

Unstoppable

Powerhouse Tiziana Tolfo refuses to let lupus slow her down.

PHOTOGRAPHY BY EDWARD POND

TIZIANA TOLFO IS A vivacious 39-year-old with an infectious laugh and bigger-than-life personality.

She also has a severe form of lupus, a group of autoimmune diseases that cause inflammation in the skin, muscles and joints. The heart, lungs, kidneys, blood vessels and the nervous system can also be compromised.

Tiziana was diagnosed at the age of 20, and over the past 19 years she has endured more tests, specialist visits and hospital stays than most people twice her age. But she's Tiziana, so she's not just optimistic, she's making lemonade from the big bag of lemons life has tossed her way.

"This isn't the way I pictured my life,"

explains Tiziana. "But you know what? Life is good right now – I want to do as much as I can when I am feeling well."

Life has not always been so good. Tiziana was a healthy child and adolescent, so when she experienced a sudden rash, extreme fatigue, fever and swollen joints for two weeks during her final exams in college, she was surprised but not >



Tiziana Tolfo with husband, Louis, and son, Justin

especially worried. She finally made time to see the doctor, who immediately suspected lupus and sent her to a rheumatologist. The rheumatologist confirmed the diagnosis and admitted her to hospital, where she stayed for three weeks.

“It all happened so quickly,” says Tiziana. “I barely understood what lupus was. It seemed inconceivable that one month earlier I felt entirely normal. I cried constantly.”

The sun shone brighter in 1990 when Tiziana married Louis Tolfo, the love of her life and her anchor when the disease incapacitates her. She continued to be treated with prednisone, a common and effective therapy for treating lupus patients, but one that can cause weight gain, hair loss, mood swings, diabetes, bone loss and osteoporosis. Following her wedding in 1990, Tiziana underwent a fibular graft, surgery she describes as “hell.” This surgery preceded two hip replacement surgeries in her mid-20s, and two revision surgeries several years later.

Tiziana’s greatest challenge came in 1998 when she discovered she was pregnant.

“Pregnancy is supposed to be filled with excitement and joy, but all I could feel was a tremendous fear,” she says.

Pregnancy for women who have lupus is challenging. Unlike other arthritis and autoimmune diseases such as rheumatoid arthritis, in which the disease often goes dormant during pregnancy, women with lupus are still susceptible to flare-ups, increasing the risk of complications to the mother and child. After a very difficult pregnancy, Tiziana and Louis welcomed their son, Justin. As Tiziana struggled to bring her body back to good health, she worried about her baby who, born just shy of 30 weeks, had his own set of challenges to face. Following six weeks in the hospital, Justin was sent home and is now a healthy, happy eight-year-old.

Tiziana describes her journey as a wild roller-coaster ride. “I’m on an involuntary path, but I continue to find strength through the support of the wonderful people I have around me.”

So – what advice would Tiziana give to newly diagnosed patients?

“I would tell them to hang in there, to stay strong. I would tell them that there is light at the end of the tunnel. Take it one day at a time, and do everything you can do today – don’t put it off until tomorrow.” ●



DID YOU KNOW?

- **Lupus affects more than 50,000 Canadians.**
- **Women are affected by lupus up to 10 times more often than men.**
- **Lupus is a systemic illness, affecting not only the joints and tissues but also the blood vessels, lungs, heart, kidneys and brain.**
- **In the past four decades, lupus mortality has diminished from more than 50% at five years to current levels of less than 20% at 20 years.**

*Sources: Toronto Western Hospital Lupus Clinic, Arthritis Community Research & Evaluation Unit

The Lupus Clinic at the Toronto Western Hospital was established in 1970 as a patient-care referral centre designed to promote expert care for patients with lupus, to train future rheumatologists and to facilitate research into this disease. Today Drs. Murray Urowitz, Dafna Gladman and Paul Fortin oversee the care of more than 1,280 patients who are registered in the Lupus Clinic. One of the largest centres for specialized lupus care and research in the world, patients in the clinic are evaluated according to guidelines established by lupus experts, including a detailed history, physical examination and blood and urine tests.