



It's a young person's problem, too

Most people don't realize arthritis affects thousands of teenagers and young adults. Here's why that matters and what Krembil Research Institute scientists are doing about it

By Elizabeth Chorney-Booth

Susan Rivers was just 10 when she experienced "growing pains." It turned out to be a form of arthritis, which she's learned how to manage over time.

The back and leg pain started when Susan Rivers was just 10 years old. Her family doctor – followed by a succession of other physicians – told her parents the aches were a simple side effect of growing. But as other kids' "growing pains" dissipated, Rivers' back issues got progressively worse. Both she and her family believed it went beyond normal adolescent discomfort. Yet, it never occurred to Rivers' physicians that she could be suffering from arthritis, a condition commonly associated with old age.

By the time Rivers graduated from high school in Parry Sound, Ont., she had spent nearly half her life in often debilitating pain. The sporadic stiffness and aching she'd experienced as a child had grown more frequent, and Rivers could no longer ignore it or shake it off. "I felt old, but I wasn't old," she says. "It was very frustrating."

At the age of 18, Rivers was referred to a rheumatologist, who diagnosed her with ankylosing spondylitis (AS), a form of arthritis that triggers inflammation of the vertebrae, causing severe pain. If it goes untreated, AS can also cause permanent damage to the spine, limiting mobility. "My first reaction to the diagnosis was, 'I'm not crazy,'" says Rivers, now 38. "It was something this whole time."

When Rivers first met Dr. Robert Inman, a rheumatologist and medical director of the Arthritis Program at University Health Network, as well as a researcher at the Krembil Research Institute, 20 years ago, she was struggling. She had started attending university, but she couldn't climb stairs or walk more than short distances, and her medical team had a hard time finding drugs that worked without causing unacceptable side effects, such as nausea, headaches and dizziness. Rivers withdrew from her friends and found it difficult to pay attention in class because it hurt to sit. It took her 10 years to complete her degree. "I went through an extreme depression," she says. "I was

in a lot of pain and thought, what is the point of living if you can't live your life?"

IMPACT ON THE YOUNG

Rivers is far from alone in her story. Dr. Nigil Haroon, co-director of the Spondylitis Program at Toronto Western Hospital and a scientist at Krembil, says that spondyloarthritis – a group of inflammatory diseases that impact the joints, along with the sites where tendons and ligaments attach to bones – affects just over one per cent of the population, or more than 300,000 Canadians, nearly all of whom get it when they are between 15 and 40.

People are usually surprised by the diagnosis. But young people suffer from a variety of arthritis types – rheumatoid arthritis has similar occurrence rates as AS, and osteoarthritis, which is typically associated with aging, can also affect the young. Dr. Haroon hopes that by educating the medical community about recent advances in diagnosing AS, especially in primary care, this may help to reduce wait times for patients to receive a diagnosis.



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Susan Rivers
Arthritis Program patient

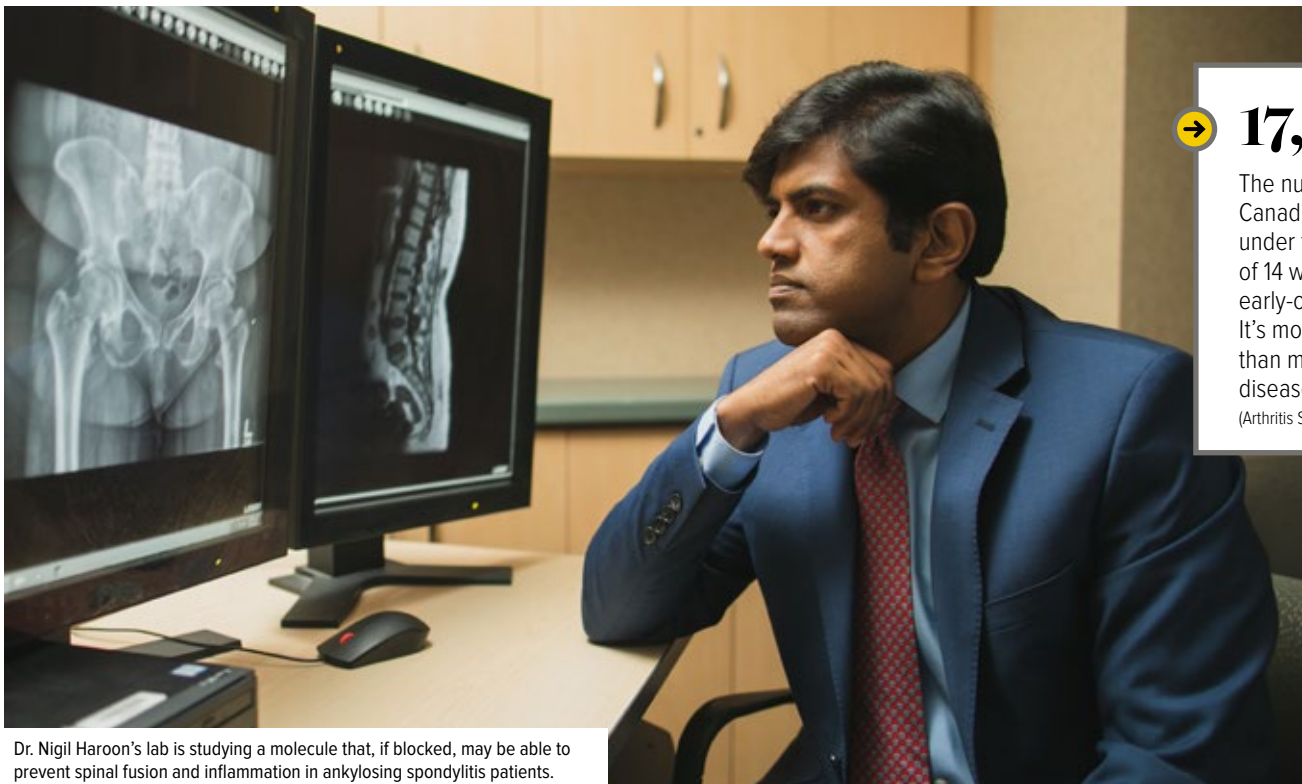


Dr. Vinod Chandran (centre) and his team are hoping to identify a blood marker that can help diagnose psoriatic arthritis.

Some of the signs of AS include morning stiffness that improves with activity and nighttime pain that interrupts sleep. The trouble is those symptoms can also point to other, more easily explained ailments, which means physicians often don't consider a diagnosis of AS and refer to a rheumatologist.

Another complicating factor is that AS comes with no obvious physical signs of inflammation in the back, making it harder to diagnose than, say, rheumatoid arthritis, which produces visible swelling of the joints. There are some telltale clues, however, such as inflammation in the eye or inflammation in the gastrointestinal tract, which could represent an inflammatory bowel disease such as Crohn's disease, says Dr. Inman.

This is all related, because Crohn's and eye inflammation are, like AS, rooted in a patient's immune system. Rheumatologist and Krembil researcher Dr. Vinod Chandran specializes in what's called psoriatic arthritis – a form of arthritis that is either preceded or accompanied by psoriasis, a chronic skin disease that causes itchy scales to form on the skin. Such autoimmune issues are often hereditary, though they might manifest with differing symptoms, which means primary-care physicians should delve into a patient's family history in search of similarities. "You could also see patients in a family where one person has psoriasis, another has Crohn's disease and a third person has ankylosing spondylitis," Dr. Chandran explains. "They're all in the same family of diseases." Dr. Chandran wants to identify blood markers and develop a blood test to help diagnose psoriatic arthritis.



Dr. Nigil Haroon's lab is studying a molecule that, if blocked, may be able to prevent spinal fusion and inflammation in ankylosing spondylitis patients.

→ **17,400**

The number of Canadian children under the age of 14 who have early-onset arthritis. It's more common than most chronic diseases in children (Arthritis Society)

THE IMPORTANCE OF EARLY DIAGNOSIS

Anything doctors can do to diagnose a young patient faster will impact their quality of life. According to Dr. Inman, studies show that AS patients experience back pain for an average of five years before getting a diagnosis. It's not just five years of pain, either: AS and other forms of early-onset arthritis often cause significant fatigue, and many patients – like Rivers – experience depression as they watch their peers build careers and have families. “It certainly impacts patients’ recreational activities and has a very significant impact on work productivity,” Dr. Inman says.

Typically, AS is diagnosed with an X-ray that shows changes in a patient’s sacroiliac joint in the pelvis, but new research has shown an MRI can confirm an AS diagnosis before those changes even start happening. That’s crucial, because Dr. Inman is seeing evidence that early diagnosis can slow down the progression of the disease, which can cause significant disabilities as patients age. If left unchecked, chronic arthritis of the spine can cause the spine to fuse together, meaning patients end up with very limited mobility and a deformed posture.

Fortunately, there are treatments available. Exercise and physiotherapy, along with anti-inflammatory drugs, can help alleviate symptoms. Krembil researchers are also studying the use of biologic drugs that work to slow the progression of the disease. Dr. Haroon pub-



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Dr. Robert Inman
Medical director, UHN Arthritis Program

lished a landmark study in 2018 that showed drugs that target a molecule in the blood called TNF can decrease the chance of AS progression by 50 per cent.

But there’s a short window of opportunity for achieving optimum results, says Dr. Haroon. The potential to slow progression is at its highest if treatment is started within the first few years of symptoms appearing. Dr. Haroon hopes that, one day, AS can be stopped altogether. “My lab is studying a molecule that can drive both inflammation and bone formation,”

he says. “If we are successful in blocking this molecule, we hope we can directly block both spinal fusion and inflammation in AS patients.”

All of this is great news for patients like Rivers. Through a clinical trial with Dr. Inman, she was able to find a biologic drug that alleviated many of her symptoms with no significant side effects. “After my treatment started, I improved so much, I thought I was cured,” she says. “I could even jump on the trampoline with my sister’s kids. I could work more hours and make money, rather than depending on my family to help.”

There have been hiccups: In 2007, UHN’s Dr. Rod Davey performed a double hip replacement because Rivers’ joints were already damaged so much that she could feel bone grinding on bone. But she recovered quickly, thanks in part to her age, and in the intervening years she has gone from a young woman struggling with chronic disease with little hope for a pain-free future to an active person who is able to fully participate in work and family life.

Where once Rivers needed assistance to perform routine physical tasks, she now has two jobs — working in administration at the front desk of a local hospital and as a part-time waitress. Her condition hasn’t disappeared, but finding the right treatment means she can look forward to a good quality of life for years to come. “I never thought children could get arthritis,” says Rivers. “It turns out, that’s what I had this whole time.”