

2021

CROHN'S AND COLITIS CANADA

# RESEARCH REPORT



Report period: January 1 to December 31, 2021 | Pictured: Dr. Harry Brumer



Crohn's and  
Colitis Canada  
Crohn et  
Colite Canada

# A MESSAGE TO THE COMMUNITY

As pandemic circumstances caused a second year of challenges for Canadians from coast to coast to coast, our community pulled through as best we could, together.

In 2021, as COVID-19 continued to upend both lives and research operations, the community that surrounds Canadians living with inflammatory bowel disease (IBD) came together to ensure progress wasn't lost, innovations were made, funds were raised, and support reached those who needed it.

Here at Crohn's and Colitis Canada – one of the world's largest non-governmental funders of IBD research – we ensured our major grant competition continued uninterrupted. In 2021, we proudly invested \$4.7 million in the most promising research projects on Crohn's disease and ulcerative colitis.

At the same time, we made the most of our leveraged funding opportunities to ensure every donor dollar reached as far as possible. Partnerships with bodies such as the Canadian Institutes of Health Research help allocate a greater pool of funds towards initiatives targeting the prevention and cures of IBD and improving the quality of life for those who live with them.

As the pandemic wore on, our COVID-19 Task Force took on extended and heightened importance. This group of IBD experts kept abreast of the latest science on what the coronavirus meant for patients and clinicians, and held frequent

webinars to translate this evidence in real time to keep everyone safe and informed. Thank you to them for their time and commitment.

One of our hallmark projects, the PACE Network, evolved as collaborators took strides to pursue greater digital health progress. Collectively, they are helping address systemic gaps to ensure all Canadians with IBD gain equitable access to standardized specialist care no matter where they live. More on PACE, including helping teenagers transition to adults in the system, is detailed herein.

Lastly, it is our responsibility to recognize research and clinical excellence across Canada. To that end, we issued four awards to deserving professionals through our Rising Star, Research Leadership, and two Women in IBD research awards. Congratulations to all!

Thank you for staying engaged in our mission, and for reading about the great work taking place in our vast community of researchers and clinicians. Their efforts would not have been possible without charitable contributions from our donors. Together, we are closing in, year by year, to a future free of IBD.

Kaley Wilson, Chair, Research Committee  
Lori Radke, President & CEO  
Kate Lee, VP, Research & Patient Programs



# FUELING RESEARCH BY

## ADVANCING DISCOVERY

Powering the research discovery process that is driving new treatments and cures.

### FINDING CAUSES AND TRIGGERS

Uncovering the multiple triggers that predict or lead to the onset of the disease.

- Discovering environmental triggers
- Discovering markers

### DISCOVERING NOVEL TREATMENTS

Discovering new ways to block inflammation, treat complications, improve therapy, and create a healthy gut.

- Blocking inflammation
- Creating healthy gut ecosystems

### SUPPORTING EARLY CAREER IBD RESEARCHERS

Providing funding to up-and-coming researchers to help advance their careers.

- Fellowships
- New investigator awards

## IMPROVING LIVES

Getting the best care and symptom management into the hands of Crohn's and colitis patients.

### HELPING MANAGE SYMPTOMS

Finding the best ways to get novel treatments into the hands of patients.

- Treating complications
- Predicting disease course

### GETTING THE BEST CARE

Exploring new ways to provide the best treatments and multidisciplinary care to patients.

- Creating health service models
- Promoting evidence-based practice

### EDUCATING PROFESSIONALS

Ensuring that healthcare professionals have access to the very latest and best information.

- Hosting medical conferences
- Supporting IBD nurses
- Supporting women in the IBD field

# RESEARCH HIGHLIGHTS

## IN 2021:

OVER  
**\$140**  
MILLION

invested in more than 380 research projects since our founding in 1974.

**4** IBD research awards given to inspiring professionals.

For every **\$1 / \$10** we invested, were leveraged from government and industry.

**100%**

of grants featured collaborations among leading scientists and partners across Canada.

**4.7 MILLION** invested in research in 2021.

**37** research projects and initiatives supported.

**NEW FINDINGS**

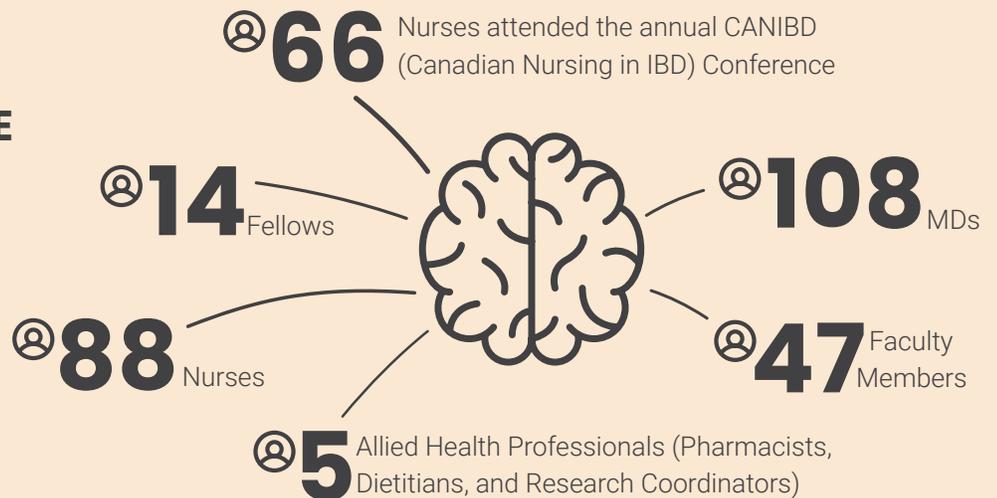
**17** major hospitals and universities supported.

*Innovations* grant study finds new way of delivering drugs to the gastrointestinal tract. You can read more about this exciting research on [page 5](#).

*Grants-In-Aid* of Research study highlights crucial pathway linked to Crohn's disease. You can read more about this significant finding on [page 12](#).

## ATTENDED THE MEETING OF THE MINDS CONFERENCE

Meeting of the Minds is an annual conference that brings together Canada's talented community of IBD researchers and healthcare providers to share best practices in clinical care and latest research in IBD.



# NEW WAY TO DELIVER DRUGS CARRIES POTENTIAL TO CHANGE LIVES

Drug treatment for IBD is a delicate balance of optimizing delivery while mitigating side effects. One big challenge is that many oral IBD drugs are absorbed too early, in the stomach or small intestine, requiring higher doses to ensure enough still reaches its target: the lower gastrointestinal (GI) tract.

Dr. Harry Brumer, a Crohn's and Colitis Canada funded researcher at the University of British Columbia, has keyed in on a way to realize the full potential of IBD drugs, including small fragments of proteins – called peptides – by developing a way for them to be released at the right spot.

## INTRODUCING: “GLYCOCAGE” TECHNOLOGY

Dr. Brumer started down this path by studying how dietary fibre is broken down in the gut, and specifically the interplay there between our microbiota and complex carbohydrates.

From these observations, his team wondered if “caging” oral IBD drugs by attaching them to small fragments of common vegetable carbohydrates would allow the drugs to successfully reach the lower GI tract where the medication would only then be released by our endogenous gut bacteria. This is known as GlycoCage technology.

Through Crohn's and Colitis Canada funding, Dr. Brumer and his team developed a unique chemistry to create GlycoCaged peptides with anti-inflammatory properties – and watched how gut bacterial enzymes release them in a test tube. Based on these successful results, the next steps include testing in mouse models of IBD.

## PROMISING ADVANCEMENTS FOR DRUG DELIVERY

“This is the first delayed release technology to come from a natural complex carbohydrate,” says Dr. Brumer. “Our work is an exciting example of a natural process, driven by our microbiome, that ensures treatments are released where they need to be.”

Through this technology, people with IBD could be given lower doses of a medication that would be as – or more – effective. This notably includes, as collaborator British Columbia Children's Hospital investigator Laura Sly points out, younger patients.

“GlycoCage technology has the potential to open up treatment options for children that are currently limited by systemic side effects,” Dr. Sly says. “It would be of great benefit to give young patients lower treatment doses of drugs by activating the drugs at the exact site of inflammation.”

*“IBD takes a huge toll on people, and by extension, on the health-care system and the economy,” says Dr. Brumer. “Our ultimate goal in this research is to scale back that burden with medications that are more effective.”*



# CONGRATS TO THE 2021 GRANTS-IN-AID FUNDED RESEARCHERS

## FINDING CAUSES AND TRIGGERS

What causes Crohn's and colitis? What are the triggers that worsen symptoms? These questions drive our researchers as they examine environmental triggers and genetic markers responsible for IBD.

### THE ROLE OF MICROBIAL METABOLISM IN FOOD INTOLERANCES ASSOCIATED WITH INFLAMMATORY BOWEL DISEASE



Dr. Alberto Caminero  
McMaster University  
Term: 2021-2024  
Amount: \$375,000

Patients with IBD report a variety of food intolerances; however, many dietary triggers are unknown. Although gut microbiota may help in digestion, IBD patients often demonstrate altered microbiota, which may limit the ability to digest certain foods, causing various food intolerances.

Dr. Caminero's study aims to broaden our understanding of whether the microbes in the gut of IBD patients have a reduced digestive capacity against certain types of foods, thus causing adverse effects. The study will also look into the effects of different dietary components in animal models of colitis.

The findings of this study will help develop dietary advice in clinical practice and pave the way for novel approaches in IBD patients with food intolerances.

### FUNCTION OF FOLLICULAR DENDRITIC CELL SECRETED PROTEIN IN ULCERATIVE COLITIS



Dr. Jean-Eric Ghia  
University of Manitoba  
Term: 2021-2022  
Amount: \$50,000

People living with ulcerative colitis (UC) are known to have inflammation and imbalances of microbes in the gut. Dr. Ghia and his team aim to study the effects of a protein, more specifically follicular dendritic cell secreted protein. This protein will be studied in terms of regulating inflammation, the immune system, and gut microbes.

Preliminary results from the team have demonstrated that the expression of this protein is higher in patients with UC compared to those without. Moreover, this protein may be a target in future therapies if it is shown to have an impact in the development of colitis. This protein may not only serve as an indicator for UC but as a future therapeutic target.

## DISCOVERING NOVEL TREATMENTS

These grants discover new ways to block inflammation, treat complications, improve therapy, and create a healthy gut.

### NOVEL P2Y6 ANTAGONISTS AS A POTENTIAL THERAPY FOR INFLAMMATORY BOWEL DISEASE



Dr. Jean Sévigny  
Université Laval  
Term: 2021-2024  
Amount: \$375,000

Dr. Sévigny is studying a molecule that could be an effective alternative treatment for IBD.

Components of the immune system can cause chronic inflammation of the gut in people living with IBD. Dr. Sévigny's previous study on mouse models found that chronic inflammation of the gut could be prevented by blocking these components from binding to the P2Y6 receptor found on the intestinal surface.

Dr. Sévigny will test novel P2Y6 blockers that may lead to a novel IBD treatment envisioned as a pill that would be more economical and practical for patients than current immunotherapies.

### ROLE OF THE GUT MUCIN SIALOME IN PROTECTION FROM MICROBIOTA-DRIVEN COLITIS



Dr. Kirk Bergstrom  
University of British Columbia  
Okanagan Campus  
Term: 2021-2024  
Amount: \$375,000

Ulcerative colitis is a chronic condition where the intestinal tract launches inflammatory responses against gut microbes causing damage to intestinal tissues.

A universal treatment has yet to be discovered. Therefore, understanding how to manage microbiota is vital. The goal of Dr. Bergstrom's research is to learn how sugar molecules attached to secreted mucus in the intestine interact with gut microbes to prevent colitis.

New data suggests that sialic acid – a key sugar molecule on the mucus – is essential for healthy gut-microbe relationships. Dr. Bergstrom's research will advance our understanding of how sialic acid can protect the gut from colitis. The results of this study will potentially find innovative pathways to prevent or treat chronic diseases like ulcerative colitis.

# CONGRATS TO THE 2021 GRANTS-IN-AID FUNDED RESEARCHERS CONT'D

## DISCOVERING NOVEL TREATMENTS

These grants discover new ways to block inflammation, treat complications, improve therapy, and create a healthy gut.

### USING INTESTINAL ORGANOIDS TO MODEL CHRONIC INJURY AND REPAIR IN IBD



Dr. Theodore Steiner  
University of British Columbia  
Term: 2021-2024  
Amount: \$375,000

Intestinal epithelial cells (IEC) are essential for absorbing nutrients, regulating fluid balance, and forming a tight barrier to keep bacteria and certain food products out of the bloodstream.

IECs are constantly replaced to keep the intestine healthy and primed to respond to damage. However, when the damage is severe, the dead cells can be replaced in unhealthy ways thus causing people with IBD, to develop chronic gut dysfunction.

In this study, Dr. Steiner plans to understand specifically what changes are taking place in the damaged gut cells, and how they compare to the permanent changes seen in people with IBD. The results of this study will aid in the testing of novel drugs and treatment options for IBD.

### THE USE OF SGLT2 INHIBITORS IN THE TREATMENT OF INFLAMMATORY BOWEL DISEASE



Dr. Karen Madsen  
University of Alberta  
Term: 2021-2024  
Amount: \$375,000

Empagliflozin (EMPA) is a drug that is used in the treatment of diabetes to help reduce levels of glucose in the blood. However, in large clinical trials, it has been shown to have beneficial effects on the heart and kidney by reducing inflammation.

Dr. Madsen and her team tested the ability of EMPA to reduce inflammation in an animal model of IBD and found it to be very effective at healing gut inflammation. They are now exploring EMPA's effects in immune cells from IBD patients. Results from this study may provide evidence that EMPA could be used to treat IBD as a novel therapeutic agent.

## HELPING MANAGE SYMPTOMS

These grants focus on treating complications and predicting the disease course of IBD.

### ASCERTAINING POPULATION-BASED LONG-TERM OUTCOMES IN INFLAMMATORY BOWEL DISEASE PATIENTS WITH PRIMARY SCLEROSING CHOLANGITIS



Dr. Amanda Ricciuto  
The Hospital for  
Sick Children  
Term: 2021-2024  
Amount: \$375,000

Up to 8% of people with IBD have a liver disease called primary sclerosing cholangitis (PSC). PSC causes inflammation and scarring of the bile ducts. Patients with IBD and PSC (PSC-IBD) are at high risk of end-stage liver disease, colon cancer, and bile duct cancer. PSC is a leading cause of death in IBD populations. Research about IBD complicated by PSC has been limited so far.

Dr. Ricciuto's study aims to examine the long-term health outcomes (cancer, intestinal surgery, liver transplant, and death) and health services utilization (hospitalization, emergency department visits, colonoscopy, and imaging) in patients with PSC-IBD complications in order to inform resource allocation and risk stratification initiatives that include patient counselling.

## GETTING THE BEST CARE

People living with Crohn's or colitis need access to the best treatments. These projects are looking to create evidence-based health service models to ensure patients receive the best care.

### DEFINING TIME-TRENDS, REGIONAL VARIATIONS, AND IMPACT OF HEALTH-CARE UTILIZATION ON PREGNANCY OUTCOMES IN WOMEN WITH INFLAMMATORY BOWEL DISEASE



Dr. Geoffrey Nguyen  
Sinai Health System  
Term: 2021-2024  
Amount: \$237,423

Inflammatory bowel disease commonly affects women of childbearing age. Women with IBD are at an increased risk of adverse pregnancy outcomes (e.g. preterm delivery, low birthweight infants, etc). Awareness regarding effective IBD care during pregnancy has increased however, it remains unknown whether these adverse pregnancy outcomes have decreased over time. Furthermore, the impact of geographical residence, ethnicity, and specialty care on pregnancy outcomes remains unknown.

Dr. Nguyen's research will explore whether the risk of adverse pregnancy outcomes have decreased in women with IBD over time. The findings of this study will allow researchers to determine new ways of standardizing care in pregnant women with IBD. The study will also assess the impact of specialty care to develop healthcare models that optimize quality of care for this population.

# YOUR DONATION DRIVES RESEARCH NATIONALLY

Crohn's and Colitis Canada is able to fund these important research activities and more, thanks to your support.

## LEGEND

**IN-KIND PARTNERSHIPS** - Crohn's and Colitis Canada offers in-kind support for IBD Research.

**GIA** - Grants in Aid of Research: These are investigator driven research that fall under 4 domains: finding causes and triggers, discovering novel treatments, helping manage symptoms, and getting the best care.

**PACE** - The Promoting Access and Care through Centres of Excellence (PACE) network brings together leading inflammatory bowel disease centres from across the country to improve health outcomes, address gaps in care, and develop solutions that can create changes in the public healthcare system.

**GEM** - The Genetic, Environmental, Microbial (GEM) Project is a global research study that looks to uncover possible triggers of Crohn's disease.

**WOMEN IN IBD** - is an initiative to support women specializing in inflammatory bowel disease at various stages in their careers to achieve leadership positions reflective of their expertise and qualifications.

**MATCHING PARTNERSHIPS** - are co-funding partnerships with other organizations to support a research project.

**CIRC** - the Canadian Inflammatory Bowel Disease Research Consortium is a network of clinician scientists working together to promote and conduct clinical research in inflammatory bowel diseases through collaboration of multiple Canadian centres.

**CANIBD** - is a Community of Practice for nurses working across Canada in the field of inflammatory bowel disease (IBD) with a vision of improving the quality of care of people living with IBD.

**MEETING OF THE MINDS** - is an annual conference that brings together Canada's talented community of IBD researchers and healthcare providers to share best practices in clinical care and latest research in IBD.



# FUNDED RESEARCH

Table of currently funded research\*

Study Title	Principal Investigator	Institution	Total Commitment	Year	Amount funded this year
A unique model for studying how stress influences Crohn's disease.	Dr. Brian Coombes	McMaster University	\$375,000	2 of 3	\$125,000
Investigating how the lymphatic system modulates Crohn's disease.	Dr. Pierre-Yves von der Weid	University of Calgary	\$370,000	2 of 3	\$124,000
Understanding a new target to alleviate chronic IBD pain.	Dr. Christopher Altier	University of Calgary	\$375,000	3 of 3	\$32,000
Novel peptides to enhance mucosal healing.	Dr. Wallace K. MacNaughton	University of Calgary	\$375,000	3 of 3	\$73,000
LRRK2 gene variant may offer a new therapeutic target for Crohn's disease.	Dr. Dana Philpott	University of Toronto	\$375,000	2 of 3	\$63,000
Pursuing new Crohn's therapies linked to SHIP deficiency.	Dr. Laura Sly	University of British Columbia	\$375,000	2 of 3	\$125,000
Understanding how bacteria control the gut environment in IBD.	Dr. Carolina Tropini	University of British Columbia	\$375,000	2 of 3	\$137,000
Exploring how E. Coli damages the gut and developing new drugs to clear them.	Dr. Bruce Vallance	University of British Columbia	\$375,000	2 of 3	\$125,000
Investigating new IBD abdominal pain relief drugs with minimal side effects.	Dr. Stephen Vanner	Queen's University	\$375,000	2 of 3	\$133,000
Investigating gut bacterial function for new ulcerative colitis treatments.	Dr. Elena Verdu	McMaster University	\$375,000	2 of 3	\$125,000
Designing new prodrugs to safely repair and protect the intestinal lining.	Dr. Robert Young	Simon Fraser University	\$375,000	2 of 3	\$142,000
A new molecular pursuit to put IBD into remission.	Dr. Fernand-Pierre Gendron	Université de Sherbrooke	\$375,000	3 of 3	\$63,000
Creating pro-healing immune cells to treat IBD.	Dr. Derek McKay	University of Calgary	\$375,000	3 of 3	\$63,000
Imaging the brain to understand depression, anxiety, and fatigue in IBD.	Dr. Charles Bernstein	University of Manitoba	\$375,000	3 of 3	\$179,000
Targeting Vitamin D treatments to prevent relapses in children with Crohn's disease.	Dr. Prévost Jantchou	CHU Sainte-Justine	\$375,000	3 of 3	\$100,000
Using population data to study trends in cancers, surgeries, and hospitalizations in Canadians with IBD.	Dr. Sanjay Murthy	Ottawa Hospital Research Institute and University of Ottawa	\$320,000	2 of 3	\$125,000

\*Grants started prior to Jan 1, 2021.



To learn more about these ongoing research projects, please scan the QR Code or visit the [funded research section](#) of the Crohn's and Colitis Canada Website.

# IMPACT OF YOUR DONATIONS

## TARGETING MICROBES COULD LEAD TO NEW THERAPIES FOR CROHN'S DISEASE

*E. coli* bacteria live inside all our guts in tiny, usually benign amounts. But for many with Crohn's disease, "adherent-invasive *E. coli*" (AIEC) becomes dominant and behaves unusually – sticking to intestinal walls, forming new colonies, invading other cells.

Dr. Brian Coombes, a Crohn's and Colitis Canada funded researcher at McMaster University, is studying AIEC to understand its unique behaviour, and how it can trigger or worsen Crohn's disease.

In studying this burdensome microbe, researchers also proved that risk factors believed to trigger Crohn's disease are indeed disrupting the microbiome and sparking inflammation in pre-clinical models.

## KNOWN RISK FACTORS CAUSE AIEC TO FLOURISH

Dr. Coombes and his team believe that being exposed to different risk factors over years or decades weakens the immune system. This repeated exposure creates an environment where AIEC can grow exponentially and alter the microbiome.

"We introduce AIEC and then expose them to antibiotics, food poisoning, stress and other known triggers for Crohn's," explains Dr. Coombes.

"In our lab we study the collective impact of these risk factors in animal models," says Dr. Coombes.

"Incredibly, we found that in every case, AIEC expands dramatically through the gut – up to 1,000-fold – after those risk factors are introduced."

This could have tremendous clinical benefit for those with or at risk of Crohn's, improving their quality of life, keeping them out of the hospital, and even reducing their need for expensive treatments.

"This sets the stage for using targeted therapy to block AIEC from expanding in someone at risk, which could work to prevent IBD onset or keep someone in a state of remission," he says.

## WHY RESEARCH FUNDING MATTERS

Importantly, these discoveries are propelled by trainees who are the engines of every lab. Dr. Coombes says that Crohn's and Colitis Canada funding enables him to attract and retain talented young researchers.

"This investment in people can't be overstated," says Dr. Coombes. "Grant funding allows us to build succession plans for our lab, to be able to hire new talent to move the research forward."

Thanks to this promising research, the Coombes lab has sparked new partnerships to commercialize novel IBD therapies. These partnerships will accelerate discoveries that will eventually lead to new ways to treat, and possibly even prevent, Crohn's disease in the future.



*"Grant funding allows us to build succession plans for our lab, to be able to hire new talent to move the research forward."*



## WORLD-RENOWNED GEM PROJECT YIELDS NEW CLUES TO ORIGINS OF CROHN'S DISEASE

Crohn's and Colitis Canada took a chance 14 years ago on a major, long-term research program that sought to unearth what causes Crohn's disease in those at risk.

It is called the GEM (Genetics, Environment and Microbiome) Project: the world's only prospective study to follow healthy people over time until they developed IBD – and try to understand why. To explore its vast potential, we committed \$12.5 million with an additional \$9.7 million of leveraged funds from the Leona M. and Harry B. Helmsley Charitable Trust.

Beginning in 2008, GEM researchers have monitored the diet, immune function, intestinal barrier, microbiome, genetics, and environmental factors in 5,100 siblings and children of people with Crohn's across seven countries.

"We're grateful for these volunteers who devoted time and energy for research," says Dr. Ken Croitoru, GEM Project Architect and Lead Investigator based at Mount Sinai Hospital. "In those who developed Crohn's, we can look back and spot what differences were already there that could be tied to future development of Crohn's Disease."



## NEW INSIGHTS EMERGE

In the past year, researchers have mined GEM's data, particularly from the 95 people who developed Crohn's disease. To date, findings reveal possible targets for early detection and prevention in those at risk:

- Results from the GEM study proved that an abnormal gut barrier function ("leaky gut") exists before Crohn's disease is diagnosed
- Another analysis found higher antimicrobial antibodies in people who develop Crohn's – an early predictive signal of the disease
- By analysing the gut microbiome, GEM researchers found a bacterial signature that was different in healthy people who later developed Crohn's

"The path that leads to Crohn's is not simple or linear but, instead, a complex interplay between our body, genetics, immune system, and microbiome," says Dr. Croitoru.

"With important observations from GEM, we can find specific targets to help prevent or treat IBD in each individual. This is big because right now there is little doctors can tell someone that truly changes their risk for Crohn's disease."



The project has drawn waves of attention. GEM's unique database is highly sought after by researchers around the globe – with hundreds of requests for collaboration.

Dr. Croitoru believes, just as the famous decades-long "Framingham study" found vital clues for heart disease, this prospective study could do the same for IBD.

So, what comes next? Crohn's and Colitis Canada will be turning to scientific experts and people with lived experience to identify opportunities to harness GEM results and accelerate its impact "on the bedside".



## PACE NETWORK ADVANCES EQUITABLE ACCESS TO CARE ACROSS CANADA

Canada is the only country with a national effort to unite IBD centres of excellence in a common mission. It is called the PACE (Promoting Access and Care through Centres of Excellence) network and it links experts across the country in developing new solutions to help ensure Canadians anywhere can access top-quality, expert care to manage their IBD.

PACE was launched by Crohn's and Colitis Canada in 2016 and, as multidisciplinary IBD experts joined over the years, new collaborative projects emerged to address pressing issues such as inequitable access to care, the transition from paediatric to adult care, and mental health and nutrition.

Lead investigator Dr. Geoffrey Nguyen, clinician-scientist at Toronto's Mount Sinai Hospital, says specialists are concentrated in certain urban areas and it's vital that PACE deliver optimal care for rural Canadians.

"For Crohn's disease and ulcerative colitis, it's integral to use guideline-directed therapy to avoid serious complications and the need for surgery," says Dr. Nguyen. "Being seen regularly by a gastroenterologist is vital for better IBD outcomes, and PACE helps people in all communities to do so in real time."

## THE RISE OF DIGITAL HEALTH FOR IBD

PACE's driving force lies in digital health, and it is there where its projects converge and take hold to transform care.

"We started with the telemedicine program in Ontario," says Dr. Nguyen, "This program alone cut wait times to see a gastroenterologist from four months to just over two weeks." When COVID struck, they pivoted to an even more flexible virtual care model, where people connected over video or phone from home. PACE coordinators also helped set up diagnostic appointments in their area.

"Helping people from afar has been of extraordinary value to patients and, this summer, we are expanding virtual care into five more provinces," says Dr. Nguyen.

## PACE EVOLVES IN ITS SECOND PHASE

New initiatives emerged in the past year as part of this strategy for digital innovation.

Collaborators in Winnipeg created a new virtual screening tool for patients to assess their mental health, diet and nutrition needs – a real-time view into how someone with IBD is coping. They seek to build a new model of care, for use by any clinicians, that reflects the psychological and nutritional impact of IBD.

Meanwhile, in Toronto and Vancouver, researchers designed a first-in-Canada process to equip youth with IBD with the tools, knowledge and skills needed to transition well to the adult system – a particularly vulnerable time for them.

The second phase of PACE continues to gain steam in pursuit of standardising excellent IBD care across the country.



## OUR LEVERAGED FUNDS DRIVE PRECISION APPROACH TO TREATING CHILDREN WITH IBD

Paediatric gastroenterologist Dr. Aleixo Muise now sees nearly 200 children under the age of five who have inflammatory bowel disease (IBD) each year – up from just 20 a decade ago. In his lab at SickKids, Dr. Muise confronts this rising challenge by using whole exome and genome sequencing to bring precision care to these young patients with “very early onset” IBD.

Spurred first by an early investigator award from Crohn’s and Colitis Canada, Dr. Muise’s breakthrough came five years ago when DNA sequencing led his team to discover a form of IBD caused by a specific mutated gene.

“This is very important, because if someone has one of the many mutations, their IBD could be cured through a bone marrow transplant,” says Dr. Muise, who also received the Crohn’s and Colitis Canada 2020 Research Leadership Award.

Indeed, since then, his team has found the “functional cause” of IBD in numerous children at SickKids, across Canada and around the world – who are now cured after bone marrow transplants.

## THE POWER OF LEVERAGED FUNDING

This potential to discover the root cause of a child’s IBD is at the heart of research partnerships. “To support projects that require dollars exceeding the capabilities of one organization, funders pool their resources together to provide investigators the bench strength to drive cutting-edge research forward. In this way, every dollar we invest provides more funding towards advancing our research goals,” explains Dr. Kate Lee, Vice President of Research & Patient Programs at Crohn’s and Colitis Canada. “Dr. Muise is a recipient of such a leveraged funding program, in this case, developed by the Canadian Institutes of Health Research (CIHR) – Canada’s health research funding agency.”

“It’s really important to have Crohn’s and Colitis Canada step in to support grants, because they advocate and channel funding solely into IBD,” says Dr. Muise. “Its funding is instrumental in increasing research dollars, hiring the fellows and trainees who we need, including MD trainees who are critical to defining the translational research questions we must solve in the lab.”

Through this CIHR leveraged funding program, Dr. Muise is expanding the novel precision medicine approach to youth, teens and adults with severe colitis. The goal is to create tailored treatment for each person according to their unique genetics, environment and lifestyle.

“We believe that some genes may not necessarily cause IBD but instead be responsible for why it progresses,” Dr. Muise says. “With this grant we can pursue a personalized approach to each person, using treatments that target a particular genetic pathway, instead of randomly choosing medications.

“This means treating what is actually driving their disease, so they can lead a normal life.”

# NURSING-LED RESEARCH SHINES LIGHT ON PATIENT EXPERIENCES

Canadian IBD Nurses (CANIBD) is a community of practice of specialized nurses who provide advanced and quality care to those living with IBD. The group was formed in 2015 with only 80 nurses. Currently with over 190 members, CANIBD provides a national platform for IBD nurses to elevate their standards of care through continuing education and research.

We highlight two exemplary nurse practitioners and their research projects:



## RESEARCH: INCIDENCE, PREVALENCE AND DETERMINANTS OF DISCOMFORT IN INFLAMMATORY BOWEL DISEASE

Irina Nistor, MN, NP-Adult

Irina Nistor, Certified Gastroenterology Nursing Practitioner and Crohn's and Colitis Canada's PACE Transition Navigator was the recipient of the 2019 nursing-led CANIBD research grant.

Irina's research looked at the incidence, prevalence and determinants of discomfort in people living with IBD. The study found that there were varying degrees of discomfort among people living with IBD ranging from 7.5% of women in remission reporting vaginal discomfort to over 80% of patients with moderate to severe Crohn's disease.

Health literacy, disease activity, hospitalization and surgery, demographics, delayed diagnosis and local practice were found to be determinants of discomfort that could be addressed through intervention.

This study, now published, provides valuable information in considering discomfort as a symptom that impacts the quality of life of IBD patients.



## RESEARCH: PATIENTS' ACCESS TO TELEPHONE AND E-MAIL SERVICES PROVIDED BY IBD NURSES

Usha Chauhan RN, MN, BScN, ACNP

Usha Chauhan is an Adult Nurse Practitioner within the Digestive Disease Clinic at McMaster University Medical Centre in Hamilton, Ontario and has over 12 years of experience working with IBD patients. Warmly referred to as the 'IBD Mum' by her colleagues and patients, Usha is a strong advocate of nursing-led research. Her recently published study analyzed the utilization of telephone and email services by IBD patients. Results indicate that phone and email were primarily utilized for queries regarding medication, disease exacerbations, investigations, and scheduling appointments. The study also found that in the absence of telephone or e-mail assistance, older patients were more likely to call their family doctor, visit the emergency room, visit an urgent access clinic, or visit a walk-in clinic than younger patients. The study demonstrates that nursing-led services offer quick and convenient methods to address most patient-related concerns.



## FUTURE DIRECTION

As front-line workers, IBD nurses bring a unique perspective to IBD care. This positions the nurses to identify gaps in patient care and conduct research to address these unique insights. As Usha Chauhan mentions, "Patients with IBD have a lifelong journey navigating through the complex healthcare system. We need to discover innovative models of care utilizing expert specialist nurses to allow for easily accessible and quality care in order to avoid long-term complications of IBD."

# RESEARCH AWARDS



## 2021 RESEARCH LEADERSHIP AWARD

Dr. Gilaad Kaplan

Dr. Gilaad Kaplan, gastroenterologist and professor at the Cumming School of Medicine in Calgary is the recipient of the 2021 Research Leadership Award. Dr. Kaplan is internationally renowned for studying the global epidemiology of IBD and has several publications in high impact scientific journals. In 2019, Dr. Kaplan was elected to the International Organization of the study of IBD (IOIBD) and in 2020, was recognized as a Highly Cited Researcher in recognition of being in the top one percent of cited researchers globally by Web of Science.

In spite of his bragging rights, colleagues who know him describe Dr. Kaplan as being tremendously modest and supportive of the IBD research community, lending his support to hundreds of projects in his career with no expectation of credit or personal benefit.

Beyond his clinical excellence in gastroenterology and scientific accomplishments, Dr. Kaplan has been guiding Crohn's and Colitis Canada as Chair and now Past-Chair of the Scientific & Medical Advisory Council in IBD care and research. He also was instrumental in bringing together the COVID-19 Task Force providing tailored guidance to the IBD community.



## 2021 WOMEN IN IBD OUTSTANDING RESEARCHER AWARD

Dr. Maitreyi Raman

Dr. Maitreyi Raman, a fellow of the Royal College of Physicians of Canada, a gastroenterologist, and faculty member of the Cumming School of Medicine at the University of Calgary is the recipient of the 2021 Women in IBD Outstanding Researcher Award.

She is also the director of Alberta's Collaboration of Excellence for Nutrition in Digestive Diseases and the national medical lead for nutrition in gastrointestinal illness where she leads cutting edge research related to IBD and nutrition. Dr. Raman is the recipient of several teaching awards including the Canadian Association of Gastroenterology Young Educator Award for her diligent work mentoring several graduate students and residents.

Dr. Raman is a firm believer in the power of nutrition as therapy and, as an active researcher, has authored three books—one on dietary therapies for cirrhosis, another on dietary therapies for irritable bowel syndrome and, the third, an eating guide for enhancing the gut microbiome to reduce the risk of chronic diseases. She authored the first IBD food pyramid which was published in a top-tier scientific journal *Lancet Gastroenterology and Hepatology*.



## 2021 WOMEN IN IBD EMERGING RESEARCHER AWARD AND THE 2021 RISING STAR AWARD

Dr. Amanda Ricciuto

Dr. Amanda Ricciuto, a paediatric gastroenterologist and assistant professor at the Hospital for Sick Children (SickKids) and University of Toronto is the recipient of the 2021 Women in IBD Emerging Researcher Award and the 2021 Rising Star Award.

She completed her medical degree and general paediatrics training in Montreal at McGill University and then went on to pursue her fellowship training in paediatric gastroenterology at SickKids, including advanced training in the management of paediatric IBD.

Dr. Ricciuto also obtained a PhD in clinical epidemiology and health care research at the Institute of Health Policy, Management and Evaluation at the University of Toronto. Her PhD focused on IBD-associated liver disease, with an emphasis on primary sclerosing cholangitis, and longitudinal data analysis.

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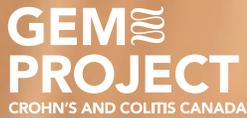
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The only national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world, investing over \$140 million in research since 1974, leading to important breakthroughs in genetics, gut microbes, inflammation and cell repair research as well as laying the groundwork for new and better treatments. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness.

Crohn's and Colitis Canada funds research projects and patient programs that fight Crohn's and colitis today, while working towards a future free of these diseases. Your donations fuel our efforts.



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