

# **FOREWORD**

Canada is home to some of the most ambitious and promising research into Crohn's disease and ulcerative colitis.

However, this was not always the case. At the time of our founding in 1974, the knowledge around these diseases was scarce. With the need to better understand their causes and find cures, our founders set out to drive research in this field. Their motivation and passion acted as a catalyst for the growth of our community, enabling us to become the second largest health charity funder of Crohn's and colitis research in the world.

Our work to find cures and improve quality of life continues as we invested \$6.7 million in research throughout the year – bringing our total investment to over \$127 million since our founding. The 47 research projects that we supported this year seek to better understand and continuously improve all aspects of the patient journey, from day-to-day life to treatments to prevention of these diseases altogether.

Within the pages of this report, we share stories that provide you with a glimpse into the brilliant minds of our research community and the research projects forging the path towards a future free of Crohn's and colitis.

We also proudly highlight our 2018 Impact of Inflammatory Bowel Disease in Canada report, which provides a comprehensive examination of these diseases and their impact on Canadians and the country as a whole. Led by the scientific community, the report identifies how research outcomes can be applied to improve the Canadian patient experience and guide new areas of investigation.

The collective support of donors, patients, volunteers, and researchers allows us to see these projects from conception to completion. Our research report represents the powerful impact that we are making – and will continue to make – together. We hope you enjoy learning about all that you have made possible.

# **ACKNOWLEDGEMENTS**

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#### Dr. Nicola Jones

University of Toronto, The Hospital for Sick Children

#### **Dr. Eric Benchimol**

University of Ottawa, Children's Hospital of Eastern Ontario

#### Dr. Brian Bressler

University of British Columbia, St. Paul's Hospital

# **2020 VISION**



Crohn's and Colitis Canada is a global force advancing transformational research and activating our community to improve the lives of people affected by Crohn's and colitis in Canada.

#### **LEGEND**

- Generate new science, knowledge and treatments for Crohn's and colitis through a diverse research portfolio
- Create an open conversation about Crohn's and colitis and grow our profile as leaders

Diversify and grow our fundraising

- Improve the quality of life and day-today experience of people living with or affected by Crohn's or colitis
- Support high performance and strategic action across the organization

# **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

#### RECRUITING HIGHLY QUALIFIED PERSONNEL



Supporting the careers of the best and brightest Crohn's and colitis researchers across Canada.

- Fellowships
- New investigator awards
- Chairships

# 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



# Meet the up-and-coming researcher determined to uncover new insights into the disease she lives with

As a teenager with Crohn's disease, Ellen Kuenzig would not have imagined how the disease would shape her future career. Ellen has taken her lived experience, combined it with a passion for better understanding Crohn's disease, and is pursuing an impactful research career that has already uncovered important new insights.

"Crohn's and Colitis Canada has been a huge part of my trajectory from the very beginning," Ellen says. "I realized I had found a supportive community where I wasn't facing this disease alone. Attending a few events soon turned into joining chapter meetings and volunteering."

master's in epidemiology at Western University, Ellen decided to concentrate on IBD research. Through her interest in this field of study, Ellen decided to attend a Crohn's and Colitis Canada Meeting of the Minds conference where, by chance, she met gastroenterologist and epidemiologist Dr. Gilaad Kaplan. The prominent researcher encouraged Ellen to study epidemiology at the University of Calgary. The PhD she earned in 2016 focused on genetic and environmental risk factors for IBD.

Now Dr. Kuenzig, Ellen received a postdoctoral fellowship funded partly by Crohn's and Colitis Canada to work in the lab of Dr. Eric Benchimol at the Children's Hospital of Eastern Ontario (CHEO) and at ICES in Ottawa. She is involved in many ongoing studies, including two key projects at both ends of the age spectrum, also funded by Crohn's and Colitis Canada. One study examines the rates of IBD in children across different provinces while exploring trends for care inside and outside specialized pediatric centres. A second study focuses on how older adults with IBD access care, looking at variations across regions, trends in surgeries, hospitalizations and outcomes, and patients' ability to access gastroenterologists.

"By identifying gaps in care, we are in a better position to address why patients with the same disease have different outcomes," says Dr. Kuenzig. "From there, we can determine the appropriate interventions to ensure patients receive the best quality of care."

In a relatively short period, Dr. Kuenzig has launched an impressive career in Crohn's research and has contributed to our understanding of the disease, including as one of the authors of Crohn's and Colitis Canada's 2018 Impact of IBD in Canada report. Along the way, she also earned an AbbVie IBD Scholarship and two separate Student Research Prizes from Crohn's and Colitis Canada, which support early-career scientists who are driving IBD research into the future.

"I would never have seen myself where I am today, when I was first diagnosed as a teenager," Dr. Kuenzig says. "I'm pretty proud of where I've come. It's so interesting to dig in and understand what the data has to say. I'm looking forward to continuing to make a difference for all Canadians like me who live with these difficult diseases."



#### EPIGENETIC MODIFIERS, ENVIRONMENT, AND IBD

Dr. Claude Asselin Université de Sherbrooke Year 3 of 3 \$125,000 Total: \$375,000

## FUNCTION OF MICROBES IN ULCERATIVE COLITIS

Dr. Elena Verdu McMaster University Year 3 of 3 \$125,000 Total: \$375,000

#### CHANGES IN GUT MICROBIOME AND INFLAMMATION

Dr. Mark Silverberg Mount Sinai Hospital Year 3 of 3 \$125,000 Total: \$375.000

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.

Dr. Asselin is examining how certain proteins, namely Histone Deacetylase (HDAC), can sense how cellular and extracellular environmental metabolites influence the cells in the gut. Metabolites are small molecules in the environment that can affect the way our genes behave without modifying their genetic code. This study's findings will help us understand which aspects of the environment cause changes in gut cells that lead to IBD, enabling the development of more targeted treatments.

Dr. Verdu is studying how microbes in the gut (microbiota) affect inflammation in ulcerative colitis by measuring the microbiota function of unique patient cohorts before and after development of the disease. The study's findings could lead to the identification of novel biomarkers that could be used to monitor disease progression and therapeutic targets.

Dr. Silverberg is studying patients who have undergone pouch surgery to evaluate how the composition of the intestinal microbiome - the bacteria that live in the gut - changes over time, and how these changes may result in the development of intestinal inflammation. The study's findings could lead to therapies which decrease the frequency of pouch inflammation and the occurrence of IBD in general.

#### NEW TARGETS TO TREAT FIBROSIS IN CROHN'S DISEASE

Dr. Simon Hirota University of Calgary Year 2 of 3 \$125,000 Total: \$375,000

Dr. Hirota is studying the way the intestine heals and how protein pregnane X receptor (PXR) influences the development of fibrosis, a condition which causes excessive muscle growth leading to intestinal obstructions. As 30 to 50 percent of Crohn's disease patients require surgery for intestinal obstructions, it is crucial to develop a treatment that can block fibrosis. This study's findings will increase our understanding of fibrosis and discover new ways to minimize and prevent intestinal obstructions.

#### DEFINING THE MICROBES INVOLVED IN CROHN'S DISEASE

Dr. Brian Coombes McMaster University Year 2 of 3 \$125,000 Total: \$375,000

Dr. Coombes is studying how adherent-invasive
Escherichia coli (AIEC), an invasive bacterium linked to
Crohn's disease, adapts to the inflamed gut. He has found unique genetic changes in
AIEC that allow it to cause inflammation in the gut and outcompete healthy microbes in the intestine. Understanding how AIEC acts as a potential trigger of Crohn's disease could lay the foundation for treatments, cures, or prevention.

# TARGETING SPINAL MICROGLIA IN IBD PAIN

Dr. Christophe Altier University of Calgary Year 1 of 3 \$125,000 Total: \$375,000

Dr. Altier is researching the underlying factors that contribute to persistent pain, a symptom commonly experienced by IBD patients. The objective of his study is to understand how microglia, a type of immune cell, through a complex interaction with neural pain circuits contribute to chronic pain, and to stop microglia promoted sensitization in order to alleviate pain.

# NOVEL PEPTIDES DRIVING MUCOSAL HEALING

Dr. Wallace MacNaughton University of Calgary Year 1 of 3 \$125,000 Total: \$375,000

Dr. MacNaughton is studying the role of novel peptides in the intestine's mucosal healing process, which is considered the gold standard for assessing the success or failure of treatment in IBD. His study could lead to the development of new therapies to keep people living with IBD in remission.



DISCOVERING NOVEL TREATMENTS

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

# EPITHELIAL INFLAMMASOMES AND IBD

Dr. Bruce Vallance University of British Columbia Year 3 of 3 \$125,000 Total: \$375,000

Dr. Vallance is studying the potential of a set of proteins called an 'inflammasome' to interrupt the cycle of changes that occur in the epithelial cells lining the intestine of patients with IBD. His lab previously determined these distinct changes are driven by the inflammasome, so this study's findings will identify ways to use the inflammsome in a targeted treatment for IBD.

#### **NANOPARTICLES**

Dr. Stuart Turvey British Columbia Children's Hospital Year 3 of 3 \$125,000 Total: \$375,000

Dr. Turvey is studying a new treatment for IBD by developing a nanoparticle that will reduce gut inflammation without suppressing the entire immune system. He has had positive results so far using this therapy to improve the health of IBD mice, and is launching larger scale studies to confirm the benefits. His research will serve as a foundation for development of nanomedicines, a type of precision medicine that employs nanoparticles to adapt treatment to the patient's unique genetic makeup, lifestyle, and environment.

# CONTROLLING INFLAMMATION

Dr. Ted Steiner University of British Columbia Year 3 of 3 \$125,000 Total: \$375.000

Dr. Steiner is studying how inflammatory responses to bacteria in the gut may contribute to IBD. The goal of this study is to harness the power of regulatory T cells (Tregs), a type of white blood cell, to suppress inflammation as a possible treatment for IBD patients. The study aims to develop a method to take a patient's Tregs, introduce genes that enhance their ability to suppress inflammation, and re-inject the Tregs into the patient where they make their way to the gut and suppress inflammation.

### IBD-SPECIFIC NANOMEDICINES

Dr. Pere Santamaria University of Calgary Year 2 of 3 \$125,000 Total: \$375,000

Dr. Santamaria's research has documented the efficacy of nanomedicines, a new type of drug composed of very tiny particles, for the treatment of IBD in mice. These drugs operate by re-programming disease-causing white blood cells into disease-suppressing 'regulatory' white blood cells, without impairing the normal functioning of the immune system. Dr. Santamaria is studying how these reprogrammed white blood cells orchestrate the molecular and cellular events that result in the resolution of IBD.

# TARGETING P2Y RECEPTORS IN IBD

Dr. Fernand-Pierre Gendron Université de Sherbrooke Year 1 of 3 \$125,000 Total: \$375.000

Dr. Gendron is investigating the therapeutic potential of molecules called UDP analogs (uridine diphosphate-mimicking molecules) for the treatment of IBD. Dr. Gendron's work, in partnership with Dr. Bilha Fischer of Bar-llan University in Israel, hopes to develop molecules that can help block inflammation and promote healing of the intestine. If successful, this will help keep people with IBD in remission.

## STOOL TRANSPLANT FOR ULCERATIVE COLITIS

Dr. Ted Steiner University of British Columbia Year 1 of 3 \$125,000 Total: \$375,000

Dr. Steiner is working to determine if an intensive, 8-week regimen of fecal microbial therapy (FMT) can induce remission in people with active ulcerative colitis. While a few studies on FMT have shown promise, he aims to determine the best way to administer the treatment and boost its success rates.

#### MACROPHAGES TO TREAT IBD

Dr. Derek McKay University of Calgary Year 1 of 3 \$125,000 Total: \$375,000

Dr. McKay is assessing the potential of cellular immunotherapy, where the prohealing ability of an individual's own macrophages, a type of white blood cell important to the immune system, are enhanced and these cells are then used to treat IBD. The outcome of this study could lay the groundwork for the development of a personalized therapy that uses a patient's own cells to treat their disease.



In any given year, 1 in 5 Canadians will experience a mental health challenge – and for Canadians living with inflammatory bowel disease (IBD), evidence shows they are at heightened risk for being among that cohort.

Through a three-year research grant, Crohn's and Colitis Canada is targeting this vital area in need of more research: the impact of IBD on mental health, and how we can help patients.

It was awarded to Dr. Dean Tripp, a professor of psychology at Queen's University who has long studied the psychosocial impact of pain. A rising swell of research in recent years has revealed alarming patterns of depression and suicidal ideation among people with Crohn's disease or ulcerative colitis.

"These threats are more prominent than we previously thought, and we must act now to help patients of all ages," says Dr. Tripp, whose research underscores pain's link to depression and a poorer quality of life for IBD patients.

This grant enables the first longitudinal study to explore how symptom flare-ups impact mental health, relationships and social interaction, work and disability, and other variables tied to quality of life. Dr. Tripp is also tackling the difficult subject of suicide, seeking to provide new insights in targeting psychological management for those most at risk, and helping them cope with the disease.

Dr. Tripp says it's important to uncover the precipitating factors that lead to mental health struggles in those who live with IBD.

"We know disease activity is one such factor – for example, when a teen starts to experience signs of IBD and it affects their social life, even their ability to go to school," says Dr. Tripp. "The disease itself is a major promoter of these adjustment problems and stressors, because inflammation and changes in our microbiome directly impact our mood, sleep, and physical mobility – even our desire to be around other people."

What results is a cycle of physical symptoms that drive negative thoughts, feelings, and perceptions, which in turn create higher inflammation and disease activity. If the body is ill, the mind tends to get ill.

"How you feel physically, what you do in your world, and then how you feel about the world and yourself – we are exploring this now more deeply to understand some of the most difficult psychological factors at play when a patient is coping with this disease."

Dr. Tripp stresses that the early moments – the months and years after someone is diagnosed – may be the most critical in terms of supporting mental health. During this time of adjustment for patients and families, there is stress, possible surgeries, and body image and illness stigma to ward off.

"The onset of IBD is like throwing a heavy rock in a calm pond," Dr. Tripp says. "It's a mini tsunami of distress that can be a serious struggle. We must focus research on this crucial period of adjustment."

There is an urgent need to develop new strategies and resources to help patients with IBD. This grant, Dr. Tripp says, will drive results he hopes will help compel action to improve their psychological welfare.

"We must reach a stage of action, not exist in a stage of investigation," Dr. Tripp says. "Crohn's and Colitis Canada is really helping move the needle with regards to research in this much-needed direction."

RECRUITING
HIGHLY
QUALIFIED
<b>PERSONNEL</b>

CROHN'S AND COLITIS
CANADA / CANADIAN
INSTITUTES OF HEALTH
RESEARCH / CANADIAN
ASSOCIATION OF
GASTROENTEROLOGY
FELLOWSHIPS

Dr. Cristian Hernandez Sinai Health System Year 1 of 2 Crohn's and Colitis Canada Contribution in 2018/2019

\$27,500

Crohn's and Colitis
Canada finances
researchers through
all stages of their
careers. We support
the entire spectrum
of IBD scholarship
from undergraduate
students all the way
through to seasoned
investigators.

CROHN'S AND COLITIS
CANADA / CANADIAN
INSTITUTES OF HEALTH
RESEARCH / CANADIAN
ASSOCIATION OF
GASTROENTEROLOGY NEW
INVESTIGATOR AWARDS

Dr. Amy Metcalfe University of Calgary Year 3 of 5

Dr. Eric Benchimol Children's Hospital of Eastern Ontario Year 4 of 5

Dr. Johan Van Limbergen Dalhousie University Year 4 of 5 Crohn's and Colitis Canada Contribution in 2018/2019

\$35,000

\$30,000

\$31,500



118 MDs

Total Funding in 2018/2019

\$55,000

Total Funding in 2018/2019

\$60,000

\$60,000

\$60,000



38 FELLOWS



21
ALLIED HEALTH PROFESSIONALS
(PHARMACISTS, DIETITIANS,
RESEARCH COORDINATORS)



**66** FACULTY MEMBERS

ATTENDED THE MEETING OF THE MINDS CONFERENCE



56
NURSES ATTENDED MEETING
OF THE MINDS & ANNUAL
CANIBD CONFERENCE



# IBD Impact Report is a call to action for policymakers, clinicians, and scientists in Canada

Understanding the scope of a problem is imperative in order to take action in healthcare. For Canadians who live with inflammatory bowel disease (IBD); for those who will; for the clinicians who treat them; and for researchers hunting for new clues, the latest Impact of IBD in Canada report published by Crohn's and Colitis Canada describes the nationwide burden of IBD and what governments and healthcare institutions must brace for.

IBD affects 270,000 Canadians today and will affect 400,000 by 2030 – a full 1 percent of the population. The cost of caring for them, which currently sits at \$2.6 billion a year, will grow in step with that trend. And there are gaps in that care: rural areas face a scarcity of gastroenterologists to expertly manage IBD. Crohn's

disease and ulcerative colitis impact Canadians at opposite ends of the age spectrum: while older adults are the fastest growing group of patients, children are the fastest growing group for new diagnoses.

This report not only explores the impact of IBD on Canadians and key scientific gaps in knowledge, but demands we hold vital conversations about the future. With IBD clinics already stressed by the volume of patients, how will they manage such a surge in demand? How can telemedicine or other new technologies and models of care provide more patients with access to specialists? How can we bring expensive biologic therapies, vastly superior to older drugs, to those who need them?

The number of Canadian children with IBD has climbed 50 percent in just 10 years. Dr. Eric Benchimol, pediatric gastroenterologist and epidemiologist at the Children's Hospital of Eastern Ontario (CHEO) and University of Ottawa, says we are identifying it earlier thanks to newer technology; additionally, the medical community has greater recognition that this is a pediatric disease and doctors are more willing to order endoscopies and MRIs to identify Crohn's and colitis in youngsters.

However, the reasons for this rising rate

"Everywhere in the Western world, rates of new diagnoses among adults are stable but rates among children are spiking," says Dr. Benchimol, co-author of the Impact of IBD in Canada report. "This alarming trend is a call for us to investigate early-life environmental risk factors and other underlying causes of IBD."

IBD early in life presents unique challenges, from inflammation causing stunted growth and early osteoporosis, to medication side effects, to the common related problems of anxiety and depression. Children must be closely monitored and require frequent visits to clinics and imaging departments.

"Our biggest challenge is getting kids fully back to a normal childhood – attending school, playing, being with friends, enjoying activities without being impeded by fatigue, pain, or other symptoms," says Dr. Benchimol. "And we have a limited time period to optimize their care and heal their bowels which often means we use fairly aggressive treatment. Children will live with this disease all their life, so we must start strong early."

Meanwhile, the cohort of older adults is rising along with the demand for IBD treatment, fueled by Canadians diagnosed in their teens and twenties who have reached retirement age. In less than two decades, boomers will elevate Canada's senior population to 9.5 million (23 percent of the country) from about 6 million seniors in 2016.

This unprecedented "silver wave" brings its own set of challenges, from meeting the demand for care to plotting how to treat Crohn's and colitis when other health conditions are present. Medication interactions, increased risk of infection, higher rates of cancer – not to mention juggling the distinct needs of newly-diagnosed seniors vs. long-term patients – are factors that create a minefield of uncertainty the medical and research community must wade through. While the ultimate impact on the Canadian healthcare system is yet unknown, we nonetheless must prepare.

"We face the significant challenge of contending with age-related comorbidities such as type 2 diabetes and cancer," says Dr. Gilaad Kaplan, gastroenterologist and epidemiologist at the University of Calgary and co-author of the report. "Managing IBD is difficult on its own, but decisions are far more complex when balancing the medical management of other conditions.

"What's more is that, every day in Canada, gastroenterologists are making a brand new diagnosis of IBD in an elderly patient."

Though the rural population in Canada is declining, those who do live outside of city centres are aging at a much faster rate than their urban and suburban counterparts. Rural Canadians often have difficulty accessing specialized care simply because there are fewer practicing gastroenterologists, and travelling long distances to see them may be difficult or undesirable. Studies have shown that this leads to disparities in care

Crohn's and Colitis Canada's Promoting Access and Care through Centres of Excellence (PACE) network is working to address this gap by establishing telehealth links with centres of excellence across the country. Instead of travelling or waiting months for an appointment, patients living in remote areas of the country can receive guidance and specialized treatment by healthcare professionals from afar.

"Embedding a specialist in one's healthcare team can lead to vastly different outcomes, including reducing the need for surgery in favou of medical therapy, which is the more desirable treatment option," says Dr. Benchimol.

The Impact of IBD in Canada report is a crucial instrument as we face the challenges to come posed by these diseases. To policymakers, it illustrates the science behind Crohn's and colitis specific to Canada. To scientists, it shines light on any gaps in research that might exist.

"Ultimately," says Dr. Benchimol, "this report asks: what are we going to have to do in the future to make a difference?"





#### HELPING MANAGE SYMPTOMS

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

#### TARGETED PAIN THERAPY FOR IBD PATIENTS

Dr. Stephen Vanner Queen's University Year 3 of 3 \$125,000 Total: \$375,000

Dr. Vanner is developing ways to improve the effectiveness of opioid therapy while minimizing its side effects as an important unmet need of IBD patients is better control of abdominal pain. The research focuses on developing a new generation of opioid medications, which will include drugs that provide sustained pain relief as well as those that specifically target inflamed gut tissue.

# DIETARY LIPID INTERVENTION AS A THERAPEUTIC AGAINST COLITIS

Dr. Deanna Gibson University of British Columbia Year 2 of 3 \$125,000 Total: \$375,000

Dr. Gibson is researching the effects of dietary lipids on ulcerative colitis by studying them in isolation as well as in a combination similar to the Mediterranean diet. It is known that differences in the chemistry of dietary lipids affect host physiology and inflammation, but the role specific fats play in altering susceptibility to IBD is unclear. This research addresses the need for evidence-based nutrition recommendations for IBD patients.

# BRAIN IMAGING IN IBD

Dr. Charles Bernstein University of Manitoba Year 1 of 3 \$125,000 Total: \$375,000

Dr. Bernstein's research focuses on determining if IBD patients have different structural and functional brain imaging compared to people without IBD, and if IBD patients with depression or anxiety have different structural or functional brain imaging than patients with IBD without mental health diagnoses. As the presence of mental health diagnoses can worsen disease course, this research will provide a greater understanding of the brain structural and physiological changes that IBD patients with depression or anxiety may have.

#### VITAMIN D FOR PREVENTION OF CROHN'S DISEASE RELAPSE IN CHILDREN

Dr. Prévost Jantchou CHU Sainte-Justine Year 1 of 3 \$125,000 Total: \$375,000

Dr. Jantchou is researching the role vitamin D might play for pediatric Crohn's disease patients. His study compares the effect of a high dose of vitamin D with a standard dose to explore its effectiveness as a supplementary therapy for Crohn's disease. This inexpensive nutritional therapy could reduce the potential for relapse and improve care.



### \$6.7 MILLION INVESTED IN RESEARCH IN 2018/19



100%
OF GRANTS FEATURED
COLLABORATIONS AMONG
LEADING SCIENTISTS AND
PARTNERS ACROSS CANADA



47
RESEARCH PROJECTS
AND INITIATIVES
FUNDED IN 2018/19



FOR EVERY \$1 WE INVESTED, \$5 WERE LEVERAGED FROM GOVERNMENT AND INDUSTRY



\$127 MILLION+ INVESTED IN RESEARCH SINCE OUR FOUNDING IN 1974



# First-ever IBD Global Rating Scale aims to improve the quality of care delivered to IBD patients across Canada

Inflammatory bowel disease (IBD) is a chronic intestinal disease that can flare at any time, and those who live with Crohn's disease or ulcerative colitis need rapid, reliable access to treatment and support. Yet, as for many diseases, there are disparities in the delivery of care across Canada – gaps that can negatively impact the lives of patients.

Spearheaded by Dr. Alain Bitton at the McGill University Health Centre, the first-ever IBD Global Rating Scale (IBD GRS) was developed – a project within Crohn's and Colitis Canada's Promoting Access and Care through Centres of Excellence (PACE) network in conjunction with the Canadian Association of Gastroenterology.

The IBD GRS is a unique online selfassessment tool that enables healthcare teams to review, evaluate, and improve key aspects of the delivery of care in their clinics. "Gaps in delivery of care lead to variations in the treatment that Canadians living with Crohn's disease or ulcerative colitis need in order to live well," says Dr. Bitton. "The IBD GRS provides milestones that clinicians can use to improve delivery of care. These include disease evaluation, management and appropriateness of treatment, as well as the patient experience, such as safety and the ability to access advice and care when they need it."

This novel rating system is a collaborative effort led by a committee of clinical scientists and physicians, and members from Crohn's and Colitis Canada and the Canadian Association of Gastroenterology. The system also includes feedback from patients on IBD quality indicators.

"We've found this tool identifies gaps that healthcare providers didn't even realize were there – for example, if patients can easily access specific information, or if a clinic offers urgent appointments," says Dr. Bitton. "From there, healthcare providers can make changes where needed and measure the impact of these changes over time."

The IBD GRS has been piloted successfully in the five PACE Centres across Canada. But that's only the beginning, as the team hopes the IBD GRS will enhance IBD care throughout the country, and beyond.

"PACE is an excellent, multidimensional initiative that brings together leading IBD experts to elevate the standard of care in Canada," says Dr. Bitton. "The IBD GRS is an example of how these efforts can result in tangible improvements for patients and their families."



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.

# SAFER PREGNANCIES

Dr. Geoffrey Nguyen Mount Sinai Hospital Year 3 of 3 \$125,000 Total: \$375,000

Dr. Nguyen is studying nursing interventions focused on improving adherence to medication regimens by pregnant patients living with IBD in order to decrease disease-related pregnancy complications. While controlling the disease through optimal medical therapy is key in preventing pregnancy complications, studies show pregnant patients exhibit lower adherence to medication regimens.

#### DRUG EFFECTIVENESS

Dr. Laura Targownik University of Manitoba Year 3 of 3 \$125,000 Total: \$375,000

Dr. Targownik is studying the effectiveness of drugs currently prescribed to patients to look for connections between the use of specific drugs and whether their use is linked to reduced IBD-related hospitalizations, operations, and corticosteroid use. She is also evaluating the impact of anti-TNF therapy on reducing costs of medical care associated with hospitalizations.

#### OUTCOME MEASURES

Dr. Reena Khanna Western University Year 2 of 2 \$67,000 Total: \$132,000

Dr. Khanna's research focuses on developing and validating outcome measures used to assess disease activity and response to treatment. Her project is directed towards developing a novel index for endoscopic assessment of disease activity in Crohn's disease using statistical methods, assessing alternative methods to score ulcers, comparing the reliability of the current endoscopic indices (SES-CD and CDEIS) and the novel index, and assessing their ability to detect changes in disease activity following treatment.

#### THE PATIENT PERSPECTIVE

Dr. Geoffrey Nguyen Mount Sinai Hospital Year 2 of 3 \$125,000 Total: \$375,000

Dr. Nguyen is researching which aspects of IBD healthcare matter most to patients.
His study quantifies patient preferences for healthcare processes and outcomes to improve patient-physician communications, adjust quality indicators, and help policymakers account for the patient perspective when prioritizing IBD-related health interventions.

#### **ONLINE PEER MENTORING**

Dr. Sara Ahola Kohut The Hospital for Sick Children Year 2 of 3 \$125,000 Total: \$375,000

# NUTRITION TO TREAT CROHN'S DISEASE

Dr. Maria Ines Pinto-Sanchez McMaster University Year 1 of 1 Total: \$50,000

#### **CIRCADIAN RHYTHMS IN IBD**

Dr. Phillip Karpowicz University of Windsor Year 1 of 1 Total: \$50,000

Dr. Ahola Kohut is researching the impact of the iPeer2Peer program, an online peermentoring program for teens living with IBD. This program helps teach teens the skills they need to manage not only the physical symptoms of living with IBD, but the emotional and social implications as well.

Dr. Pinto-Sanchez is assessing if replacing meals with nutrition formula (exclusive enteral nutrition) in addition to the use of steroids is more effective in inducing remission of Crohn's disease flares than using steroids alone. Her research also investigates if replacing meals with nutrition formula could decrease patients' use of corticosteroids. This research could lead to more effective treatments and fewer adverse events.

Dr. Karpowicz is researching how circadian rhythms affect IBD. Circadian rhythms, natural 24-hour changes in activity like sleep/wake cycles, hormone cycles, and feeding/fasting cycles, are controlled by a 24-hour timer present in the cells of the body. This research will help establish preventative strategies for people living with IBD, and identify the best time of day for therapies.



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.

# SYSTEMATIC REVIEWS

Dr. Brian Feagan Cochrane IBD Group \$60,000

The Cochrane IBD Group is part of the prestigious Cochrane Group, the world leader in producing systematic reviews of scientific literature. Crohn's and Colitis Canada has partnered with the Cochrane IBD Group to support our mutual interest in providing high-quality information to help healthcare professionals, policymakers, and researchers make well-informed decisions for IBD patients.



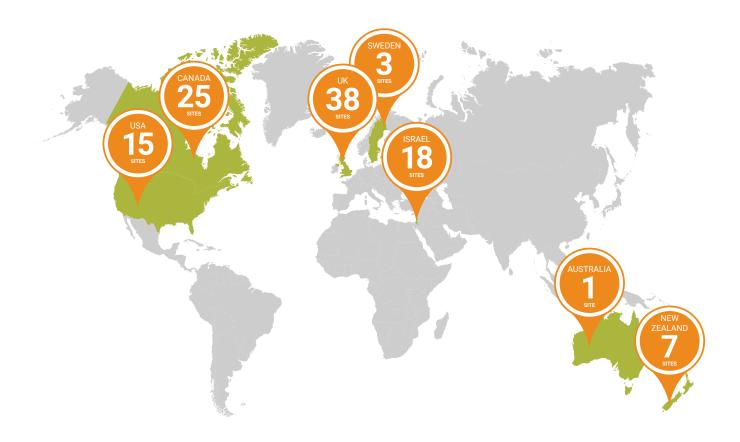


17
HOSPITALS AND
UNIVERSITIES
SUPPORTED



2,318
ARTICLES AND BOOK
CHAPTERS PUBLISHED
BY OUR RESEARCHERS

# The GEM Project



The Crohn's and Colitis Canada Genetic, Environmental, Microbial (GEM) Project aims to identify the causes of Crohn's disease. Researchers closely monitor the diet, immune function, intestinal barrier, microbiome, genetics, and environment of healthy first-degree relatives of individuals living with the disease. By comparing data from healthy participants to those who develop Crohn's disease, researchers can identify disease triggers. So far, 82 out of the 5,085 study participants have been diagnosed with Crohn's disease, which exceeds our target of 75 participants.

As the GEM Project entered its third phase, researchers have begun to discover biomarkers—changes in blood and tissue—that appear more frequently in individuals who develop Crohn's disease. Researchers will use these findings to develop predictive tests, which will in turn lead to earlier, personalized treatments, lower healthcare costs, and better quality of life.

Led by Dr. Ken Croitoru at Toronto's Mount Sinai Hospital, the GEM Project is the largest study of its kind. Research insights will not only bring us closer to cures and prevention of Crohn's disease, but also improve our understanding of ulcerative colitis. Crohn's and Colitis Canada and The Leona M. and Harry B. Helmsley Charitable Trust have proudly supported the GEM Project through a financial investment of nearly \$16 million in phases one and two, and more recently, through an investment of \$6.4 million in the project's third phase.



MEETING OF THE MINDS CONFERENCE

CANADIAN IBD NURSES (CANIBD)

We host medical conferences and support IBD nurses because we believe that true expertise requires continuously sharing the latest best practices and evidence-based information with healthcare professionals.

In partnership with leading inflammatory bowel disease (IBD) specialists and educators, Crohn's and Colitis Canada hosts Meeting of the Minds, a national event where Canadian researchers, gastroenterologists, and allied healthcare professionals convene to broaden their knowledge of Crohn's disease and ulcerative colitis and share practical applications of the latest research in this field every November. Canada's flagship educational event includes Mentoring in IBD, an intensive day of lectures, case-based workshops, and open discussions, and the Canada Future Directions in IBD conference, a forward-looking series of presentations about the best new scientific research on IBD. As part of the latter, IBD nurses host their annual Canadian IBD Nurses (CANIBD) Meeting, where they branch off into a set of presentations tailored for their unique needs and role in the patient journey. In the spirit of continuous education, Meeting of the Minds ensures the Canadian medical and research community stays at the top of their game and continues to deliver the best care to patients living with IBD.

Supported by Crohn's and Colitis Canada, the Canadian IBD Nurses (CANIBD) is a pan-Canadian community of practice of the Canadian Society of Gastroenterology Nurses and Associates (CSGNA). CANIBD was established in 2015 to help meet the need for an inflammatory bowel disease (IBD) nursing network where best practices in IBD care could be shared. Nurses interested in IBD access educational opportunities, including webinars and an annual IBD nursing conference held in conjunction with Meeting of the Minds in Toronto. IBD nurses can apply to receive financial support to lead research studies and attend education events, and novice nurses can participate in an IBD nursing fellowship where they are paired with an experienced preceptor.

IBD nurses shaping the future of healthcare transition

Noelle Rohatinsky, RN, MN, PhD, CMSN(C)

Tracie Risling, RN, BA, BSN, MN, PhD

In 2016, the Canadian IBD Nurses (CANIBD), supported by Crohn's and Colitis Canada, introduced a grant program to facilitate nursing-led IBD research. Valued at \$15,000, this grant supports a clinical research study intended to improve patient care and quality of life for people living with IBD. Nurses' ability to participate in research is often hindered by barriers, including limited time and resources. This grant program helps address these challenges, while strengthening research capacity within the IBD nursing community.

Dr. Tracie Risling and Dr. Noelle Rohatinsky – the first recipients of the CANIBD Nursing-Led Research Grant – have a longstanding passion for improving support for patients during healthcare transition (HCT). This interest led them to work with pediatric IBD patients and their families to explore the challenges and opportunities they face when transitioning to adult care.

Dr. Risling and Dr. Rohatinsky understand the importance of working with patients, healthcare providers, and community partners to improve patient care. Through the support of this grant, they set out

to advance research into HCT by incorporating the expertise of fellow Canadian IBD nurses. Today, they are diligently working to advance patient care by translating the experiences of over 50 nurses into evidence-based best practice in adolescent HCT transition assessment and support.

Following the publication of a scoping review of HCT literature focused on assessment and screening tools used to evaluate HCT readiness, Dr. Risling and Dr. Rohatinsky conducted a national survey amongst Canadian IBD nurses. The survey focused on key HCT elements identified in the review in order to prioritize the transition needs of adolescent patients. Once analysis of these survey findings is complete, Dr. Risling and Dr. Rohatinsky will put these findings into action by creating tools that support IBD nurses in evaluating transition needs and readiness.



CIHR PROGRAMMATIC GRANTS IN ENVIRONMENTS, GENES, AND CHRONIC DISEASE

The diet-microbiome-gut axis in pediatric IBD

Elucidating the gene-environment interactions that drive autoimmune disease among South Asian Canadians (The GEMINI Program) Dr. Alain Stintzi University of Ottawa Year 4 of 5

Dr. Ken Croitoru Dr. Jennifer Gommerman University of Toronto Year 4 of 5

Crohn's and Colitis
Canada works
with the Canadian
Institutes of Health
Research to support
multi-year team
grants related to
critical IBD issues.
Our contribution
to these grants
demonstrates our
confidence in this
research and these
talented teams
of researchers.

#### CIHR INFLAMMATION IN CHRONIC DISEASE TEAM GRANT

Targeting chronic inflammation of the gut, liver, and joints

Critical illness in IBD, multiple sclerosis, and rheumatoid arthritis

Preventing complications from inflammatory skin, joint, and bowel conditions

Insights into Parkinson's disease, Crohn's disease, and leprosy

Brain dysfunction in chronic inflammatory disease

NADPH oxidase function in the pathogenesis of pediatric IBD and Juvenile Idiopathic Arthritis

Linking innate immunity and inflammation to chronic disease

Dr. Bertus Eksteen University of Calgary Year 5 of 5

Dr. Ruth Ann Marrie University of Manitoba Year 5 of 5

Dr. John Esdaile University of British Columbia Year 5 of 5

Dr. David Park University of Ottawa Year 5 of 5

Dr. Mark Swain University of Calgary Year 5 of 5

Dr. John Brumell
The Hospital for Sick Children
Year 5 of 5

Dr. Dana Philpott University of Toronto Year 5 of 5 Crohn's and Colitis Canada Contribution in 2018/2019

\$10,000

\$10,000

Crohn's and Colitis Canada Contribution in 2018/2019

\$2,800

\$2,800

\$2,900

\$2,800

\$2,900

\$2,900

\$2,900

# Funding the best and brightest



I had the opportunity to experience the rigour and competitiveness of the grant review process firsthand as a lay grant reviewer. There are so many promising research projects in progress, and the care that each reviewer takes to meticulously and objectively evaluate each application gives me confidence that the projects funded by Crohn's and Colitis Canada will have a tremendous impact on our community. I am proud to support Crohn's and Colitis Canada, knowing the collective difference we are making in advancing Crohn's and colitis research and improving the lives of people affected by these diseases.

Lucie Andlauer
Patient and Supporter of Crohn's and Colitis Canada

# Crohn's and Colitis Canada

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 \$127 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.

GEMS
PROJECT









To donate now please call 1-800-387-1479 or visit

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