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— Dr. Lori Tucker, B.C. Children's Hospital

ARTHRITIS AFFLICTS ALL AGES

BY ALEXANDRA LOPEZ-PACHECO

Not that long ago, people who suffered from arthritis were advised to take it easy and avoid too much physical activity.

“Now we know it's exactly the opposite — they need to get out there and get moving. And that in itself is an important research finding,” says Jane Aubin, scientific director, Canadian Institutes of Health Research (CIHR) Institute of Musculoskeletal Health and Arthritis (IMHA). “People's understanding of musculoskeletal conditions, including arthritis, is still really behind that of a lot of other conditions. Many people don't even realize arthritis can affect individuals of all ages, including children and even babies. So IMHA is anxious to fund research that really addresses the spectrum of the disease in all ages.”

Not only does juvenile arthritis affect children, it is one of the most common chronic childhood diseases, although according to a 2010 Ipsos Reid survey, 80% of Canadians are unaware of this. In fact, juvenile idiopathic arthritis affects one in 500 Canadian children, causing pain, stiffness, difficulty doing everyday tasks and lower levels of physical activity compared with healthy children. Sadly, researchers have found that although

the average period of time it takes for a child with arthritis to be diagnosed is about four months, there are children who have arthritis for a year or longer before they are properly diagnosed.

When children suffer from arthritis, not only do they suffer from the pain and stiffness and fatigue associated with the condition, they are also at risk of it affecting their development and growth — mostly, it is believed, due to lack of sufficient physical activity.

“When children are less active, their muscles don't develop as much strength or even as large as they should. When you're growing it's muscles acting on bone that cause your bone to become stronger,” says Dr. Lori Tucker, Division of Rheumatology, B.C. Children's Hospital in Vancouver, who is part of the team of a major research project supported by CIHR through IMHA that is studying physical activity in children with juvenile idiopathic arthritis and its influence on the disorder, the children's quality of life and their bone and muscle growth and development. This research is a collaboration of pediatric rheumatology centres from all across Canada, and will involve 900 children with arthritis over a five-year study period. It will also include novel exercise programs aimed at increasing physical activity safely while improv-



Arthritis denies many Canadian children the opportunity to enjoy a normal day of play.

ing the children's muscle and bone strength.

“There is a general misconception that kids grow out of juvenile arthritis, but they don't. Sixty to 70% of kids with arthritis will continue to have problems with the condition into adulthood, particularly if they are inactive because of the other factors. We need to do this kind of study so they become healthy and functioning adults,” Dr. Tucker says.

Another major research project being supported by the Institute of Musculoskeletal Health and Arthritis is

also focused on long-term prevention. Although few people would associate hip osteoarthritis — the condition that is often treated with a hip replacement when it reaches its most severe stages — as a disorder of the young, researchers now believe in fact that this condition as well could begin early in life.

“Generally, you start to see hip osteoarthritis after age 40 unless there was a congenital anomaly, in which case it could be earlier. But that's diagnosed hip osteoarthritis with x-ray changes,” says Dr. John Esdaile

from the Arthritis Research Centre of Canada in Vancouver, who is working with a team to explore the link between physical activity and hip osteoarthritis. “What we're interested in now is that it probably starts long before you have the advanced disease, which causes pain. It may well be like heart disease. A person might not have a heart attack until their forties, but if you look at obese children there are already changes to the arteries in their heart.”

Although the cause of 90% of all hip osteoarthritis re-

mains unknown, Dr. Esdaile and his team are researching the possibility that in many cases it could be due to bumps some people are born with either on the hip bone or in the socket. “And with a lot of hip flexion, you either bring the hip bone into contact with the socket, or if the bump is on the socket, you're bringing that bump into contact with the hip bone. The consequence is that the gristle in the hip bone starts to get damaged, and this is the beginning of the process of hip osteoarthritis. So we are studying if people who have this bump and are involved in very intense hip-flexion sports such as hockey or skating, soccer or skiing, bicycling or martial arts could from a young age be starting to damage the cartilage and starting the process that will gradually become irreversible.”

This research could make it possible one day to empower young people with the knowledge of how to prevent getting hip osteoarthritis later on in life simply by taking up a sport such as swimming instead of cycling or at least not getting intensely involved with intense hip-flexing sports.

“We were lucky to get the funding, because a lot of people said thinking you can prevent osteoarthritis is a crazy idea,” Dr. Esdaile says. “But IMHA recognized that if we're right, it's going to have such a huge impact.”

Researchers, consumers unite to take on arthritis

BY MARY TERESA BITTI

In a case of strange serendipity, Dawn Richards was working with the Canadian Arthritis Network (CAN) when she was diagnosed with rheumatoid arthritis. In fact, she had just stepped into her role as director of research and development shortly before she was diagnosed in early 2007. She was 32, a runner, fit and healthy.

“Now, when I look back, the symptoms probably started two years before I was diagnosed,” Dr. Richards says. “I had a lot of fatigue, a general unwell feeling, dizziness later in the day. About a year before I was diagnosed I had morning stiffness and swelling of my feet.”

Her family doctor blamed it on her running and preference for high heels. Eight months later, her wrists and arms became weak. “I couldn't pick up a pitcher of water. I couldn't open the door with one hand. I was having trouble with some of my exercise. That's when I decided there was something more wrong than I run a lot and wear high heels.”

Rheumatoid arthritis is an autoimmune disease. Joints become swollen because the body thinks there is something foreign in the joint space even though there is not and it sends in molecules to attack what it thinks are invaders, which leads to inflammation. Once there, the molecules start to secrete enzymes in the joints. “If I wasn't diagnosed, I could have had significant joint damage,” Dr. Richards says. “I was lucky.”

She was put on an aggressive cocktail of anti-inflammatory and disease-modifying medications to slow and help stop the progression of the disease. Dr. Richards kept up her exercise regimen and long-distance running, including annual participation in a 30-kilometre race to raise money for the Sick Kids Foundation's research into juvenile arthritis. “I did not stop exercising because it is part of my life ... Though I remember ending a run one day and thinking what happens if I can't do this any more? But

I don't dwell on it; the fact is with rheumatoid arthritis you never know what's around the corner.”

Today Dr. Richards is in remission, training for the Chicago Marathon. She also moved into advocacy, as co-leader of CAN's Consumer Advisory Council, a group of patients working with researchers. “Having a positive outlook, staying active and taking control by being involved in the advocacy network is empowering.”

The Consumer Advisory Council created the Highly Qualified Consumer (HQC) Database to encourage people with arthritis to work as collaborators or consultants on arthritis research so they feel empowered and directly connected to research. “We are trying to make consumers who want to be research collaborators more accessible to the researchers,” Dr. Richards says. “Researchers can access the site [and] choose the attributes they would like in a collaborator ... That information [is] forwarded to someone at the CAN office who acts as a broker connecting the two groups. CAN has created a different model for consumers and researchers so the consumer becomes part of the research team, not just someone who is delivered the results at the end.”

It is a model that Dr. Michael Hunt, assistant professor in the Department of Physical Therapy at the University of British Columbia and network investigator through the Canadian Arthritis Network, appreciates and is using in his own research. With funding from CAN, Dr. Hunt is studying biomarkers and knee osteoarthritis and the effects of exercise on joint load. “The database is fantastic. When I started at UBC a lot of the work I'd done had been researcher driven,” Dr. Hunt says. “It wasn't until I got involved with CAN that I started to get involved in patient-informed research.”

His latest research project will examine two questions: Is there a relationship between specific biomarkers of cartilage degradation and synthesis and

joint loading? And does exercise aiming to reduce joint load lead to a change in biomarkers?

“Arthritis is the breakdown of cartilage, the smooth lining found at the ends of bones that helps to permit smooth efficient movement and redistributes load through the knee joint,” Dr. Hunt says. “Some people say that arthritis is a ‘wear-and-tear’ disease and for the most part that's true in the sense that people who have a lot of load through their knees, hips, ankles tend to develop osteoarthritis earlier. When the cartilage gets broken down, those molecules and proteins get released into the blood. Through blood tests we can measure the levels of proteins and have found that certain proteins are more prevalent in people with osteoarthritis. My work is focused on marrying the biomarkers with the biomechanics to measure the load going to the joints in people with osteoarthritis.”

To do that, he has recruited 20 patients with knee osteoarthritis to measure levels of cartilage biomarkers, joint load during walking, muscle strength and self-reported pain and function. The goal is to see if people who exhibit high levels of biomarkers also exhibit high levels of joint load during walking, to better understand the disease and how these biomarkers can be used in early detection or to monitor the patients as they progress through the disease. The patients will then be put into either an exercise group or non-exercise group. All will come back after 10 weeks to re-measure the biomarkers, joint load and strength.

“We already know that exercise is good at reducing pain and making people more functional. Unfortunately, there is no evidence to show that exercise protects against disease progression,” Dr. Hunt says. “We hope to show that these biomarkers are reduced after an exercise program. By implementing exercise interventions we want to slow the progress of the disease. We want to come up with approaches, treatment and exercises in particular that will not only improve pain and function but are good structurally for the knee.”

Dr. Hunt plans to present the findings in the fall at CAN's annual conference in Quebec City (www.arthritisnetwork.ca).

SPECIAL SUPPLEMENT FEATURE

RA inspires author to cook-up recipes for success

One night in her twenties, Melinda Winner woke up in unbearable pain and could not move her legs. After speaking with a rheumatologist, she learned she had rheumatoid arthritis (RA).

“I was very young when I first got sick, and didn't realize I was ill,” says Winner. “Once I had diagnosis, the damage had already progressed to the point that it caused an extreme disability. I thought any hope of living a normal life was gone, much less pursuing my dreams.”

After her diagnosis, Melinda gained more than 100 pounds and could barely recognize the person in the mirror. Unable to do simple everyday tasks or play with her children, she knew she had to make a change. “For years, I allowed my disease to define who I was. One day I realized that my life was passing me by, and knew I had to take control of my RA,” she says.

Although Melinda's RA made it difficult to use her hands, as a mother of three, she could not let her condition stop her from cooking healthy meals for her family. With fond memories of cooking with her mother as a child, Melinda was determined to cook again.

Working with her rheumatologist to find treatment that was right for her, Melinda's perseverance

and creativity prevailed. She got back into the kitchen, and developed some simple techniques to help her — like tying a ribbon to the refrigerator door to use her arm and body weight to open it, and using a small funnel to help

separate the egg yolks from the whites. She also recognized that cooking could be an issue for others living with arthritis.

In 2009, Melinda wrote A Complete Illustrated Guide to

Cooking with Arthritis, sharing her tips and tricks to help those living with RA regain their independence in the kitchen.

Melinda now enjoys preparing food of all types, from simple Southern to fine cuisine. She has won more than 50 national recipe contests and participated in a cook-off on a major television network. With three grown children and five grandchildren, in her spare time, Melinda now also enjoys horseback riding, swimming, traveling and hiking.

“RA is a progressive disease that can lead to permanent joint damage,” says Winner. “If you know, or think you may have RA, go see a doctor right away. It's so important that you get diagnosed, see a specialist and get treatment. They can't stop the disease, but they can certainly slow the progression and help you take control of your RA.”

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