

Recruitment Update

Site Name	Cohort 1	Cohort 2	Cohort 3	Cohort 4	Total
Alberta Children’s Hospital	14	18	7	10	49
BC Children’s Hospital	0	3	0	0	3
Beatrix Children’s Hospital, UMCG	51	41	26	3	121
Children’s Hospital, London Health Sciences Centre	7	4	3	3	17
Children’s Hospital of Eastern Ontario (CHEO)	2	0	1	1	5
Emma Children’s Hospital, AMC	42	43	7	6	98
Erasmus MC	0	1	0	2	3
Hospital for Sick Children	80	39	4	27	150
IWK Health Centre	17	9	2	3	31
Jim Pattison Children’s Hospital (Saskatoon)	6	10	1	0	17
Montréal Children’s Hospital (MUHC)	8	1	0	8	17
St. Maartenskliniek	1	0	0	0	1
Stollery Children’s Hospital	1	0	0	0	1
Wilhelmina Children’s Hospital	115	130	59	19	323
Grand Total	345	299	110	82	836

Cohort descriptions: Cohort 1 – new JIA diagnosis; Cohort 2 – starting biologic therapy; Cohort 3 – stopping biologic therapy; Cohort 4 – extreme phenotype (genetic or refractory component)

Season’s Greetings

Our UCAN team would like to express our gratitude for your incredible work and enthusiasm during the past year. Thanks for making UCAN fun and enjoyable despite the challenges of the COVID pandemic. Thanks for your partnership, dedication, and continued support.

Wishing you and your families a Happy and Healthy Holiday Season and a Wonderful New Year!



From our UCAN CAN-DU family to yours

HEcon Updates

The HEcon team is excited to announce the launch of a **second survey for Pediatric Rheumatologists about biologic tapering**. The goal is to elicit your perspective on when to taper biologics in a child with JIA, based on their patient profile. Thank you to our Dutch colleagues who have already completed the survey. **Canadian colleagues please check your inboxes for a survey from Janine van Til (noreply@qemailserver.com), with subject line “UCAN CAN-DU/CURE Biologic tapering survey 2”**.

UCAN CAN-DU Health Economics Activity Team

eHealth Updates

During the last quarter of the year, the eHealth platform has enabled a number of new features! Starting with the **cohort table**, a feature that will aid research staff in study management.

Patients can now access other JIA research studies in their country within the **Resources** section of the application. These include the following Canadian studies – **CARRA and CAPRI**; Dutch studies – **Pharmachild, ESTIS and CHAMP**. If patients and families are interested in a study, they can click the new feature **“I’m interested”** and receive information.

Lastly, the new **About UCAN** section in the platform helps patients to better understand the goals of UCAN and how the ePRO cards (i.e., questionnaire packages) play into the study. Additionally, the ePRO cards have been renamed **Pre-Clinic** (Clinic visit ePROs) and **Life with Arthritis** (Health Economics ePROs).

Congratulations!

Congratulations to the PAVE team led by Dr. Deborah Marshall on their successful European Joint Programme Rare Diseases grant submission!

The PAVE team is a strong international partnership of 6 countries (Canada, Germany, Switzerland, Spain, Israel, and Belgium) which includes clinical leaders, researchers, and social scientists and a strong engagement with patient organizations. The team will focus on the unmet needs of children and families and empower them with new ways to address the hidden burden of arthritis. The PAVE team will build a first-of-its kind value framework that will unite the voices of children and families with data-informed calls to action to measure and ultimately reduce the cost and burden of childhood arthritis. Together, they will improve the lives of children living with arthritis, reduce inequities and pave the way for improved lives for people of all ages living with rare diseases.

QUESTIONS

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