

# Living with lupus

Krembil researchers have studied lupus for half a century. They're now looking at new ways of treating, and potentially stopping, this debilitating disease

By Anna Sharratt

THIS SUMMER, LIZ ATTFIELD hopped into her car and drove for two hours to Muskoka, a cottage community north of Toronto. The Rolling Stones were playing a rare outdoor show, and she wasn't going to miss it. However, attending a concert under the blazing sun and with thousands of other people isn't easy for Attfield. She suffers from lupus erythematosus, a chronic autoimmune disease in which the body can attack the joints, skin, kidneys, blood cells, brain, heart and lungs.

Indeed, the event led to a flare-up. "I was outside all weekend - and the sun isn't good for lupus," she says. "I only have so much energy, and I have to be careful about expending it."

As one of the 35,000 Canadians who have lupus - it usually

strikes between the ages of 15 and 44 - Attfield is well versed in pain management. She's been dealing with symptoms since she was 14. "I had gone trick-or-treating and I could barely walk up the stairs," says the now 44-year-old marketing and fundraising executive.

Since she was diagnosed at age 17, Attfield has been treated by Dr. Murray Urowitz, director of the Lupus Clinic at Toronto Western Hospital and a senior scientist at the Krembil Research Institute. She has received corticosteroids and drugs to suppress her immune system, which have effectively controlled the disease.

Still, life with lupus has challenges. Attfield never thought she could have a child, as lupus patients have high-risk pregnancies. "I knew there was a chance I wouldn't be able to keep the pregnancy," she says. "That was the hard part."

And she did have trouble conceiving. Fortunately, in 2011, she delivered a healthy baby girl. "She was three weeks early," recalls Attfield. "But I had a great medical team. I am so grateful for my daughter."



Dr. Dafna Gladman Senior scientist, Krembil Research Institute

#### A POTENTIALLY FATAL DISEASE

Many people don't realize how serious lupus can be. It can cause severe joint pain, skin lesions, extreme fatigue and organ damage, as well as fatal strokes and heart attacks. In fact, it is one of the leading causes of death in voung women. New treatments and medications are sending the condition into remission, giving new hope to patients.

Krembil's researchers are working to identify biological molecules in blood and urine that may predict how lupus will develop. They're looking at ways to deliver earlier treatments



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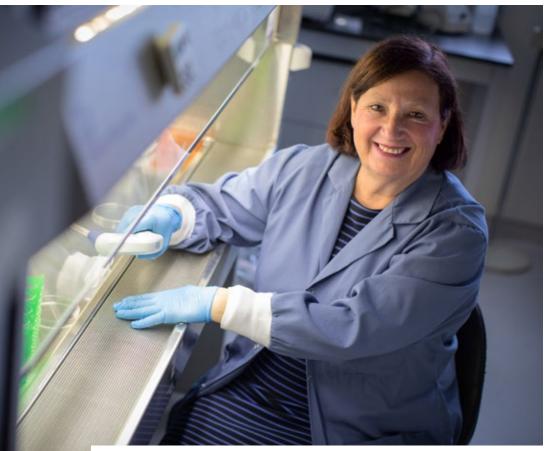
to help reduce irreversible organ damage, and they're gathering information related to the long-term health complications, such as premature cardiovascular disease, osteoporosis, bone damage and cognitive impairment.

However, lupus presents differently in every patient. Examining a patient's genetic, environmental and lifestyle factors can help predict which organs could be impacted and how responsive the disease may be to different treatments. "We understand much more about lupus than we did 10 years ago," says Dr. Dafna Gladman, a rheumatologist and senior

scientist at Krembil. "But this complicated disease requires a tailored approach."

#### THE DISEASE OF MANY FACES

Lupus can present as any number of diseases that occur due to immune system dysfunction, savs Dr. Urowitz. Since many of the 90 genes that have been linked to lupus are also found in healthy people, scientists are looking at how these genes interact with one another and produce the disease. "A specific gene might predispose a person to lupus, but only if it is present with other lupus-related genes or specific environmental triggers," says Dr. Joan Wither, a Krembil senior scientist. She's studying how Type 1 interferons, proteins that are elevated in lupus patients, disrupt immune function and interact with other types of lupus-predisposing genes. If Dr. Wither discovers a link between these proteins and the onset of lupus, stopping their formation or blocking their



Dr. Joan Wither hopes that by stopping specific proteins from disrupting immune function, she can prevent lupus' onset.



Dr. Murray Urowitz leads the Lupus Clinic at Toronto Western Hospital.

function could possibly halt the disease's progression.

Dr. Wither's studies into the immune basis of lupus also extend into other systematic autoimmune rheumatic diseases, such as scleroderma and Sjögren's syndrome. Dr. Sindhu Johnson is director of UHN's scleroderma clinic. Dr. Johnson is also playing a leadership role globally in defining criteria that enable doctors to accurately classify such rheumatic diseases.

A unique multidisciplinary Sjögren's syndrome clinic has been established by Dr. Arthur Bookman. This clinic provides one-stop care for this autoimmune disease, incorporating experts from rheumatology, dentistry, ENT and ophthalmology.

### MORE DATA, BETTER OUTCOMES

Dr. Zahi Touma, a clinician investigator with Krembil, has enrolled more than 300 lupus patients into a screening program that uses computer questionnaires and performance-based tests to detect cognitive changes, such as a decline in memory and thinking speed, attention and planning abilities. An-

other platform, PROMIS (Patient-Reported Outcomes Measurement Information System), will help doctors assess the different aspects of a patient's quality of life, explains Dr. Touma.

This data has led to many advancements in lupus research over the past 20 years, and will help doctors better understand how the disease progresses and how different treatments might work on specific patients. This can allow for a more personalized treatment regimen, adds Dr. Urowitz.

There's also been significant progress in treating pregnant lupus patients, like Attfield. Researchers have found that patients have the best chance for success when they're clinically inactive before getting pregnant, if they're put on the right medications and if they're monitored regularly. The Lupus Clinic has so far helped more than 450 patients have healthy babies. "This is why we do what we do," says Dr. Urowitz.

Attfield is happy that her lupus hasn't defined her life. "I've had a successful career, and I have my daughter," she says. "I think I've done a pretty good job of having a normal life." ()

## **Fighting arthritis for 40+ years**

### FOR MORE THAN FOUR DECADES.

University Health Network's Arthritis Program has been a global leader in arthritis-related research and treatments. Naturally, it's taken years of hard work by numerous medical and scientific teams working together with patients and volunteers to get to this point. "It has involved many champions over the years," says Dr. Mohit Kapoor, research director of the Arthritis Program.

The program has taken a multidisciplinary approach to research, education and clinical care, with a focus on orthopedics, rheumatology, hand and osteoporosis. This "complete approach," as Dr. Kapoor puts it, has been a recipe for success. "One day we will stop arthritis in its tracks."

The Campaign to Cure Arthritis, started in 2011, has been instrumental in fasttracking discoveries and accelerating their translation to improve care for patients. Philanthropy has played a huge role in the success of the Arthritis Program. Every fulltime doctor in the program has pledged a donation to the Campaign to Cure Arthritis. Their dedication has inspired hundreds of people living with arthritis and their loved ones to donate generously to the program, too. "These donations help us to continue our work as world leaders in arthritis research, education and patient care." Dr. Kapoor. "We are so grateful."

## Cure Arthritis Join us on our mission to cure

Canada's first lupus study of databank is established arthritis First in North America to perform arthroscopic surgery CAMPAIGN **TO CURE** ARTHRITIS LAUNCHED First interdisciplinary spine assessment clinic established Opening of Buchan Arthritis Research Centre in newly constructed Krembil Discovery Tower

