



Inflammation, Microbiome & Alimentation • Gastro-Intestinal & Neuropsychiatric Effects

Network Newsletter

Spring 2017

NETWORK UPDATES

It has been an exciting six months since I've joined the IMAGINE Network as Executive Director. I am truly proud to be part of such an innovative group of patients, clinicians and scientists working together to bring about transformative change for those living with IBD, IBS, and mental health issues.

Earlier this year, we expanded our Network team to include an Administrative Assistant, Veronica Vandenende. Since December, we have been focusing on building formal work plans for the Network which cover all aspects of the Network, ranging from Marketing & Communications to Research Activities. We have been working on establishing structure, financial agreements, policies, and practices to govern the Network's operations.

I am extremely excited that we have designed a new brand identity for the logo, launched a website (www.imaginespor.com), built a social media presence, and now produced a quarterly newsletter. These platforms will allow us to communicate our Network's progress and impact with our key audiences. We encourage you to follow us on Twitter and Facebook, share with your colleagues in order to stay informed on Network activities and build greater awareness.



Aida Fernandes
Executive Director,
IMAGINE Network

The Network has had tremendous progress over the past year. As many of you know, Aida Fernandes joined the Network as the Executive Director in December 2016, ensuring that we stay on task of achieving our goals.

Since our last meeting during CDDW, I am pleased to say that with the support of the Scientific Working Groups, we have finalized the listing of patient questionnaires and research protocols. The main cohort study has already secured provisional ethics approval from McMaster's local Research Ethics Board, which will expedite ethics applications from other network sites. We are also working hard to ensure that questionnaires are available on the online system so that we can start recruitment.

We have recruited five new patient representatives to ensure that there is a strong presence and engagement from the people that matter most. We hope that everyone continues to take part in the many Patient-Oriented Research training opportunities that are available so that we can optimize our impact and learn how best to collaborate with our patient partners.

I hope you enjoy this inaugural issue of our e-newsletter and I look forward to connecting with those of you joining us on June 4 for our Network Face-to-Face meeting.

Dr. Paul Moayyedi
Principal Investigator,
IMAGINE Network



UPCOMING EVENTS

June 3, 2017
IMAGINE Network Patient-Oriented Research Foundational Curriculum Training

June 4, 2017
IMAGINE Network Annual Face-to-Face Meeting

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www.imaginespor.com

CONTACT

IMAGINE Network
1200 Main St.W.
HSC 3V33
Hamilton, ON.
L8N 3Z5
vandenev@mcmaster.ca



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Strategy for Patient-Oriented Research Stratégie de recherche axée sur le patient
SPOR * **SRAP**
Putting Patients First Le patient d'abord



SPOTLIGHT: Sandra Zelinsky, Patient Lead

It was while on sick leave that Sandra Zelinsky happened upon an email introducing her to the Patient and Community Engagement Research (PaCER) program at the University of Calgary. The once small business owner was intrigued. Her curiosity soon became a passion and Zelinsky went on to graduate from the PaCER program in 2012. Since then, Zelinsky has proven to be a driving force when it comes to bringing the patient's perspective to the forefront of health research.

As IMAGINE's patient lead for the Patient Engagement group, Zelinsky says that her first priority is capacity building. "My goal is to bring the collective patient voice and expertise to the study." Zelinsky has lived with Crohn's and Colitis for the past 24 years. "I want all of the partners [physicians, researchers, clinicians, patients etc.] to have an opportunity to engage in patient-oriented research." Explaining that the patient perspective is an extremely important factor and should be included as part of the research protocol. "If we recognize the value of the patient experience and expertise and how patient-oriented research can make a difference, it will change the way we do research."

Along with her work with IMAGINE, Zelinsky is a trainer for the National Strategy for Patient Oriented Research (SPOR) Foundational Curriculum. She is a member of the CIHR SPOR review committee where she uses her expertise to review SPOR research proposals for grant funding. She was recognized by the Canadian Patient Safety Institute as a Patient Safety Champion for her work on a PaCER study done on behalf of Alberta Health Services.



L-R: Aida Fernandes, Paul Moayyedi, Mike Surette, John Marshall

Spring 2017 GUTSY LEARNING SERIES RECAP

On April 26, the IMAGINE Network partnered with Crohn's and Colitis Canada for their 2017 Spring Gutsy Learning Series. Held at McMaster University in Hamilton, Ontario, this free event gave attendees the opportunity to learn about the exciting research the IMAGINE Network is working on including the relationship between the human microbiome, GI disease and mental health.

IMAGINE's Principal Investigator, Dr. Paul Moayyedi, took the stage first, explaining the overall goals and objectives of the Network, including developing innovating therapies to improve inflammatory bowel disease (IBD), irritable bowel syndrome (IBS) and mental health. From fecal microbial therapy for ulcerative colitis (UC) and Crohn's disease (CD) patients and online cognitive behavioural therapy for treating anxiety in IBD patients to the low FODMAP diet for IBS patients, Dr. Moayyedi revealed the numerous trials and studies that IMAGINE is currently working on. He also explained the Network's large cohort study focused on microbiome changes in people with IBD (inflammatory bowel disease) and IBS (irritable bowel syndrome), and their associated mental health disorders, that will follow 8,000 adults and children annually for up to five years using questionnaires and diet history along with blood, urine and stool samples.

Aida Fernandes, IMAGINE's Executive Director, followed with an overview of Patient-Oriented research. Fernandes explains that IMAGINE is focused on looking at new and effective treatments that could be very cost effective to the healthcare system utilizing patient engagement as an important factor. "Meaningful and active collaboration. Not research that's being done 'on' patients, but rather research that's being done 'with' patients. It's really about patients being partners and not just subjects for research," explains Fernandes who went on to give an overview of the guiding principles for patient engagement in research (inclusiveness, support, mutual respect, and co-building), along with who is involved in patient-oriented research and the various roles for patients when it comes to research.

IMAGINE's Co-Investigator, Dr. Mike Surette, gave an introduction to the human microbiome and talked about how IMAGINE is doing research using the microbiome to treat GI disease such as using a healthy microbiome to fix the imbalance of the microbes in the immune system in UC and Crohn's disease patients via fecal transplantation.

You can watch the entire presentation, including a panel discussion on IBD and the human microbiome at www.crohnsandcolitis.ca/Support-for-You/Gutsy-Learning-series.