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## **Teens Take Charge: A new evidence-based online resource for teens with juvenile idiopathic arthritis (JIA)**

### **Research at CHEO makes an impact**

It is a common assumption that arthritis is a disease that affects adults only, however an estimated 24,000 Canadian children and teens live with one or more forms of childhood arthritis, of which juvenile idiopathic arthritis (JIA) is the most common, affecting about 10,000 (one in 1,000) children in Canada.

JIA causes inflammation in the joints and impacts kids' and teens' physical, emotional and social wellbeing.

In an effort to help teens with JIA better manage their arthritis and improve their transition to adult health care, a team of researchers from 11 academic centres across Canada, including the Children's Hospital of Eastern Ontario (CHEO), developed and tested an online program called 'Teens Taking Charge: Managing JIA Online Program', which is now publicly available on [aboutkidshealth.ca](http://aboutkidshealth.ca).

This project was led by Dr. Jennifer Stinson at The Hospital for Sick Children (SickKids), and the primary investigator at CHEO was Dr. Ciaran Duffy, Chief of Pediatrics. About 30 CHEO families participated in this study; kudos to everyone Clinic C-1 for their support and efforts to advance this project.

"This is a wonderful educational resource for teens with JIA, who through being better informed about their disease and its management, will have a better quality of life," says Dr. Ciaran Duffy, Chief of Pediatrics at CHEO and senior scientist at the CHEO Research Institute.

"As teens mature and gain independence in many areas of their lives, they are similarly expected to take on more responsibility for managing their arthritis," says Dr. Stinson, principal investigator of this research and Nurse Clinician-Scientist in the Chronic Pain Program at SickKids. "Previous research indicates that for teens with a chronic condition, learning to manage their complex medical condition on their own is very challenging and if not done effectively can negatively impact their health."

This interactive internet-based program was designed for teens with JIA as well as for their parents as a reliable, easily accessible resource to be used throughout the course of their illness. The content, delivered in 12 modules, was developed by rheumatology health care professionals across Canada. It includes not only information about JIA, its treatments, and self-management strategies (for example, how to deal with physical symptoms like pain, stiffness, fatigue and emotional symptoms like anxiety and depression), but also facilitates peer support through discussion boards, as well as videos featuring patients, their families, and health-care providers offering instruction, personal insight and inspiration.

Feedback from teens and their families was that there was not one reliable place where they could get the information they needed and their questions answered.

“As a teen, I found myself asking a lot of questions about how JIA would affect my future, how it’ll be when I’m in university, what does this mean when I have a job and how long these medications will be affecting my life? Going through the modules in the Teens Taking Charge program helped me better understand arthritis, which gave me the self-confidence to manage what I was going through,” says Madeleine Dempster, 19, former SickKids patient and research participant on this project. “The doctors and nurses have always been great at explaining things to me during my appointments, but this website provides more of a base knowledge and a deeper understanding since I can go through it at my own pace. This is very reassuring and makes me feel more in control of my life.”

The website was tested for effectiveness using a randomized controlled trial of 333 adolescents from 11 paediatric centres across Canada, including CHEO.

“The results so far have shown that teens who used this online resource tended to experienced less overall pain, and less pain interference with sleep and enjoyment of daily life as well as self-efficacy, compared to teens who did not use the site,” says Stinson.

The majority of teens with JIA, as well most chronic health conditions, do not receive comprehensive education, disease management strategies or social support, because of difficulty accessing services, limited availability of trained professionals, and the costs associated with running in-person education programs. Stinson and her team hopes Teens Taking Charge program will help patients develop the skills they need to better care for themselves as they grow up, understand how different lifestyle choices will impact their condition and importantly, learn to advocate for themselves.

To learn more, check out the [full site available on aboutkidshealth.ca](https://aboutkidshealth.ca).