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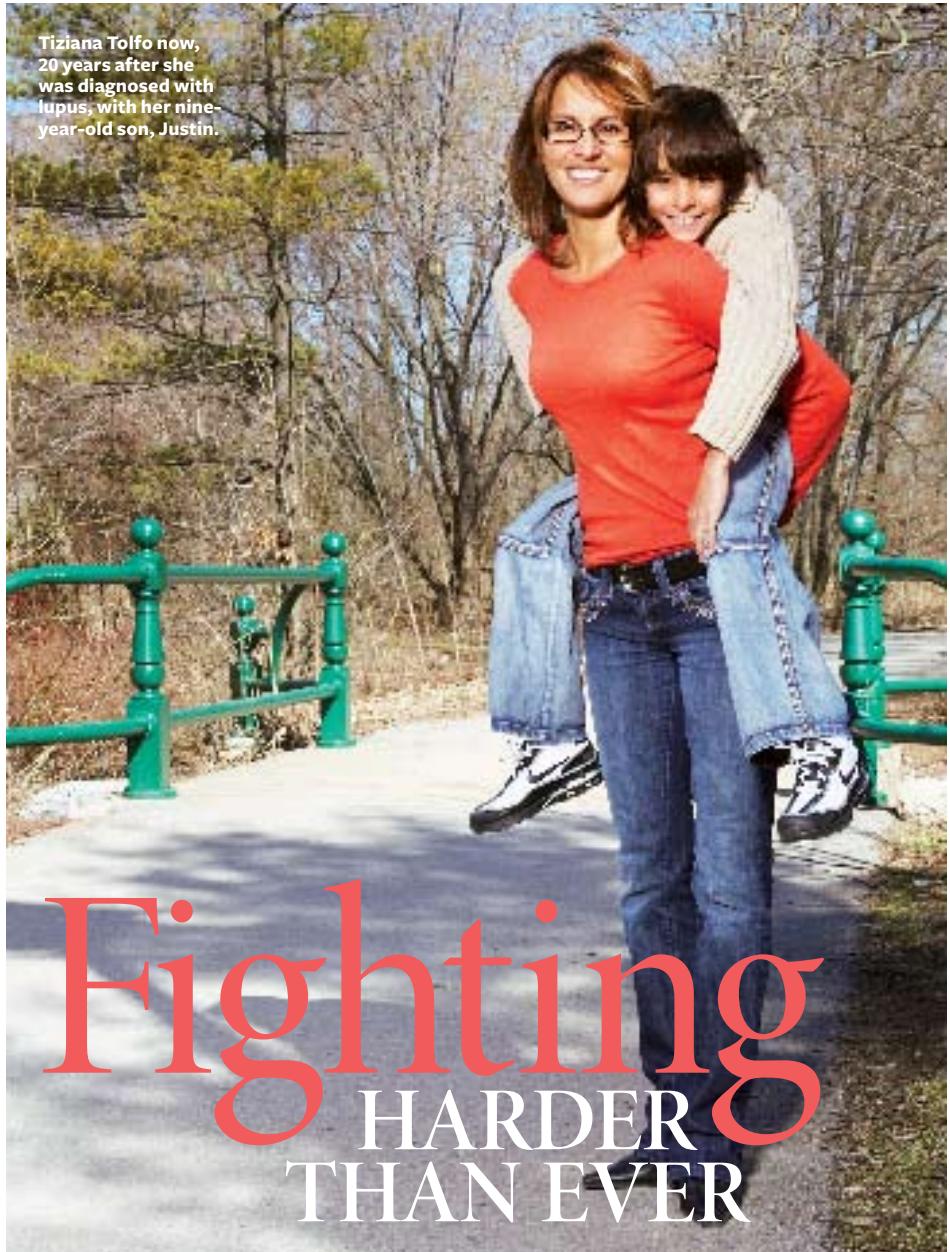
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Tiziana Tolfo now, 20 years after she was diagnosed with lupus, with her nine-year-old son, Justin.



Throughout my battle with lupus, I've felt debilitating pain, suffered from diabetes and had both hips replaced. But it was only when I became pregnant unexpectedly that I was truly terrified – and strengthened.

by Tiziana Tolfo,
as told to Jen O'Brien
photograph by Joanne K.

Lupus is called “the disease with a thousand faces” because no two cases are exactly alike. Symptoms can come on suddenly or develop slowly, be mild or severe, be temporary or permanent. Some lupus sufferers gain weight; others lose weight. Some develop fevers and rashes; others suffer fatigue and headaches. Some have chest pain and bruise easily; others suffer dry eyes and memory loss.

Twenty years ago, I was diagnosed with the disease. A healthy immune system makes antibodies to protect it against viruses,

bacteria and other invaders. My immune system can't tell the difference between foreign substances and its own cells and tissues. So it turned against my body, making antibodies that attacked my organs.

Lupus can affect almost any organ or system in the body: the skin, joints, heart, lungs, blood, kidneys or brain. It strikes more women than men, often during their child-bearing years. Women with lupus used to be told they shouldn't have children. If they got pregnant, they had abortions. The cause of the disease is still unknown. >>

One side effect is that your face and neck swell. You look like you weigh 500 pounds, but only from your shoulders up.



ABOVE: Tiziana and her husband, Louis, after her first hip replacement.
BELOW: The couple skiing before Tiziana's diagnosis.

I have systemic lupus erythematosus, the most severe form. When I was 20, in my final year at college in King City, Ont., I started to feel tired and feverish. Before that, I loved horseback riding, and my boyfriend, Louis, was teaching me how to ski. I also developed this funny rash on my face, almost like little pimples. I thought, *I must be stressed out*. I wrote my first exam, but after that things started getting worse.

My knee and finger joints swelled. I went to my family doctor. He popped me up on the table and said, "I think you might have lupus." I gave him a stupid look and asked, "What does that mean?" He said, "Don't worry. It's nothing like cancer."

He referred me to a rheumatologist, who admitted me to the hospital that day. I had no idea what was going on; I'd thought I was just going for some tests. "I don't know how long I'm going to be here," I told my mom over the phone. "You have to bring me some clothes and come get my car."

I stayed at the hospital for three weeks. The doctors gave me a high dose of a medication called prednisone, which suppresses the antibodies that are attacking the organs. I felt better after a few days and I thought, *This isn't so bad*. But then my appearance began to change.

Barely recognizable

One side effect of high doses of prednisone is that your face and neck swell like a balloon. You look like you weigh 500 pounds, but only from your shoulders up. My hair started falling out, and thin, dark hairs grew on my chin and upper lip. Louis told me over and over, "You're beautiful," but I couldn't look in the mirror without crying.

Another side effect of prednisone is that you can become diabetic. So I learned how to give myself insulin shots, which I had to do twice a day for a year, until the doctors lowered my dosage of prednisone.

I thought, *This is the prime of your life*. But that year was awful. At a family picnic that summer, my cousin did a double take when she saw me. At my college graduation, people stared. I left right after the ceremony. I was also tired all the time.

I never wanted to go anywhere.

One good thing did happen: A year after my diagnosis, Louis asked me to marry him. I was so happy that I almost forgot about having lupus. For our honeymoon, we'd planned to go skiing in Austria. But my hips had started to hurt. Because of the lupus and the medication, I had developed a condition that wasted away my bones.

After our honeymoon, the doctors set a date for hip surgery. They didn't want to do a full hip replacement because I was only 24; they thought a fibular graft might be enough. The procedure involves grafting part of your leg bone onto your hip bone to strengthen it. They had to cut my leg open from hip to ankle. I cried all night before the operation.

When I was released, I was on crutches. Months after the operation, I was still in pain. When my other hip started deteriorating, the doctors decided that I should have both hips replaced. After that, I wasn't in pain anymore, but I couldn't jump up and down, run or sit cross-legged.

Blindsided, again

Just when my disease seemed to be stabilizing, I started to feel strangely ill. My family had booked a trip to the Dominican Republic, but days before leaving, I felt nauseous and achy. I thought, *Not again*. Then, out of the blue, it occurred to me that I might be pregnant. Louis and I had been having unprotected sex for years and I'd never gotten pregnant, so it seemed impossible, but I went to the drugstore and bought a test anyway. Days later, I took the test, and it was positive. I was terrified. I barely had time to talk to my doctor before getting on the plane, so Louis and I kept it quiet. Halfway through the trip, I broke down and told my mom. She freaked out. We were both scared that I'd get sicker.

When I got home, the doctors told me that I'd probably miscarry late in the pregnancy. I might get a lot sicker, or even die. Louis and I had given up on having a family years ago. But now, we decided to go for it.

The pregnancy made me feel awful. The doctors increased my dosage of >>

