one child every child

Making the Invisible Visible

How families and researchers are changing the journey of childhood arthritis

Co-Impact Narrative Report | 2026

UNIVERSITY OF CALGARY

Making the Invisible Visible

How Families and Researchers Are Changing the Journey of Childhood Arthritis

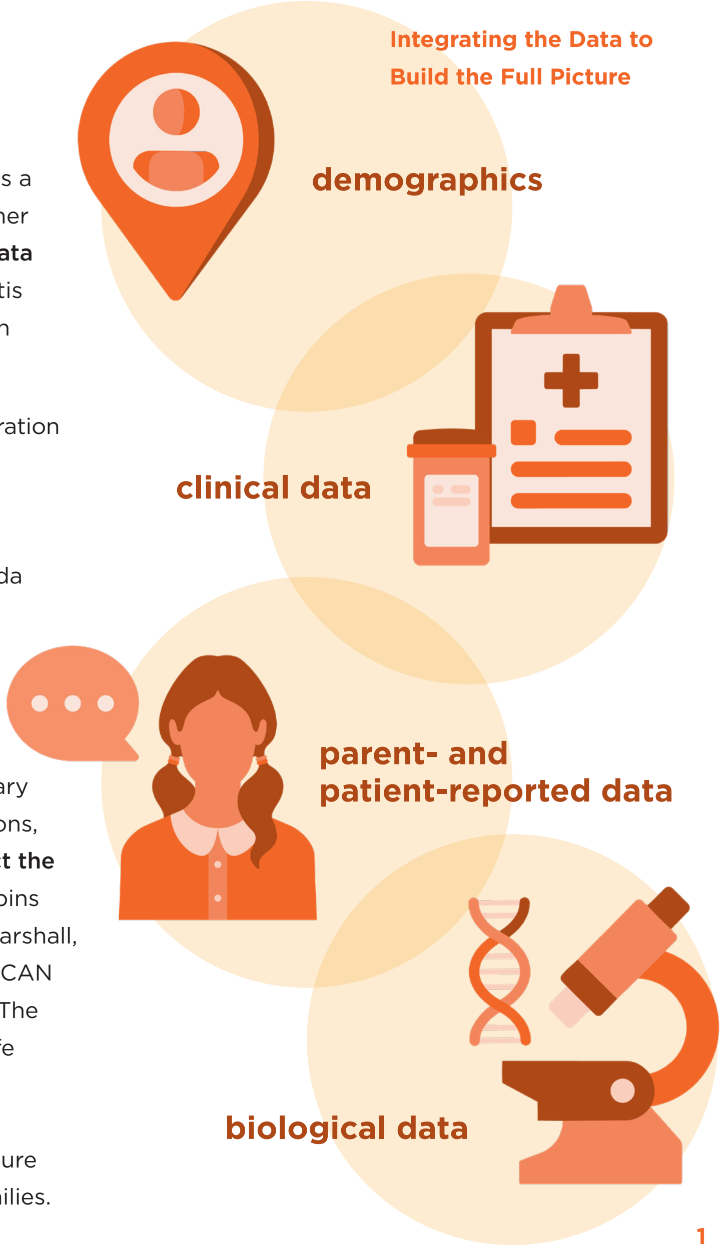
Dr. Deborah Marshall, PhD
Professor and Lead Researcher,
University of Calgary

It often starts subtly. A child wakes one morning and hesitates to stand. Her knee appears swollen, and she moves cautiously. Initially, it seems like a minor injury. But pain and stiffness returns each morning, along with fatigue, and she begins avoiding weight on her leg and does not want to play or go to school. Finally, sometimes after a long process, a diagnosis is made: Juvenile Idiopathic Arthritis (JIA). This marks the start of a long-term journey through chronic disease management that affects children and their families.

JIA affects approximately 10,000 children in Canada. JIA causes persistent joint pain, stiffness, and swelling, which can lead to irreversible damage if untreated. So far, there is no cure. Management focuses on controlling inflammation and preserving function through medications, physical therapy, and psychological support for children. While treatment reduces long-term harm, ongoing care places substantial emotional, physical, and financial burden on families.

ucan can du

Integrating the Data to Build the Full Picture



Research Network and Partnerships

Behind this story of the often unseen impacts of childhood arthritis is a research network working to see the whole picture – bringing together **demographic, clinical, biologic, and parent- and patient-reported data** to understand not just the disease activity, but how childhood arthritis shapes daily life, access to care, and long-term outcomes for children and families that focus on the socioeconomics impact.

Launched in 2017, **UCAN CAN-Du/CURE** is a Canadian–Dutch collaboration co-funded by the Canadian Institutes of Health Research, Ontario Genomics, Genome Alberta, and Genome Canada, alongside Dutch funding partners ZonMW and ReumaNederland. This precision health grant network connects every pediatric rheumatology clinic in Canada and the Netherlands through a coordinated, team-based research model supported by advanced data-sharing infrastructure.

UCAN CAN-Du/CURE aims to help children with JIA get the right diagnosis sooner, the right treatment at the right time and, one day, a cure. Through long-term collaboration between University of Calgary researchers, international partners, and patient advocacy organizations, the program has **collected data and created shared tools that reflect the real experiences** of children and families. This collective work underpins much of the evidence you'll see throughout the story. Dr. Deborah Marshall, Svare Chair in Health Economics, Value and Impact, is a co-lead of UCAN CAN-Du/CURE and leads the network's health economics program. The team focuses on understanding the socioeconomic and quality-of-life impacts that children with JIA and their families face now. This work provides critical evidence to inform policy development, service planning, and resource allocation, to alleviate these burdens and ensure that care systems better reflect the real-world needs of affected families.

The Hidden Burden of JIA

Dr. Marshall and her team have quantified the costs borne by families of children with Juvenile Idiopathic Arthritis. **Out-of-pocket expenses** related to medical appointments and allied health services average several thousand dollars annually. These costs include **travel** to specialist visits, diagnostic tests and treatments, emergency care and hospitalisations and travel as well as additional fees for allied health professionals. The economic impact extends beyond out-of-pocket costs for families. Research led by Dr. Marshall and her team shows that caregivers of children with JIA often reduce their paid work hours to meet care demands. Missing work results in an average annual income loss of approximately $6000 per family. Even when at work, parents report difficulty being fully productive (approximately 15% of the time). Adolescents with JIA are also affected as they enter the workforce - the novel research from the team indicates an average impairment in productivity while at work of approximately 25%.

These findings are further contextualised by patient- and family-reported experiences captured through the research. Parents describe the **substantial time commitment** required for ongoing treatment, including regular hospital visits for intravenous infusions that can last several hours and often involve long travel times. Scheduling constraints, with many appointments available only during standard business hours, add to these challenges. Youth with JIA report pain, stiffness, and limited mobility that affect daily activities such as walking, sitting, and getting up in the morning, and **restrict participation** in school, sport, and recreational activities. Evidence suggests that these challenges can persist into adulthood. Research co-led with patient partners and focused on youth transitioning to adult care has identified a clear need for enhanced social and mental health supports during this period.

Cassie + Friends

Cassie + Friends, a national charity supporting children and families affected by JIA and other childhood rheumatic diseases, has worked closely with Dr. Marshall and her team to co-design and deliver community-informed research.

As Executive Director Jennifer Wilson notes in an interview:

> *“Parents tell us about the financial and emotional toll of juvenile arthritis. But [Marshall and team’s] work is giving their reality an academic weight and a visibility it didn’t have before. It’s incredibly empowering for families to see their struggles recognised in research that is shaping policy and funding decisions. It creates not only resilience for the day-to-day challenges of life with JIA, but hope that, you know…that they are seen and supported not forgotten…”*
>
> *Jennifer Wilson, ED of Cassie + Friends*

From Evidence to Action

As Jennifer Wilson explains, Marshall and her team's research is intentionally designed to translate evidence into action. Rather than remaining on the shelf, findings are mobilized to **create real-world impact for children** and families. Through close partnership with Cassie + Friends, research documenting the emotional and financial impacts of JIA has directly informed practical supports that reduce immediate socioeconomic pressures and improve quality of life for families.

The Equipment Cupboard

Cassie + Friends has expanded and strengthened their **Equipment Cupboard** and **Family Funds** program across 16 pediatric rheumatology clinics in Canada informed by this evidence-based approach. These cupboards provide essential items such as splints and braces, orthotic insoles, heat and cold packs, numbing cream, and tools to reduce needle-related anxiety, as well as grocery and gas cards. Together, these targeted, low-cost interventions help reduce day-to-day burdens and support families in managing care more effectively.

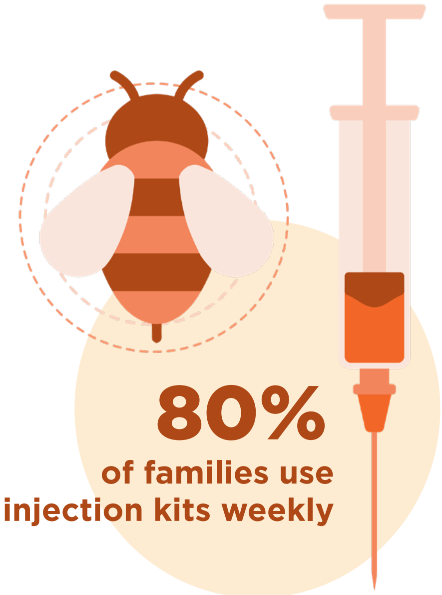
> *"My daughter needed specialized footwear and Cassie + Friends were able to help with the cost. They also provided a shoehorn and she can now take her shoes off and on by herself, where before the arthritis in her hands made it impossible,"*
>
> *- Parent of a child with JIA from Cassie + Friends*

The Injection Support Kit

The **Injection Support Kit** program was developed by Cassie + Friends due to the research highlighting the high emotional toll from the weekly injections that many JIA patients require for effective disease management. These kits include numbing creams, shot blockers, mindfulness tools, and letters from youth mentors. The aim is to support families through treatment, helping them stay on track so children can get optimal results from therapies like biologics. For many families, this has meant fewer tears and bloodwork visits that feel calmer and more manageable.

One parent wrote to Cassie + Friends about how this small, practical intervention has impacted their experience:

> *"I wanted to share that our injection kit arrived on Wednesday and her bloodwork was today and it was the first time bloodwork was tear-free! She showed everyone her kit and used the numbing cream and it was a life-changing experience.*
>
> *Thank you so much for the work you guys do!"*
>
> *- Parent of child with JIA*



Healthcare Providers See the Difference too:

> *"Today I met with a 5-year-old boy in the clinic who is starting injections. He was quite anxious about the idea of needles, so we talked about items he could use to create his own 'Injection Support Toolkit'. He tried the Buzzy Bee and the numbing cream and loved it! Today, tears were replaced with a plan and a smile ... and a greatly relieved parent....*
>
> *These supports make a big difference!"*
>
> *-Pediatric Rheumatology Nurse*

Another example of turning research into action is the range of programs offered by Cassie + Friends designed to support youth transitioning from pediatrics to adult care. These were launched as a direct result of patient-partner led research supported by Marshall and team. Cassie + Friends have subsequently brought more voices into transition planning by involving allied health professionals in webinars and events and introduced regular youth-led workshops where teens can share tips and build confidence together. To keep progress moving, they also created a dedicated **Youth Transition Working Group** focused on improving the transition experience for every young person navigating this critical step.

OCEC SHINE

leveraging UCAN-Du/CURE data

OCEC VIKM

accelerating pathways to value and impact

UNIFIED

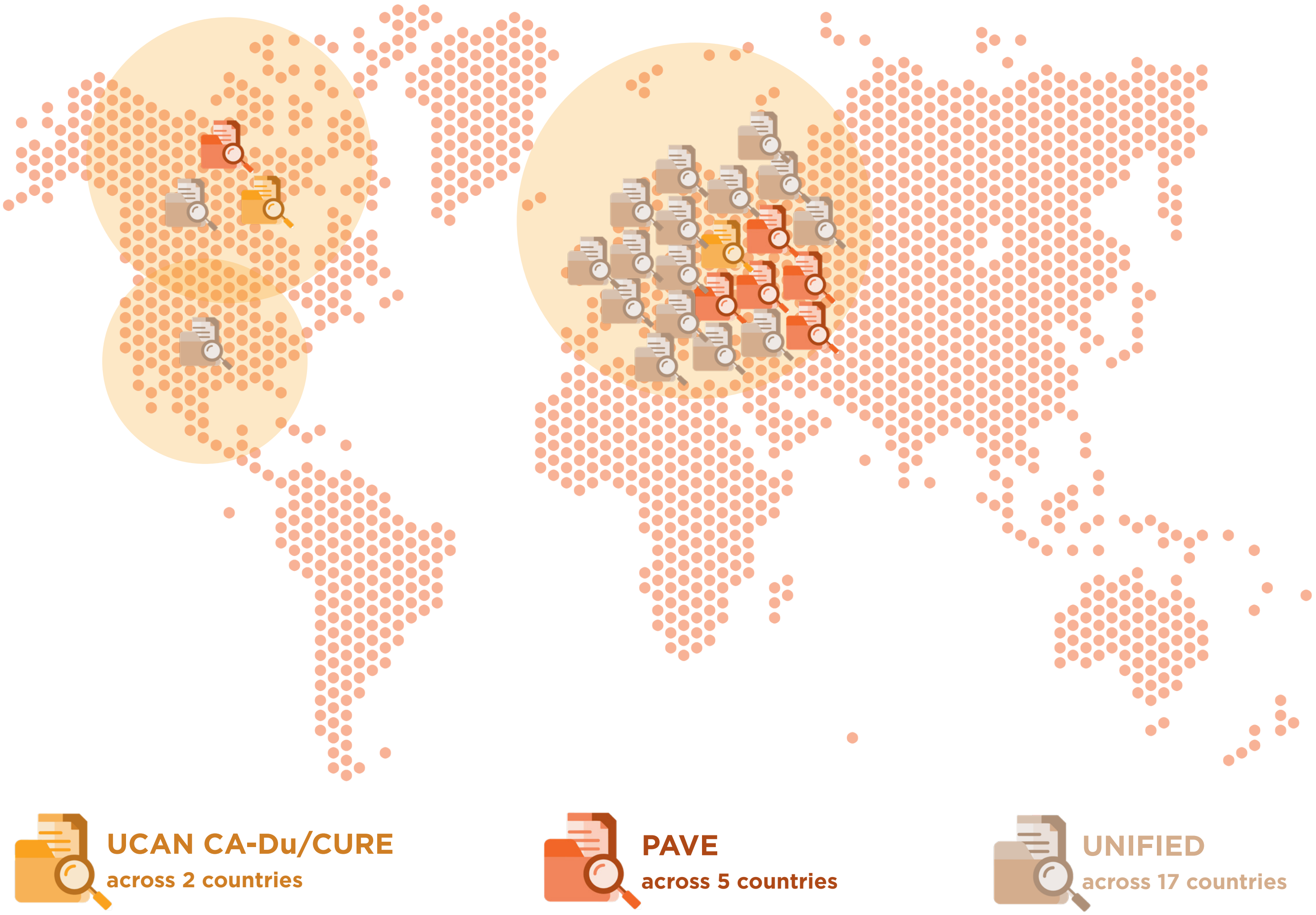
new international partnership

Shaping Future Research

What Matters Most to Children with Diseases and Their Families.

Marshall's work was one of the essential contributions that informed **One Child Every Child (OCEC),** a Canada First Research Excellence Fund initiative launched in 2023 to transform child health research nationally. OCEC's mission is to optimise child health, demonstrate world-leading research, and contribute to an economically sustainable Canada.

Within OCEC, the **Value, Impact, and Knowledge Mobilization (VIKM)** Accelerator, led by Marshall, ensures research integrates what children and families value most. Building on data generated through UCAN CAN-Du/CURE, the new **SHINE project** explores the hidden socioeconomic impacts across Canada and the Netherlands, with the goal of informing more responsive and equitable child health systems. Funded through OCEC, SHINE draws directly on the shared UCAN CAN-Du/CURE evidence base. Leveraging the rich longitudinal UCAN data - including parent and patient reported survey data alongside clinical information, SHINE brings these impacts into sharper focus illuminating the often-overlooked socioeconomic consequences of chronic childhood disease for children and their families.



Global Reach: JIA and Beyond!

The momentum generated through the **international collaboration** within **UCAN CA-Du/CURE** has shaped and accelerated Deborah Marshall's research program into a set of strong global partnerships. This work is helping redefine how "value" is understood in childhood disease research internationally.

Through the European Joint Programme on Rare Diseases funded **PAVE (Producing an Arthritis Value Framework with Economic Evidence)**, the Canadian team is co-designing with patients and parents – including Cassie + Friends as a patient and family partner - a framework that captures the full range of ways that JIA affects families. European partners are contributing complementary data that includes social and family costs, caregiver burden, equity considerations, and dimensions of quality of life often missing from standard economic assessments. While initially focused on JIA, the PAVE framework is designed to be transferable to other rare childhood diseases. Together, SHINE and PAVE share a common aim: to create actionable evidence to support services and policies that better alleviate the real-world impact of chronic childhood disease.

In a major success, UCalgary is a partner in **UNIFIED**, a new international research initiative funded through the Horizon Europe programme which includes leading universities, hospitals, patient organizations, regulatory agencies and industry partners. Marshall and her team, including Cassie + Friends, are contributing to the development of a framework that integrates patient-centred outcomes, preferences and digital measures to establish a clear pathway for patient perspectives to inform healthcare decision-making across research, clinical, and policy contexts. Building on the momentum of her earlier work and the partnership with Cassie + Friends, Dr. Marshall was uniquely positioned to bring JIA forward as one of the five UNIFIED clinical use cases, embedding a pediatric and family centred focus within this global partnership. The result will be clear answers about what parents and children consider treatment success in JIA clinical trials: which outcomes truly matter, which side effects are acceptable, which digital tools feel supportive rather than intrusive, and how trial participation intersects with school, sports, and daily life.

Closing

When research listens to families, it brings into focus evidence that makes visible the often-unseen impacts of childhood disease.

Guided by a commitment to what matters most to children and their families, Marshall and her team work to identify hidden burdens and **translate lived experience into action** — strengthening measurement tools, informing decision-making, and enabling practical supports that ultimately empower children and families to live healthier, more fulfilling lives.

Acknowledgments

The impact journey for this body of research has only been possible over many years and the involvement of many people and supports: co-investments across multiple funders, Dr. Marshall's research team, the UCAN CAN-DU/CURE PI core team (Drs. Rae Yeung, Susa Benseler, Joost Swart, Sebastiaan Vastert, Deborah Marshall) and UCAN CAN-DU/CURE consortium members, and all the patients and families who contributed data. Also, the PAVE Consortium and the PAVE patient and research partners. Particular thanks to members of Dr. Marshall's research team who worked on this socioeconomic research: Drs. Gillian Currie, Rodrigo dal Ben, and Ana Fuhrmann. Special thanks to Cassie + Friends, and in particular Jennifer Wilson, whose partnership fundamentally enables the meaningful impact of this research program.

This co-impact narrative was designed to reflect the multiple voices and perspectives in our ecosystem to realize positive impact for children with juvenile idiopathic arthritis and their families. We would like to thank all of those involved and thank John Bang, Morgan Harris, Trish Snyder, Jennifer Wilson and Dr. Rae Yeung for your enthusiastic participation in the interviews.

For more information, please contact: currie@ucalgary.ca

Prepared by:
Dr. Adrienne Levay, VIKM Post-Doctoral Fellow; Dr. Gillian Currie Value Strategic Lead, VIKM Accelerator; Dr. Deborah Marshall, Value, Impact and Knowledge Mobilization Lead, VIKM Accelerator; Dr. Kathryn Graham, Impact Strategic Lead, VIKM Accelerator; Melissa Boisvenue, Communications Advisor, OCEC; Medea Myers Stewart, Knowledge Mobilization Specialist, VIKM Accelerator.

On behalf of the OCEC Value, Impact and Knowledge Mobilization (VIKM) Accelerator:
Dr. Deborah Marshall, Value, Impact and Knowledge Mobilization Lead, VIKM Accelerator; Dr. Kathryn Birnie, Knowledge Mobilization Strategic Lead; Dr. Kathryn Graham, Impact Strategic Lead; Dr. Sam El Hassar, Project Manager, Impact & Knowledge Mobilization; Dr. Gillian Currie, Value Strategic Lead; Medea Myers Stewart, Knowledge Mobilization Specialist.