


2023 Annual Report

# Discovery, impact and hope



**Lori Radke**  
President and CEO

**Susan Cowan**  
Chair, Board of Directors

# A message

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**from the  
President and  
CEO and Chair  
of the Board of  
Directors**

There are moments that inspire and lift your spirits. They stay in your memory. They change what you believe can be achieved. We were fortunate that 2023 offered us several of those exceptional, inspiring moments of discovery, impact, and hope.

Fifteen years in the making, the Genetic, Environmental and Microbial (GEM) Project published a breakthrough finding that gives hope that our investments in research

can deliver a cure. It was discovered that the combination of gut bacteria from people who develop Crohn's disease is different from those who remain healthy – and can be seen years before they develop Crohn's. This landmark discovery offers realistic hope for a cure, the ultimate impact we dream of achieving. We are determined to accelerate the research effort so those affected can benefit – soon.

Another inspiring moment was the publication of the 2023 Impact of Inflammatory Bowel Disease in Canada report – a comprehensive snapshot of the state and future implications of Crohn's disease and ulcerative colitis. This detailed, insightful assessment is a unique undertaking among Canadian health charities. First issued in 2008 and published every five years thereafter, the report offers a deep understanding of the status of Crohn's and colitis in Canada. It is a treasure trove of evidence-based quality information to help plan and measure the impact of care currently available and where needs are arising. Each new edition is an enormous collaborative effort over several years and an inspiration to our community. It is an essential resource for anyone working in the field, studying these diseases, or advocating for change.

The launch of Crohn's and Colitis Connect, an online community for anyone touched by these diseases, is another example of inspiration and hope. It is a place to share stories and experiences, find support, offer support, ask questions, and most importantly, connect with a

community of people who 'get it'. One of the things we constantly hear is the need for people in our community to connect and feel solidarity with others facing similar challenges.

Of course, hope generated by discoveries and progress needs to become impact. We have the roadmap needed to deliver that greater impact – our 2023-2026 Impact Strategy. We are thrilled that our first year of implementing the strategy has delivered discoveries, hope and impact.

The strategy drives us to accelerate the momentum of research, addressing key factors that speed up the timeline from discovery to impact. We continue to reach further, broadening the diversity of people reached through our patient programs, making a greater effort to reach them in the early stages of diagnosis. We are driving system change through advocacy efforts. And we are boosting awareness and understanding of Crohn's and colitis by telling real stories of those living with these diseases.

Thank you to everyone for your support! Your dedication, time and contributions drive us forward and create the discoveries, impact and hope that inspire us. We are confident that our shared journey will create even more positive changes in the year ahead.

Lori Radke  
President and CEO

Susan Cowan  
Chair, Board of Directors

# Impact Strategy 2023-2026

## Promise

We aspire to cure Crohn's disease and ulcerative colitis and to improve the quality of life of everyone affected by these diseases.

## Live the Values



### Courageous

Be gutsy!



### Inclusive

Be open!



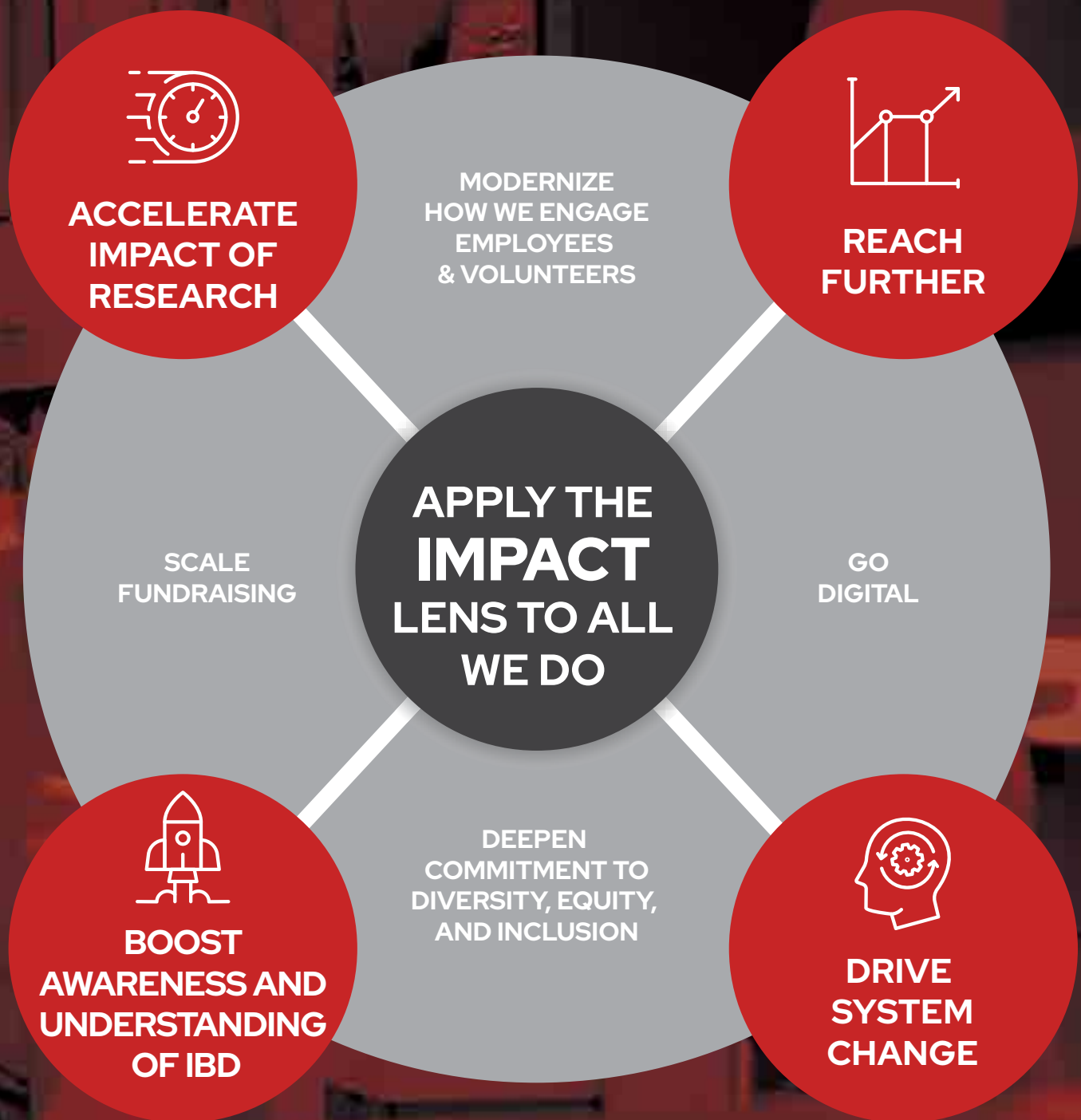
### Authentic

Be intentional!



### Collaborative

Do together!



## Collective Impact Goal

Crohn's and Colitis Canada collaborates with others to improve the quality of life of people with Crohn's disease and ulcerative colitis.

We measure and report publicly on the quality of life of people with Crohn's and colitis to account for the part we play in this collective impact.



# Accelerate impact of research

Address key gaps and success factors and  
accelerate the timeline from discovery to impact

## Preventing Crohn's disease

We took a major step towards a cure for Crohn's disease in 2023 when the Genetic, Environmental, Microbial (GEM) Project made a breakthrough discovery, namely, the combination of gut bacteria is different in those who go on to develop Crohn's compared to those who remain healthy. These differences are present years before they develop Crohn's. The project also found that the gut barrier becomes "leaky", also years before onset of disease.

These discoveries open the way to:

**Predict a person's risk of  
developing Crohn's disease**

**Find ways to prevent Crohn's  
disease before symptoms  
appear**

**Develop new treatments for  
those who already have the  
disease**

GEM goes back to 2007, when Crohn's and Colitis Canada challenged its research partners to propose a study to accelerate the discovery of a cure for Crohn's and colitis. They came back with the proposal for what would become the GEM Project.

Dr. Ken Croitoru of Mount Sinai Hospital in Toronto, part of Sinai Health, GEM Project Architect and Lead Investigator, said: "This is going to move us a step forward in understanding how to better treat patients or prevent Crohn's disease because now we know what bacteria may be contributing to, or triggering it. I'm hopeful that within five years, we'll see patients benefitting, specifically through more evidence-based treatments focused on the gut bacteria or diet."



# 2008

Start of Crohn's and Colitis Canada's

## GEM PROJECT



# 107

participant tracking international sites in 7 countries: Canada, USA, United Kingdom, Israel, Australia, New Zealand and Sweden



# \$22

million

invested to date. A major fundraising partner is the Leona M. and Harry B. Helmsley Charitable Trust



# 5,000

healthy first-degree relatives (children, siblings) of people with Crohn's disease being followed



# >100

participants have developed Crohn's disease



# 17

scientific publications since 2015

## Our research investments By the numbers



Invested more than **\$6.8 million**

in research in 2023, supporting **41 active research projects**



Through the multi-partner **TRIANGLE**

training program, supported **4**

**postdoctoral fellows** conducting Crohn's and colitis research



Brought together close to **450**

**clinicians, scientists and partners** from across Canada for the Meeting of the Minds continuing medical educational and research conference

# Reach further

Broaden the reach of programs to impact more people with Crohn's and colitis and their caregivers

## A community that 'gets it'

Crohn's and colitis can be lonely diseases. If you have them, you often do not want to talk about them publicly.

Over the years, we have offered in-person and online programs to address isolation and stigma. These programs have evolved as needs and technology have changed. In recent years, we heard from the Crohn's and colitis community that they wanted an online meeting place where they could interact, including through live events. They wanted support and knowledge from peers and experts. We put our heads together and came up with Crohn's and Colitis Connect. It is an online community where those affected can share stories and experiences, find support, offer support, ask questions, and most importantly, connect with people who 'get it.'

This meeting place is now the online go-to location, helping members make more informed decisions and decrease isolation. It allows people to navigate the ups and downs of living with Crohn's or colitis with a community that understands and supports them.





'This online community has been a safe, positive and caring space for people living with Crohn's and colitis to express their thoughts and feelings about their disease. Though I am currently doing much better due to my biologic drug, the reality is that colitis will always play a role in my life, so I am grateful for the people who regularly contribute to the community chats and events. Checking in and lifting one another up keeps me motivated to continue even on days when my whole body hurts and things feel heavy and hard.'

Michelle J.

'I find that I don't feel alone when others have experiences like me. I also get to ask those questions that my gastroenterologist certainly can't answer since he doesn't take the medication nor have food issues like we do. I enjoy sharing my experiences over my decades with Crohn's and since I'm a senior, it gives others an idea of what life may be like for them when they get older.'

Sue W.

'Being bedridden for a year, it is hard to feel understood by those around me, but with Crohn's and Colitis Connect, I find myself surrounded with people who care. I have been developing new friendships with those who really get me. I like that it isn't all serious, there are moments of bonding over heating pad brands and guilty pleasure foods, while also being a resource where a question can quickly be answered with other people's experiences.'

Katarina M.

# Our programs By the numbers



Our online information was accessed

over **1 million** times in 2023



**139** postsecondary students have

received a **\$5,000** AbbVie IBD Scholarship Program grant since 2012, including 15 recipients in 2023



**16 clinical care pathways** were updated

and released, offering healthcare providers in Canada evidence-informed strategies aimed at standardizing care and health outcomes for people with Crohn's or colitis



**75 youth** attended Camp Got2Go

# 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

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

**INN** - The Innovation in IBD grant aims to finance creative and original methods for conducting research on inflammatory bowel disease (IBD). It is designed to encourage and facilitate research that may not fit into the conventional framework of medical research.

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

**Early Career Researchers** - In 2023, Crohn's and Colitis Canada is committed to supporting early career researchers (ECRs) in building their independent research programs within the IBD space. This commitment ensures that a portion of the funds allocated through the GIAs and INNs specifically target ECRs.

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

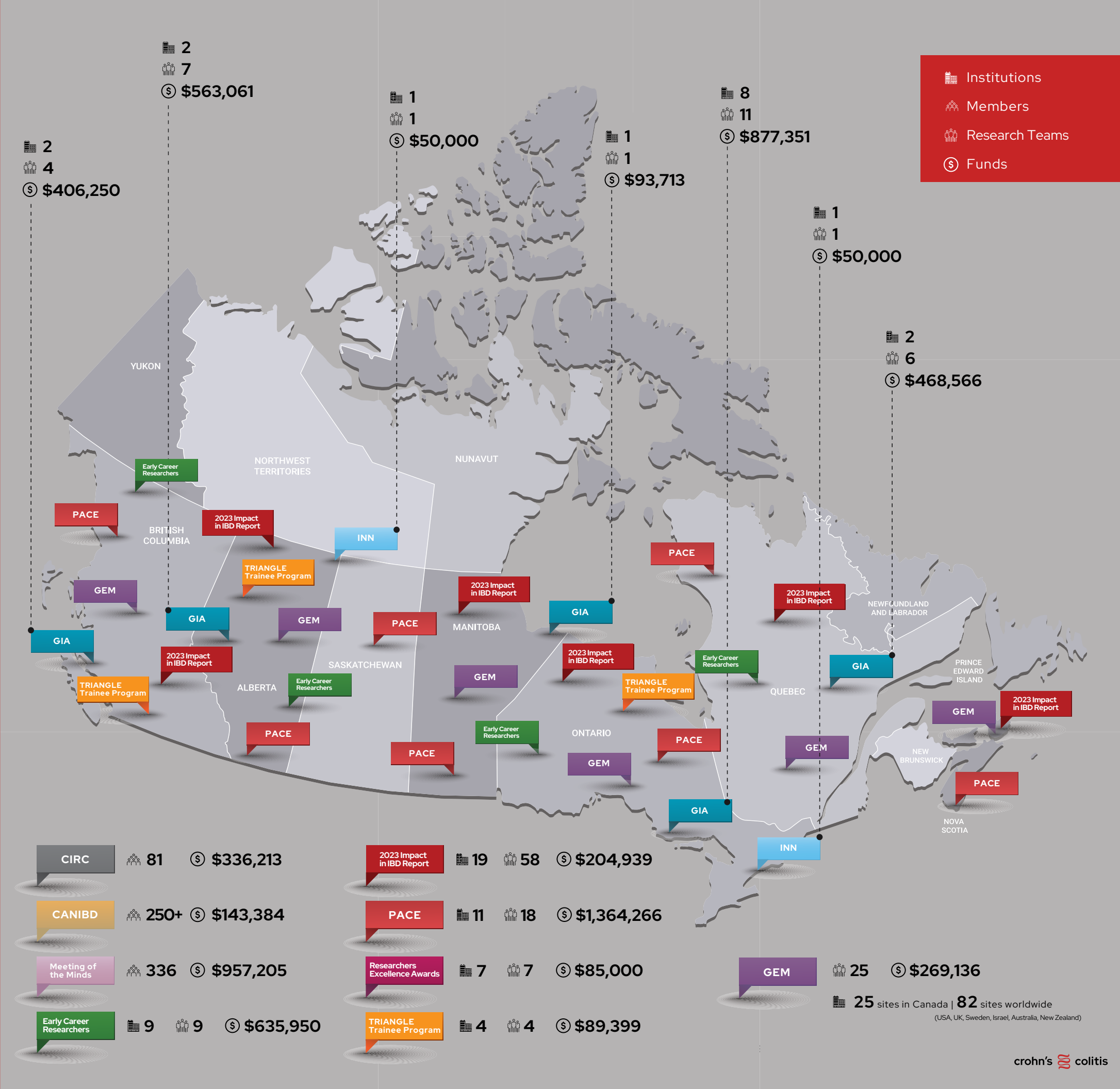
**CANIBD** - A Community of Practice for nurses working across Canada in the field of IBD with a vision of improving the quality of care of people living with IBD.

**Meeting of the Minds** - 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.

**TRIANGLE Trainee Program** - In collaboration with the TRIANGLE Program, Crohn’s and Colitis Canada supports postdoctoral fellows in IBD research, to foster the upcoming generation of scientists.

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

**2023 Impact in IBD Report** - Every five years, leading Canadian gastroenterologists and researchers collaborate to produce the most up-to-date and comprehensive report on health statistics related to IBD in Canada.



# Boost awareness & understanding of Crohn's and colitis

Engage and motivate Canadians through a compelling brand approach

## Gutsy Walk keeps on rolling

Launched in 1996, Gutsy Walk is our premiere annual fundraising event held on the first Sunday of June across Canada, the largest community event for those affected by Crohn's or colitis in Canada.

Gutsy Walk is a fun, family-friendly day to bring people together – showing them they are not alone. Even more, those affected celebrate their resilience and experience the reality of being in solidarity and creating connections with each other.







It embodies Crohn's and Colitis Canada's promise of hope and impact.

Nancy Nagy was diagnosed with Crohn's disease in 1981 in her teens. She started volunteering with Crohn's and Colitis Canada in 1984. She has lived in a number of cities in Western Canada. She did her first Gutsy Walk in Regina in 1997, then Edmonton and now Winnipeg where she lives. She has raised more than \$30,000.

'Gutsy Walk is a fun day. It's good to be able to go out and do something. With Crohn's, you're on your own a lot. You miss out on a lot of fun. This is a day I can enjoy with my kids and grandkids.'



# gutsy By the walk the numbers



**\$52**million  
raised to date



**\$2+**  
million raised annually



**3,500**  
participants annually



**50**  
locations from  
coast to coast



**5km**  
usual walk distance –  
but any distance or  
activity can count



**500**  
volunteers annually

# Drive system change

Advocate and partner to influence change



## A deep understanding that will lead to impact

Accurate, up to date data is essential to build a case for change that will deliver impact. That is precisely what Crohn's and Colitis Canada did with the publication of the 2023 Impact of Inflammatory Bowel Disease (IBD) in Canada report – published every five years since 2008.

These reports, unique to Crohn's and Colitis Canada, provide a snapshot of the state of the diseases, care and implications for the future.

The findings show a compelling need for change to handle the growing number of people in Canada living with these diseases. The findings include:



More than 11,000 people are diagnosed annually – currently one every 48 minutes



322,600 people are living with the diseases in 2023 (0.8% of the population), growing to 470,000 in 2035 (1.1% of the population)



The number of new diagnoses is rising most rapidly in children under the age of six years old, causing particular challenges for them and their families because of their age



Seniors are the most rapidly growing group since people with Crohn's and colitis are living longer due to better therapies – and our population is aging



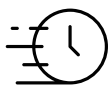
Those with low socioeconomic status, who live in rural, remote and Northern communities, and Indigenous peoples face additional barriers to care



## More voices heard

An innovation for this edition of the Impact of IBD in Canada report was to involve patient reviewers. One of them was Léa Caplan of Calgary. She was diagnosed with Crohn's disease in 2020: "I was really happy to be one of the dozens of patient reviewers. It's meaningful to know that this report was prepared with individuals with Crohn's and colitis and is for those living with these diseases. Our voices are being heard."

Driving the change to address the growing financial and human resources needs has been part of Crohn's and Colitis Canada's activities for years. Specifically, since 2016 our Promoting Access and Care through Centres of Excellence (PACE) program has brought together leading specialists from across Canada to address gaps in care, improve the quality of care available to people with Crohn's or colitis and improve their health outcomes. These projects aim to develop solutions that will provide:



Equitable and timely access to care, especially in rural areas



Standardized delivery of care across Canada

Solutions piloted include:



Digital tools for healthcare practitioners to monitor patients' health needs in-between visits



Support in preparing youth for adult care



Expanding and standardizing virtual care



Integration of mental health, diet and nutrition as a part of standard clinical visits

Crohn's and Colitis Canada is hopeful that within the next two years, these pilot innovations will start being rolled out across Canada and lead to better care.

# Our advocacy By the numbers



Met with **21** government officials to

advocate for the needs of people affected by Crohn's and colitis



**2** advocacy campaigns carried out

with **4,660** emails from community members sent to government officials



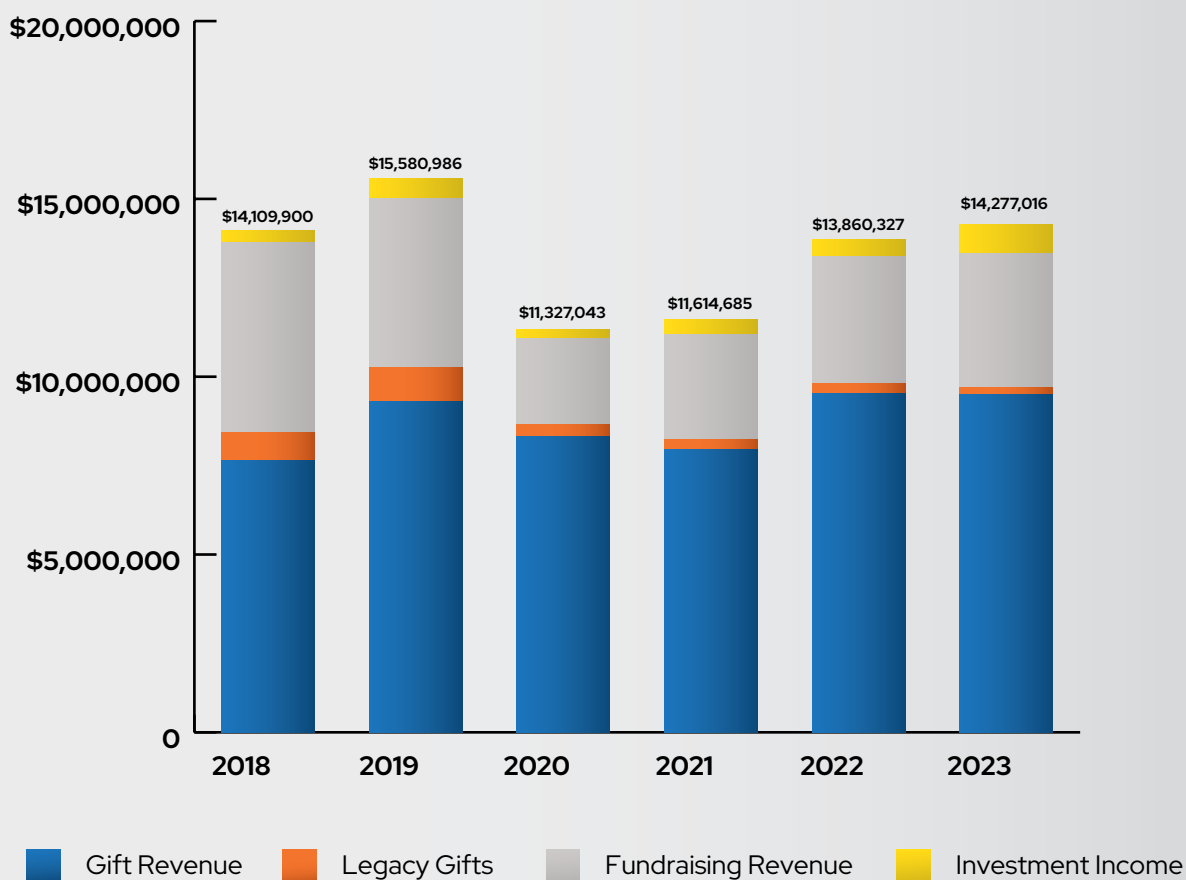
Provided the patient voice for **8**

drug reviews, which were being reviewed by the Canadian Drug Agency on whether to recommend their listing for reimbursement by the provinces

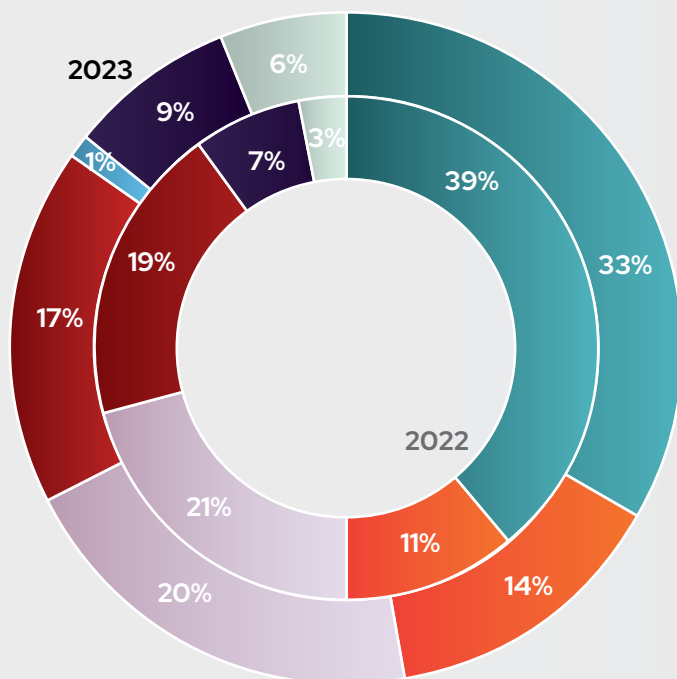
# Financial highlights

Total 2023 Revenue: \$14,277,016 million

## 5 Year Revenue Comparison\*



\* Excludes foreign exchange gain or loss, unrealized gain or loss on investments and COVID-19 subsidies

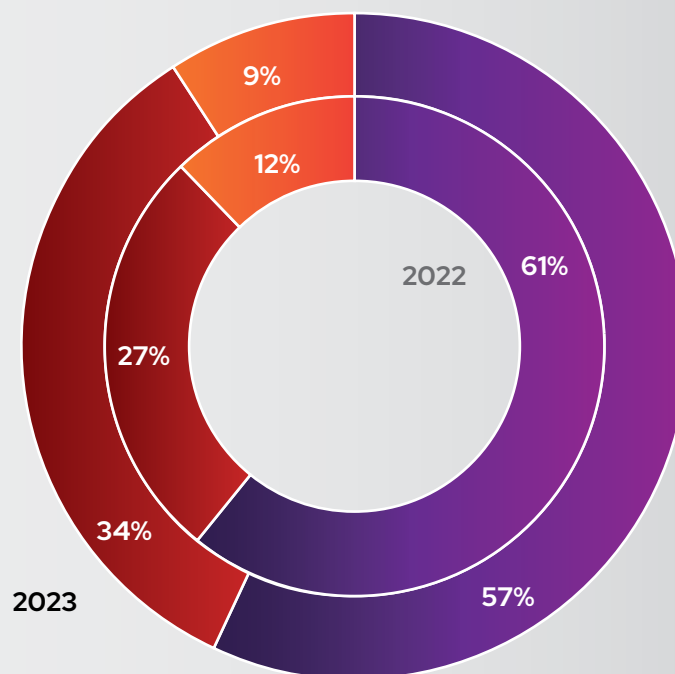


## Revenue Sources

- Corporate Philanthropy for Programs
- Annual and Workplace Giving
- Gutsy Walk
- Major Gifts
- Community Fundraising
- Investment
- Corporate Engagement

## Use of Funds

- Mission
- Fundraising
- General & Administration



A woman with dark hair, wearing a dark cap and a lanyard with a 'VOLUNTEER' tag, is smiling. A large white speech bubble graphic is overlaid on the right side of the image, partially obscuring her face and the background. The background is a blurred outdoor setting with trees.

“


'I volunteer with Crohn's Colitis Canada because living with IBD can be isolating. As a mentor and patient partner, I connect with others facing similar struggles, and I contribute to research that directly aims to improve our lives. Knowing that I'm not alone and that I'm helping to create a better future for those with IBD is what inspires me.'

Maxime Bergevin  
Volunteer  
Montreal, QC

'We have proudly been supporting Crohn's and Colitis Canada through unrestricted giving for 20 years. Our decision to offer unrestricted gifts stems from our unwavering confidence in the organization's ability to allocate funds where they are most urgently needed and where they hold the greatest potential for impact. We take immense pride in knowing our contributions enable researchers and patient program leaders across the country to boldly pursue groundbreaking research and transform the future of IBD for families impacted by these diseases.'

John and Dian Bell  
Donors  
Cambridge, ON





'In 2016, I participated in my first Gutsy Walk not long after my diagnosis. I met an amazing group of people in the Vancouver chapter who became like family for me. Since then, I've had the pleasure of working with volunteers from coast to coast on initiatives both local and national. All these initiatives have helped give me a sense of purpose.'

Matthew Sebastiani  
Volunteer  
Vancouver, BC

'I know our donation is hard at work within Crohn's and Colitis Canada, and that gives me shared hope – whether it's a patient hoping for better medication, or a researcher hoping for new equipment, or a parent hoping for a healthy future for their children.'

Tera Johnson  
Donor  
Calgary, AB

'I'm really grateful for Crohn's and Colitis Canada because during my most difficult times when I was about to go to emerg or when I had just come out of the hospital, I reached out to their peer support program and their virtual group calls. There is a community there for you. You are not alone.'

Alexandra Chaves  
Program Participant  
Cambridge, ON

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crohn's  colitis

**be a champion of hope  
to brave today and believe  
in tomorrow**



**Accredited  
IMAGINE  
CANADA**

The Standards Program Trustmark is a mark  
of Imagine Canada used under licence  
by Crohn's and Colitis Canada.

To donate please  
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Follow us @getgutsycanada on



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