

UCAN Newsletter

(July to September 2024)

Site/Cohort*	1	2	3	4	Total
Wilhelmina Children's Hospital	221	255	124	23	623
Hospital for Sick Children	171	98	16	66	351
Beatrix Children's Hospital	105	104	67	4	280
Emma Children's Hospital	93	93	9	10	205
St. Maartenskliniek	66	41	17	3	127
IWK Health Centre	62	33	6	3	104
Alberta Children's Hospital	37	35	10	21	103
Montréal Children's Hospital	64	9	3	19	95
Erasmus Medical Center	18	32	26	9	85
BACKOFF	0	0	81	0	81
Jim Pattison Children's Hospital	20	25	10	1	56
Children's Hospital, London Health Sciences	27	14	6	3	50
British Columbia Children's Hospital	6	16	1	0	23
LUMC, Willem-Alexander Kinderziekenhuis	8	11	1	1	21
McMaster Children's Hospital	12	6	1	1	20
Stollery Children's Hospital	12	3	0	1	16
Children's Hospital of Eastern Ontario	6	2	1	2	11
The Children's Hospital of Winnipeg	1	1	1	5	8
Radboud UMC, Amalia Kinderzkhs	1	5	0	1	7
Janeway Children's Health and Rehabilitation Centre	0	0	0	1	1
Total	930	783	380	174	2267

*Cohort 1 – New JIA diagnosis; Cohort 2 – Starting Biologic Therapy; Cohort 3 – Stopping Biologic Therapy; Cohort 4 – Extreme Phenotype

Health Economic Highlights

Congratulations to the Health Economics team on their recent publication! They examined the psychometric properties of the EQ-5D-Y-5L parent proxy instrument for children with JIA, and also looked to see if the EQ-5D-Y-5L could describe patients with different severity.

Ohinmaa A, Wen J, Currie GR, Benseler SM, Swart JF, Vastert SJ, Yeung RSM, Marshall DA. Validation of the EQ-5D-Y-5L parent-proxy version among children with juvenile idiopathic arthritis. Qual Life Res [Internet]. 2024 [cited 2024 Aug 16]; Available from: <https://link.springer.com/10.1007/s11136-024-03682-4>

Congratulations to the PAVE team!

Congratulations to our collaborating partner, the PAVE team led by Dr. Deborah Marshall, on their first publication! The paper describes the international PAVE project ("Producing an Arthritis Value-Framework with Economic Evidence), funded by the European Joint Programme on Rare Diseases.

Deborah A. Marshall, Brittany Gerber, Gillian R. Currie, Jordi Antón, Lien De Somer, Michelle Dey, Tsiipi Egert, Yona Egert, Lia Henan, Jens Klotsche, Laura Martinez Mifsut, Kirsten Minden, Christophe Normand, David Porte, Rotraud K. Saurenmann, Joost F. Swart, Yosef Uziel, Jennifer Wilson, Carine Wouters, Amit Ziv, Susanne M Benseler, on behalf of the PAVE Consortium. Uncovering the hidden socioeconomic impact of juvenile idiopathic arthritis and paving the way for other rare childhood diseases: an international, cross-disciplinary, patient-centered approach (PAVE Consortium). *Pediatr Rheumatol* 22, 74 (2024). <https://doi.org/10.1186/s12969-024-01012-z>

Questions?

Canadian and Study Questions, please contact:
Amy Xu
 Project Manager
Amy.Xu@sickkids.ca

Dutch Sites, please contact:
Regina de Geus
 Dutch Coordinator
R.deGeus@umcutrecht.nl

General Study Updates

Happy Autumn! There are a few more months to recruit participants and achieve our goal to advance personalized medicine approaches for all children with JIA. Keep up the good work!

UCAN CAN-DU is registered on ClinicalTrials.gov! [Link to the website.](#)

It's [National Pain Awareness Week](#) November 3-9, 2024 in Canada!



Thank you to our study sponsors and funders for their ongoing support!

