THE CATALYST

A Gutsy Move

Welcome to the fourth story in the MHCC & series, designed to get to know our HealthPartners membership, and learn about where our realities intersect, and how best to support each other. In recognition of Crohn's and Colitis Awareness Month, observed every November, and to mark the 50th anniversary of Crohn's and Colitis Canada, the MHCC's Director of Marketing and Communications, Debra Yearwood, sat down with Lori Radke, President and CEO of Crohn's and Colitis Canada, to learn about a legacy spanning five decades, and the long road ahead.

By: Debra Yearwood | Posted: October 24, 2024

My conversation with Lori Radke, President and CEO of Crohn's and Colitis Canada got real, very quickly.

Given that 2024 marks Crohn's and Colitis Canada's 50th anniversary, I asked Lori to reflect on that legacy. "Where have you been, and where are you going?"

"I can't remember a time when Crohn's and colitis wasn't a thrum in the background of my own life," explained Lori, an only child, whose mother was diagnosed while pregnant. "That's over 50 years ago. And back then, there was zero information. Nothing."

Five decades ago, despite its severity of symptoms, the disease was sloughed off by medical professionals as simply "all in your head."

Mapping the mind-gut connection

Today, inflammatory bowel disease (IBD), of which Crohn's and colitis are the most common forms, is understood to inflame the lining of the gastrointestinal tract. During acute flares, IBD can interrupt the digestive process from start to finish, including properly absorbing nutrients and eliminating waste. This can cause relentless diarrhea, severe cramping, and bloody stools. Treatments may stop working, and surgery is a frequent recourse.

In addition to physical symptoms, as many as a third of people living with IBD also experience anxiety and depression.

"Of course, today, we understand there is a deep mind-gut connection, and if we can successfully manage symptoms of stress through cognitive behavioural therapy, for example, we can better manage physical symptoms – but often that comes with an out-of-pocket cost. The hard truth is, we still don't know what causes these incredibly painful and terribly inconvenient bowel diseases. And a cure isn't yet on the horizon, though I hope we're getting closer."

Tech to the rescue

And it's that gap, between where they are today, and a future cure, that Lori finds herself navigating.

“We were founded in 1974 by a group of concerned parents. Understandably, they wanted to find a cure. So, our efforts remained laser-focused on that, raising $150 million and distributing 400 grants – for research that is giving us realistic hope.”

But about six years ago, patients began urging the organization expand their mandate

“And we listened,” said Lori.

Patients affirmed that while finding a cure must be job one, improving quality of life, in the here and now, was a close second. Following those marching orders, Crohn’s and Colitis Canada quickly regrouped, zeroing in on the power of technology to open new doors – literally and figuratively.

The GoHere app is a prime example.

Conceived to serve an urgent community need – and created with the support of Amazon Web Services – it provides detailed information about publicly available washrooms in Canada with no-questions-asked access.

Retail chains, municipal buildings, government offices, and restaurants agree to be identified on the app. After downloading it, people can better plan trips and outings, or locate emergency washroom facilities nearby, without having to make a purchase or beg for admission.

It’s been downloaded 46,000 times, offering a trail of breadcrumbs to 3,450 publicly available washrooms, and counting.

Lori Radke, President and CEO, Crohn’s and Colitis Canada

Tackling the taboo

“It’s a simple idea, but it’s a huge game-changer,” explained Lori. “Having IBD isn’t like that one time when you or I had diarrhea last year. It can be utterly debilitating, and you can quickly find yourself isolated. Incontinence is still taboo. We all have bodily functions, but we have not normalized talking about them. GoHere is one way we’re trying to make a practical change –

and, in doing that – change mindsets at the same time.”

In short, Crohn’s and Colitis Canada is striving to lessen the double burden of symptoms and stigma.

“We’ve created Crohn’s and Colitis Connect – a Facebook-style online platform exclusively for people living with IBD, and their caregivers – in direct response to a pressing desire for peer support among those living with the illness. It affects almost 0.9% of the population, so while it’s not uncommon, it’s rare enough that you may not know anyone who has walked a mile in your shoes.”

Which is where the Gusty Walk comes in.

Walking the talk

Held in 50 locations across the country, and racking in nearly $2.4 million, it’s both a major fundraiser, and a deeply valued community-building exercise.

“I remember this one family, and the daughter was just over the moon. She was practically glowing as she said to her dad, ‘Look! Look at the Port-o-Potties lining the route! You’re going to be able to do this!’ That kind of inclusion…we just don’t see enough of it.”

Speaking of inclusion, I asked Lori how workplaces are doing on the accommodation front, and what steps could be taken to make life easier for people who already bear the added burden of managing a complex, episodic illness – with often unpleasant and painful symptoms.

“I think there are small things employers can do, proactively. Tell people to take breaks throughout meetings should they need them. Normalize that. Offer wellness days, so people can choose to take time without having to give reasoning. But really, because gut and digestive health are not only invisible, but traditionally out of bounds for ‘polite conversation’, the only real solution is to ask for what you need. And that can be difficult.”

But Lori went on to say one of the things that brings her great joy is watching the tide slowly turn.

“Within our community, we have this brave group of influencers, like Paula Sojo, who lives with Crohn’s.”

The power of influence

Sojo underwent 15 surgeries and had an ostomy at 18. She’s turned something she says she once found repellant into a fashion statement, creating her own custom ostomy bag cover business.

“She is refusing to remain unseen, or to be silenced because her experience might make someone uncomfortable. She is standing up and saying, ‘I am beautiful, I am powerful, and above all, I am alive.’”

Because, added Lori, “As terrifying as the prospect of an ostomy can be, it can save your life.” And it’s this message, of pulling back the curtain, to better educate the public and even health-care providers, that is informing the way forward for the organization.

Life – interrupted

Awareness breeds understanding, which alchemizes into empathy. And empathy is critical for people living with Crohn's and Colitis.

"It's the only way we'll create a society where the adults living with this today can speak openly and serve as role models to the overwhelming number of children who are being diagnosed and will have to navigate this journey throughout their whole lives."

And while people are most often diagnosed before the age of 30, since 1995 the incidence of Crohn's and colitis has doubled in kids under ten.

"It's alarming, that's for sure," said Lori, who notes that in 2023, 11,000 people were diagnosed, meaning a new diagnosis every 48 minutes.

"It's about so much more than numbers," said Lori. "These are lives. Lives about to veer in a direction no one wanted or expected."

Lives like a good friend of Lori's 14-year-old daughter, who was supposed to spend the summer at camp, enjoying a carefree time with friends.

But instead of canoeing and campfires, she endured the season lying in a hospital bed, on a feeding tube, with a temporary stoma, having had 25 centimetres of her bowel resected.

After sharing this story, Lori paused, collecting herself. She glanced down at her desk and rifled through her papers.

"I prepared for this [interview], but this wasn't in my notes. I was thinking about how when we go to see my daughter's friend in hospital, my job is to support her mom. And if I wasn't in this job, would I have the slightest idea how to do that? The answer is likely no. And that's what we're working so hard to change."

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A communications pro with more than 20 years of executive experience in the health sector, expertly navigating everything from social marketing to crisis comms. When she's not advising on the boards of Health Partners or Top Sixty Over Sixty, she's busy finishing her book on thriving in later life (because why stop now?). Certified Health Executive by day, diversity advocate and magazine contributor by night—Debra's the one you call when things need fixing or explaining.

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