By Kristi Whitney-Mahoney
and Jo-Anne Marcuz

March is Juvenile Arthritis Awareness Month

Juvenile idiopathic arthritis (JIA) affects 1 in 1000 Canadian children under the age of 16. That makes it more common than cystic fibrosis and childhood diabetes. JIA is an umbrella term that is further classified into seven subtypes characterized by their disease course and features. These subtypes range from mild disease limited to 4 or fewer joints to those with polyarticular involvement and/or significant systemic, extra-articular manifestations, such as serositis or eye inflammation (uveitis). The disease severity and prognosis is variable even within a subtype but we now know that this is not a disease that children will "outgrow" with up to 2/3 having disease persist into adulthood.

Children are not "little adults" and have unique clinical presentations that are important for the Physiotherapist (PT) to be aware of. For example, a typical presentation may be that of a two year old that has stopped walking and reverted to crawling with a noted swollen knee in the absence of any known trauma. Older children and adolescents may present with a gradual decline in participation in their higher level activities and fatigue. The symptoms of JIA can vary greatly between individuals and even within an individual over time with periods of remission and exacerbation. All JIA is characterized by joint swelling (synovitis) noted in at least one joint that persists for at least 6 weeks with all other causes having been excluded.

JIA also has the unique opportunity to impact the developing child and their skeleton, resulting in alterations in gross and fine motor development and physiological changes to growing bones. Open growth plates respond to inflammation by demonstrating increased maturation and alterations in growth. As a result, early development of the carpus can be noted on radiographs of affected wrists, or accelerated growth of long bones such as the femur resulting in a leg length discrepancy. Undergrowth in other areas such as the mandible and digits can also be observed resulting in jaw deformity and orthodontic concerns and shortened fingers or toes. Early identification

and eradication of inflammation can prevent or minimize these sequelae.

With significant medical advances made over the last decade the majority of children and teens with JIA have good control over their symptoms and lead normal, active lives. These disease modifying advancements have also directly changed the role of physiotherapy.

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Historically, PTs would focus on a gentle approach to rehab with activity restriction, splinting and accommodations. Early and effective medical therapies aimed at control of inflammation have allowed most children and teens with JIA to experience dramatically less physical disability and complete return to full participation in age appropriate activities.

Physiotherapists may be the first health provider to see a child with JIA. Early identification and triage to specialty care (paediatric rheumatologist) is key in ensuring access to appropriate and aggressive treatment and optimization of outcome. Once the diagnosis is confirmed they can help to provide strategies to decrease pain and stiffness and maintain movement in the acute stages of the disease. As the inflammation resides a PT can assess and monitor the disease and advise how to improve physical abilities and fitness levels and return to activity, sport and competition safely. Resources for families and providers can be found on "About Kids Health" at SickKids (www.aboutkidshealth.ca) and via The Arthritis Society (www.arthritis.ca).

The care of kids with JIA in Ontario is also complemented with the implementation of a unique model of care; the "Extended-Role Practitioner" (ERP). SickKids piloted a "Physical Therapist Practitioner" model in 1994 to enhance the care of children with JIA. This pilot project was a success and an expanded program was born, training two additional physiotherapists (including a Northern Ontario candidate) and became inter-professional with addition of an occupational therapist. Subsequent to this, the Advanced Clinician Practitioner in Arthritis Care (ACPAC) program was born out through collaboration with SickKids, St. Michael's Hospital and the University of Toronto. This program has graduated more than 30 individuals practicing across the province with 4 PTs and 1 OT specializing in the care of paediatric rheumatic disease.

The ERP roles provide support to facilitate new diagnosis of JIA and other rheumatic diseases as well as a strong role in the delivery of on-going follow up care. The provision of care includes the ability to communicate a diagnosis, make referrals to other specialists and order investigations (including diagnostic ultrasound, x-rays, MRI and a variety laboratory tests) and is facilitated with the use of medical directives. The ERP role provides quality care that is accessible, timely, consistent and efficient. It allows the paediatric rheumatologist to see those patients most in need of their expertise and assists in ensuring that the right person is seen by the right provider at the right time, depending on their current needs. High levels of satisfaction have been demonstrated both on the part of the child/family and the provider. These roles continue to grow, meeting the needs of children and families with JIA across the province. For more information on the ACPAC program, please visit the website at http://chronicdiseases.ca/. Ultimately, the hope is that a program such as ACPAC will serve as a model for education that will enhance the provision of care to a variety of chronic disease populations utilizing the expertise of the physical therapist.

The care of children with JIA is best provided by an inter-disciplinary team with unique expertise in childhood arthritis. The Physical Therapist, both traditional model and extended role practitioners, plays a critical role in the identification, treatment and follow-up care for children with arthritis and their families. The goal of promoting early disease identification and timely access to care should be at the forefront of the Physical Therapist seeing a child with suspected arthritis.*