

- Welcome 1
- UCAN CAN-DU personnel 2
- Progress updates 3
- Save the date! Childhood Arthritis and Beyond 3

September 2018
Issue 1 Volume 1

Welcome!

Dear all,

We are excited to share this first **UCAN CAN-DU** newsletter with all of you. In the past 18 months, the team has been working very hard to get the **UCAN CAN-DU** project off the ground. Timelines and progress of the **UCAN CAN-DU** activities have been shared in Canadian and Dutch designated meetings; however, much of the important and preparatory activities have been performed outside of the sight of the extended research team. Therefore, it is now time to start the process of sending more regular updates

to the entire research team on a regular basis to introduce you to some of the research members and update you on important goals and future endeavours.

We hope you will enjoy the first **UCAN CAN-DU** newsletter! We will also keep you updated on exciting new events in the upcoming year.

On behalf of the **UCAN CAN-DU** investigator team and the eCommunications Platform,

—Marinka Twilt and Bas Vastert ■

Introducing UCAN CAN-DU people across the centres

Research Administrative team



Alexander Mosoiu
UCAN Program Lead, Toronto

Alex Mosoiu is an experienced project manager with background in information technology (IT) implementations, healthcare process improvement projects, and complex multi-site initiatives aimed at improving kids' health. Alex brings years of experience managing clinical software implementations, including surgical and enterprise imaging applications, and acted

as SickKids lead on the Canadian Paediatric Surgical Wait Times project, which implemented a consensus-based system to track elective surgical waits for children and youth at participating hospitals across Canada using a novel diagnosis-based access target system. The project helped identify surgery types for which access targets were exceeded most frequently and led to measures to substantially reduce wait times in those areas at SickKids. Following a move to the research information technology group at the SickKids Research Institute, he managed the implementation of the Institute's centralized biobanking solution and led a team focused on the development and imple-

mentation of IT solutions in the clinical research context. Alex is tremendously excited about supporting the goals of **UCAN CAN-DU** and all the **UCAN** projects and its amazing team.



Trinh Hoac
UCAN CAN-DU Project Lead,
Toronto

Trinh Hoac received her Master of International Public Health degree from the University of Queensland and Bachelor

of Science degree from the University of Toronto. She is experienced in managing large international multi-centre clinical research studies, from study initiation and implementation through close-out and analysis. She is interested in research to improve the health and well-being of children.

Trinh is the Project Manager for the **UCAN CAN-DU** study. She is looking forward to working with the study team across Canada and the Netherlands.



Ana Sepulveda
UCAN CAN-DU Canadian National Lead, Calgary

Ana Sepulveda completed her Bachelor of Science, majoring in Health Sciences with a double minor in Chemistry and Psychology, at Mount Royal University in Calgary, Alberta. Ana started her involvement with research in the early years of her undergrad degree,

where she worked with Professor Brett McCollum (PhD) in Scholarship of Teaching and Learning (SoTL) projects looking at student preferences in education technologies for organic chemistry. She began with the team at Alberta Children’s Hospital as a student research volunteer in her senior year, and her passion for learning and research led her to her current role as a Research Coordinator for the section of Rheumatology. Her role with the **UCAN CAN-DU** project will be as the Canadian coordinator. She looks forward to working with all Canadian and Dutch team members and hopes to gain valuable experience in clinical and translational research.



Fenna Mossel
UCAN CAN-DU Dutch National Lead, Utrecht

Fenna is the Research Coordinator for **UCAN CAN-DU** in the Netherlands.

After working as a central monitor within the University Medical Centre Utrecht (UMCU) for 5 years. Fenna has gained great knowledge of International Council for Harmonisation-Good Clinical Practice (ICH-

GCP) and national guidelines according to the performance of clinical research. She currently also works as a quality assurance officer research in the Wilhelmina Children’s Hospital in Utrecht for the Division of Woman and Baby. This makes her familiar with accompanying researchers with setting up their research projects and monitoring while executing these trials.

All these experiences make Fenna a good sparing partner for the participating centres in the Netherlands in setting up **UCAN CAN-DU** in their own centre.

eHealth team



Akib Uddin
Center for Global eHealth, Toronto
eHealthInnovation @ University Health Network
UCAN CAN-DU eHealth Platform Manager

Akib holds an MHS in Clinical Engineering and a BSc in Electrical and Computer Engineering from the University of Toronto.

Akib is interested in building technology that can make a difference and help people lead healthier and happier lives. He first joined the eHealth Innovation for his masters, focusing on wearable sensors and biofeedback for blood pressure management, under the supervision of Dr. Joe Cafazzo. He has worked on the team in

various roles, first as an intern, then as a Product Manager of multiple mobile platforms for chronic pain, juvenile arthritis, kidney disease, and heart failure. Akib has also contributed to the development of interoperability standards for diabetes devices and has worked on workshops with manufacturers for knowledge transfer.

Biobank team



Sytze de Roock
UCAN CAN-DU Program Manager, Department of Pediatric Rheumatology and Associated Researcher in the van Loosdregt-Vastert laboratory, University Medical Center Utrecht

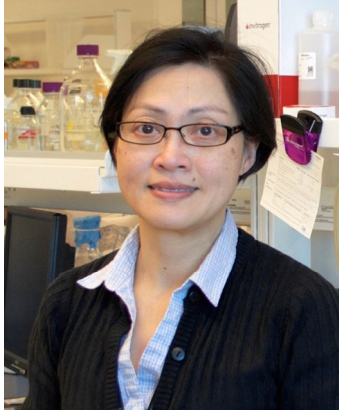
Sytze de Roock is trained as a biologist at the University of Utrecht. He obtained his PhD at Wilhelmi-

na Children’s Hospital, University Medical Centre Utrecht, focusing on the development of the human adaptive immune system in the first years of life. After this, he focused his research on Juvenile Idiopathic

Arthritis (JIA).

He has studied the pathology of systemic JIA with a main interest in the role of phagocytes. He has investigated (phagocyte related) biomarkers that predict disease progression and therapy re-

sponses in international projects. For **UCAN CAN-DU** he will be focusing on the integration of clinical datasets with the laboratory derived datasets to translate these into clinical benefit.



Trang Duong
Yeung lab, Toronto

Trang Duong completed her graduate work at the University of Western Ontario in Microbiology and Immunology. She did her post-doctoral training at The Hospital for Sick Children Research Institute in the Developmental & Stem Cell Biology Program. She is currently a Senior Research Associate and Laboratory Manager of the Yeung Lab. Trang's role includes maintaining and overseeing the day-to-day operations, supervising and mentoring research and non-research trainees, supporting staff and providing continuity for on-going research. Dr. Yeung's lab also houses the Rheumatology biobank as well as the biospecimen repository for a number of national and international clinical research studies. One of Trang's responsibilities is to oversee and manage these operations. ■

UCAN CAN-DU progress updates

Ethical approval status

Canada

Both Calgary and Toronto have successfully gained REB approval for the **UCAN CAN-DU** study. The research coordinators in Canada are currently completing a package for the Canadian centres to help with their REB submission. We will be sharing this soon and Ana Sepulveda as the Canadian lead will be available to help the centres to go through their local REB.

Utrecht/the Netherlands

The procedure to obtain ethical approval of **UCAN CAN-DU** is a little different in the Netherlands compared to Canada in the sense that ethical approval, once obtained for

one centre, will automatically extend to all participating centres in the Netherlands. The caveat of this procedure, however, is that in preparation of submission of a study protocol to the ethical board in Utrecht, all other participating **UCAN CAN-DU** centres will have to submit supportive documents and sign trial agreements with Utrecht before any submission will be processed and reviewed by the ethical board. Given the complexity of data and sample flow within the Netherlands (and Canada) and back and forth from the Netherlands to Canada, we are still in the finalization phase of the submission of **UCAN CAN-DU** to the ethical board in Utrecht. Review and decision is

foreseen late September/early October 2018.

First UCAN CAN-DU paper submitted

The **UCAN CAN-DU** Health-Economic Working group has been working diligently since the kick-off and have been so successful they have been able to submit the first **UCAN CAN-DU** manuscript "Seeking the state of the art in standardized measurement of health care resource use and costs in juvenile idiopathic arthritis: a scoping review." The manuscript is currently under revision! Congratulations to the **UCAN CAN-DU** Health-Economic Working group! And a good start for many more **UCAN CAN-DU** manuscripts to follow! ■

SAVE THE DATE!

Childhood Arthritis & Beyond

April 23-26, 2019 🍁 **Lake Louise, AB, Canada**



BANFF NATIONAL PARK

Please join us in beautiful Lake Louise for the Childhood Arthritis and Beyond Conference.

We will bring together Clinicians, Researchers, Patients and their Families to share new knowledge and build the future of research in childhood arthritis




UCAN Ride For Arthritis! Across the Rockies Tour 2019

A Charity bike ride across the Rockies from Lake Louise, AB to Vancouver, BC



