

UCAN CURE: Transforming Care and Optimizing Outcomes of Children Living with Arthritis

By Rae S. M. Yeung, MD, PhD, FRCPC; Alexander Mosoiu, PMP; and Susa Benseler, MD, PhD, FRCPC

Childhood arthritis — juvenile idiopathic arthritis (JIA) — is the most common chronic inflammatory musculoskeletal disease affecting more than 25,000 children in Canada. Many children with arthritis will continue to suffer from active disease as adults, and some will experience severe disability. One in three children with arthritis requires targeted biologic therapies — selected with limited guidance for the individual child and without a treatment end date. Biologic therapy can dramatically improve disease activity and prevent the progression of inflammatory injury to the joints. Some treatments such as the interleukin-1 inhibitors in children with systemic JIA¹ have been shown to change the biology of the disease and prevent disease chronicity when selected and started within an early window of opportunity.

The key challenge remains the clinical and biological heterogeneity of childhood arthritis.² The lack of good clinical and/or biomarker predictors hinders an evidence-based precision health approach. The result is our current trial-and-error approach, where biologics can often only be accessed after failing traditional therapies, resulting in critical delays in accessing effective drugs, exposure to unnecessary risks, and money wasted on ineffective treatments. This imposes not only health risks to the child, but also substantial economic burdens on patients, families, and society.

In 2017, the Canadian pediatric rheumatology community partnered with our Dutch colleagues to establish an international consortium focused on precision health in childhood arthritis. Our research program is rooted in the Canada-led Understanding Childhood Arthritis Network (UCAN) initiative, developed to enable national networks to not only capture clinical data from patients, families, and health care teams but collect biological specimens in a standardized way, supporting national and international collaborations in translational research. UCAN has become an international federation of research networks in childhood arthritis, with a unique focus on translational research. UCAN has built standardized international research platforms to support rapid translation of basic science findings to improve clinical care. Our Canadian and Dutch collaborative research initiatives (UCAN CAN-DU and UCAN CURE) capitalize on the recent, rapid pace of innovations in genomics medicine, eHealth tools and frameworks, and health economics.

Our research agenda was co-developed with children, families, and national family organizations including Casie & Friends. Together, we have built an integrated and

comprehensive precision medicine program, which is developing and delivering novel genomics-based tools to determine when and how specific biologic agents should be safely and effectively used and when they can be discontinued. We have a multi-pronged approach with a core focusing on biomarker science linked to molecular mechanisms, machine learning, economic modelling, and innovative integrated knowledge translation — achieved through the following thematic research programs:

Genomic Science Program

We are developing genomics-based predictive tools to determine when specific pharmaco-therapeutic agents should be safely and effectively used, thus improving outcomes, limiting risk, and reducing socioeconomic burden. Our innovative rapid detection biomarker-based tests for clinicians will help predict risk for long-term disability, enable rapid selection of targeted biologic therapies and help manage safe discontinuation of drugs.

Integrated Health Economics Analysis

We are developing a novel, updatable model of risks, benefits, and costs associated with genomics-based medicine for childhood arthritis. Together with families and pediatric rheumatologists across both countries, we are developing a standardized measurement framework and key performance indicators to measure clinical and economic outcomes; define preferences for the important risks and benefits affecting biologic-based treatment for children with JIA; and model clinical and health policy decisions.

Integrated Precision Medicine eHealth Platform

Our state-of-the-art eHealth platform has transformed patient engagement, joint decision making, and information sharing for the 21st century, supporting clinical management and encompassing the entire patient experience from eConsent to multi-directional information sharing between researchers, clinicians, policy-makers, patients and families, to the gamification of the research pipeline and early education of the future generation of genomic researchers.

Importantly, each of the three key activities is generating important data collection tools, measurement and value frameworks, and patient and physician preferences. These are leveraged and transferred to support multiple current and future research initiatives across the spectrum of childhood inflammatory and rare diseases. The im-

New Resources for People Living with Arthritis

By Trish Barbato, President and CEO, Arthritis Society Canada



In September we shine the spotlight on arthritis for Arthritis Awareness Month.

We launched our fiery new awareness campaign last September and have been working hard over the past 12 months to turn up the heat through all that we do. We recently awarded more than \$1.2M to our inaugural Ignite Innovation Grants, invested in four Arthritis Ideators to help bring their innovations to those who need them most, and launched a new Social Impact program.

And while we've been raising the alarm about the seriousness of arthritis, we've developed new high-impact resources for people living with the disease. This includes our *Your Finances and Arthritis* web pages so that people are armed with important information on topics such as tax credits and benefits.

We've also launched a comprehensive *Pain Management Guide*. Both these resources can be accessed by scanning the respective QR codes to the right.

In addition to regularly adding new resources, we continue to offer our popular monthly Arthritis Talks webinars — which last year reached more than 107,000 people. And we're proud to be supporting a growing number of people through our free Arthritis Line, where people can have their questions answered by phone at 1.800.321.1433 or email at info@arthritis.ca.

Thank you for sharing our resources with your patients and continuing to shine a spotlight on arthritis every day.

Arthritis Pain Management Guide



Your Finances and Arthritis



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pact of the added value has been multiplied in the current COVID pandemic, which has provided unique opportunities for our technologies and platforms to support virtual care in our rapidly changing healthcare system.

Our national funders, including the Canadian Institutes of Health Research (CIHR) and Genome Canada, together with the Stop Childhood Arthritis Initiative at The Arthritis Society, and Dutch partners in ZonMw and RheumaNetherlands have been key enablers of our work. The engagement and commitment of all pediatric rheumatology care providers across Canada and the Netherlands to the UCAN mission of real-life integration of innovative precision medicine strategies into care provision are continuing to transform the care of children with arthritis in Canada and around the world.

References:

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2. Eng SW, Duong TT, Rosenberg AM, Morris Q, Yeung RS; REACCH OUT and BBOP Research Consortia. The biologic basis of clinical heterogeneity in juvenile idiopathic arthritis. *Arthritis Rheumatol*. 2014 Dec; 66(12):3463-75. doi: 10.1002/art.38875.

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