysis. She also found out she had cervical cancer, possibly brought on by her compromised immune system, and had to undergo a hysterectomy.

Despite her rough road, Melissa remains upbeat, focusing on the positives in her life — a cousin is donating a kidney next year, she is down to three medicines, and her dialysis has been reduced to twice a week.

"I've been through it all," she said recently. "There is always one more step in the road and you get over it."

Manhattanite Candy Cheung, a 27 year old news associate with CNBC, sees a positive attitude as essential for lupus patients like herself.

As a child and teen, competitive swimming provided a way to relieve her lupus symptoms.

"Swimming was the only venue I had to express any frustration I had with myself and the disease," she said.

Candy got an early diagnosis because of a hard-won awareness of the disease.

"My mom's twin sister had lupus. She was misdiagnosed and passed away," recalled Candy. "My mom knew and sought the best medical attention; she didn't want that happening to me."

Frustrating for patients and doctors alike are the limited drugs available. "There has been no drug approved for lupus in 40 years," said Dr. Jill Buyon, Professor of Medicine and Vice Chair, Department of



Photo: Kenyon Images

Melissa Correa has had lupus since she was 11, but it was not diagnosed until six years later. She currently undergoes dialysis twice a week.

Rheumatology at NYU School of Medicine. "But the good news is that over 10 trials are going on to try and change this."

Dr. Buyon said that recent research has resulted in new discoveries of how the immune system works, which is leading to new treatment possibilities. Most crucial now, she said, is to get patients into drug trials, so new drugs can be approved.

"I encourage patients to participate in trials," said Dr. Buyon. "If we are going to get FDA approval and get these new drugs out, everyone has to chip in. You can't bring out a new drug without patients."

The SLE Foundation, which has helped raise millions for lupus research in the past few years, is working to educate patients about drug trials and enrol them.

"We launched a new pro-

FOR MORE INFORMATION:

■ The S.L.E. Foundation: www.lupusny.org; (800) 74-LUPUS.

■ Lupus Research Institute: www.lupusresearchinstitute.org; (212) 685-4118.

■ Lupus Foundation of America: www.lupus.org; (800) 558-0121.

■ Lupus trials: www.lupustrials.org; (877) 95-TRIAL

gram, Lupus Together For Clinical Trials, at the behest of physicians," said Peggy Dowd. "The website, www.Lupustrials.org, provides information about trials in the community."

In the New York area, the SLE Lupus Foundation also provides support programs, with centers in The Bronx, Manhattan and Brooklyn, children's camps and online education and communities.

Patients, doctors and lupus advocates remain frustrated by the overall lack of attention given to lupus.

"Lupus is considered a 'woman's disease,'" said Melissa Correa. "It's overshadowed."

"Lupus does not have celebrity endorsement," agreed Candy. "I hope the day comes when someone takes notice."