

SPRING 2023 IMPACT REPORT

Empowering Patients To Take Charge of Their Health



A Message from our Leadership

Michael Osso, CEO & Brent Polk, MD, AGAF, Chair of the Board

We are excited to share our Spring 2023 Impact Report. We bring you these reports three times a year to keep you informed of our progress in driving new treatments and supporting people living with inflammatory bowel disease (IBD).

In this issue, you can learn how we're empowering patients to take care of their health, including the creation of our new online recipe finder. Gut Friendly Recipes is designed to help everyone with IBD and other gut issues find recipes that work for their diets and nutritional needs, and help reduce the stress of meal preparation. All recipes offered are evidence-based and approved by dietitians for gut-friendly eating. It is just one of many new tools we have introduced for patients and caregivers.

We also report on some of our recent advancements in the areas of drug development and improving surgery outcomes. And you can read about our recent national survey that highlights the alarming shortage of accessible restrooms and the critical need to make more restrooms available to people with medical needs.

These achievements would not have been possible without the trust and commitment of supporters like you who inspire us with your courage and resilience and drive our sense of purpose. We look forward to building on these successes to create a new future for people who live with IBD and those who care for them.

With warm regards,



Michael Osso
President & CEO



Brent Polk, MD
Chair, Board of Trustees

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How We're Making an Impact

\$66 million

invested in our mission in 2022, the most in Foundation history

2,500

total number of research projects we have supported to date

200+

research projects supported in 2022

50,000+

restrooms on our We Can't Wait App

70 million

viewers of our PSAs

Making an Impact: Changing the Future for Her Son

Mary Amrhein-May of Pittsburg, Pennsylvania

My son, Patrick, was diagnosed with Crohn's disease when he turned seven. By getting involved with the Foundation's Take Steps Walk and Team Challenge, we made connections with many families who live with IBD and are grateful that we haven't been alone in our journey.

Through the years, I've seen friends who were denied access to medicine they were prescribed by their doctor. They could wait months to get on a new drug because they had to fail first on another cheaper one. I couldn't see the common sense in that. This could easily be Patrick one day.

I wasn't sure my first visit with the office of my U.S. senator to advocate for step therapy reform made a difference. But over time I developed a connection with his office. I saw how my efforts and that of my fellow advocates were having an effect and how our elected officials were working hard for us. We told our stories to legislators through visits, phone calls, and participation in Days on the Hill to help the bill gain momentum in the state.

It was thrilling to watch step therapy legislation pass unanimously in our state legislature last year. The Crohn's & Colitis Foundation has given me a microphone and shown me I can change the future for my son and everyone affected by IBD. It has given me a network of friends and support and hope for a cure.



From left: Charles, Mary's husband; Emma, Patrick's girlfriend; Patrick; and Mary.

Advancing New Therapies

Research to uncover new treatments and bring us closer to cures

New IBD Treatment Blocks Gut Enzyme

Foundation-supported project yields novel oral therapy.

IBD patients have significantly increased levels of a protein called GCPII in their guts, which contribute to inflammation and a leaky gut barrier that allows bacteria and toxins through. With financial support from our venture philanthropy program, [IBD Ventures](#), which was established to advance novel products for IBD, Johns Hopkins researchers have created an oral drug that blocks GCPII biological function and demonstrated its efficacy in animal models of IBD as well as in human gut organoids (miniature organs grown in the lab from patient cells).

The new oral drug, currently known as (S)-IBD3540, is administered by mouth and stays within the gut without getting absorbed into the bloodstream so it should have fewer side effects compared to therapies that reach the bloodstream. “The whole idea came from observations in patients, who hugely overexpress this protein in their guts. In inhibiting it, we see remarkable protective effects,” says Barbara Slusher, PhD, director of Johns Hopkins Drug Discovery Program.

Dr. Slusher and her team are now actively pursuing pharmaceutical partners in an effort to move this candidate drug into clinical trials. Meanwhile, her co-researcher Diane Peters, DVM, PhD, is using [IBD Plexus®](#), the Foundation’s transformative IBD research platform, to identify biomarkers that could pinpoint which patients are most likely to benefit from this novel treatment. The Foundation has also funded Dr. Slusher through our Chronic Abdominal Pain in IBD initiative to explore the role GCPII may have as a treatment for abdominal pain in IBD.



Barbara Slusher, PhD, director of Johns Hopkins Drug Discovery Program.

Better Surgical Outcomes Ahead

Foundation-funded research studies are shedding light on how to improve techniques and post-operative care.

About 70% of people with Crohn's disease and 30% of those with ulcerative colitis will require surgery at some point, yet there's been a lack of research on the long-term outcomes. Patient enrollment is now underway for IBD SIRQC, our research study dedicated to following patients who undergo IBD surgery, which launched in 2021 at nine sites in the U.S.

Stefan Holubar, MD, of the Cleveland Clinic, and Samuel Eisenstein, MD, of UC San Diego Health, are leading IBD SIRQC, which stands for IBD Surgical Innovation, Research, and Quality Collaborative. The project is following adults with IBD who are about to have GI surgery from pre-op until two years post-procedure with an eye on tracking complications and disease recurrence.

The Foundation is also supporting surgery-related research by Liliana Bordeianou, MD, MPH, professor of surgery at Massachusetts General Hospital, who has developed a scoring system to measure the more challenging symptoms experienced by many patients who had J-pouch surgery.

Using data from numerous patient surveys, focus groups, and physician input, Dr. Bordeianou has coined and defined the term ileoanal pouch syndrome (IPS). IPS is a summary term that would include all of the more challenging possible symptoms and consequences experienced by some patients who had J-pouch surgery. Dr. Bordeianou then created a scoring system to make it easier for gastroenterologists to evaluate and treat IPS, as well as to provide surgeons with insights that might enable them to refine surgical techniques aimed at avoiding severe IPS in future patients.

Dr. Bordeianou's latest study appears in *Annals of Surgery*.



New research is dedicated to following patients who undergo IBD surgery.

Our Impact in New Therapies

\$36 million invested in research in 2022

5,000 patients enrolling in our **IBD-SIRQC** long-term surgery study

Improving Quality of Life and Driving Toward Remission

New resources to empower and support patients and caregivers

Our New Recipe Finder Makes Eating With IBD Easier

Discover hundreds of IBD-friendly recipes.

Finding something tasty and nutritious to eat isn't always easy when you have IBD, but we're hoping to change that. The Foundation is proud to launch [Gut Friendly Recipes](#), our new online resource that is designed to help everyone with IBD and other gut issues find recipes that work for their diets and take some of the stress out of meal preparation.

At [GutFriendlyRecipes.org](#), you can:

- Search **more than 500 recipes** for different meal types and occasions. Make a snack for yourself or feed a crowd!
- **Filter your recipe search** using your food and diet preferences.
- Register to create **weekly meal plans**.
- **Save your favorite** recipes so you can make them again.

All diets included in this recipe finder have research supporting their benefits for gut health, and have been reviewed and approved by dietitians that are experts in nutrition and IBD. We recommend you consult your doctor and dietitian about your diet and meal plans to be sure you're getting the nutrients and care you need.

"Diet affects every patient very differently, which is why the Foundation is supporting research into Precision Nutrition and providing a variety of educational resources regarding diet and nutrition," says Catherine A. Soto, MPA, senior director, Patient Education & Support. This free recipe resource, which is powered by Nestlé Health Sciences, makes identifying foods that might be helpful for IBD much easier, she says, adding that the recipes include information for how to adjust them if you're currently flaring or have strictures.

"It empowers patients, in conjunction with their healthcare team, to find new recipes that suit their needs," says Soto.



See all the recipes at [GutFriendlyRecipes.org](#).

Diet affects every patient very differently.

Catherine A. Soto,
senior director, Patient
Education & Support

Educating and Empowering Patients

Our new resources support patients throughout their treatment journey.

Patients who are engaged in their treatment decisions have better health outcomes and better quality of life but taking an active role in your care requires a solid knowledge base. The Foundation has introduced these new resources:

Making sense of medication: Our new IBD Medication Guide

Patients who want to learn more about their current medications or explore new drug therapies can turn to our newly updated **IBD Medication Guide**. This user-friendly digital tool allows users to search by drug name, class, and administration method. Fact sheets, brochures, and videos are available on the site.

Finding the right healthcare providers

Seeing the right healthcare expert is crucial, yet some patients don't know where to start or understand the difference between types of specialists.

Our new **“Meet Your IBD Care Team”** video highlights the roles of the various providers who can be involved in your care—including gastroenterologists, psychologists, and colorectal surgeons—and the importance of coordinated care.



Patients who take an active role in their care have a better quality of life.

Annual Crohn's & Colitis Congress Brings IBD Experts Together

The world-class symposium featured lectures, exhibitions, and networking opportunities unified by one goal: making life better for patients.

More than 1,300 IBD clinicians, researchers, and industry experts from across the globe convened in Denver in January for the sixth annual Crohn's & Colitis Congress, co-sponsored by the Crohn's & Colitis Foundation and the American Gastroenterological Association. Attendees shared the latest in research, therapies, and treatments for Crohn's disease and ulcerative colitis.

Highlights included a Shark Tank–inspired panel on leading-edge treatment approaches, a patient-led discussion on diversity and inclusion, and a keynote presentation on artificial intelligence. Nutrition and surgical complications were also covered.

No matter the topic, patient centrality reigned, says Tina Aswani-Omprakash, a patient advocate and founder of Own Your Crohn's who served as a patient reporter at Congress. “There was a great focus on multidisciplinary care, including diet, mental health, and overall quality of life,” she says. “Even when talking about stem cells, wearable tech, or remote monitoring, all the speakers kept bringing it back to the patient.”



Tina Aswani-Omprakash, patient reporter, at the sixth annual Crohn's & Colitis Congress.

“There are a lot of strides being made in the IBD space that have the promise to prevent the onset of IBD or control the disease earlier. I want the patient community to know that there is hope for us and I’m excited for the future of our care.”

—Tina Aswani-Omprakash, IBD patient advocate and Crohn's & Colitis Congress reporter

Our Impact in Quality of Care

1,300 IBD clinicians, researchers, and industry experts attended the sixth annual **Crohn's & Colitis Congress**

5,00+ recipes on our new **Gut Friendly Recipe Finder**

Improving Access to Care

Breaking down barriers to optimal care for everyone with IBD

Lack of Restrooms Is a Public Health Crisis

Many IBD patients require a liquid formula diet, yet insurance companies rarely pay for it.

Being able to access a public restroom when nature calls is important for everyone but absolutely critical for those who live with IBD and experience the urgency that goes along with it. Yet 53% of the general public who responded to a recent Foundation survey said that they or a family member had trouble finding or accessing a public toilet within the prior seven days.

Furthermore, though many U.S. states have passed legislation to require businesses to open their restrooms to the public in the event of a medical emergency, only 10% of respondents in those states were aware that such legislation had been passed—showing a need for heightened business and public awareness campaigns for these laws.

The survey results also indicated that moving forward, private businesses have an opportunity to create greater public restroom access and simultaneously build stronger customer relationships. For instance, when choosing between two similar competing businesses, 61% of respondents say the business with an open public restroom would positively influence their decision where to shop.

“These findings bring to light the experience of not only patients but all people with an urgent need of a restroom,” says Cassie Ray, director of advocacy. “This is why the Foundation continues to advocate at the federal, state, and local level for increased restroom access.”



“Restroom access should be a basic human right.”

Michael Osso,
president and CEO of the
Crohn’s & Colitis Foundation

Public restrooms are too hard to find



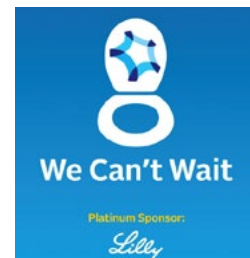
53% of people

said that they or a family member had difficulty finding or accessing a public toilet within the last seven days



23% of people

say they've been denied access to a business' restroom when they asked in an urgent situation



We Can't Wait App

Our free app makes it easy to locate publicly accessible restrooms on the go. Download it from the [App Store](#) or [Google Play](#).

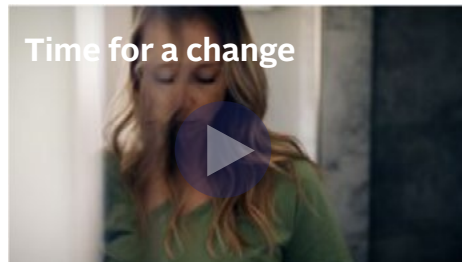
50,000 restrooms

26,000 downloads

New TV PSAs Spread Message of Knowing Your Treatment Options

If more patients are aware of their symptoms, then more will be able find the best medication.

Our three new “Spill Your Guts” public service announcements target patients who are diagnosed but still have breakthrough symptoms. Two TV spots (right) focus on patients who have been using steroids to manage symptoms over the long term. Another spot reminds patients that there are now more therapy options and to talk to a specialist.



U.S. Navy Secretary Shares His IBD Story

Ray Mabus is helping to educate other veterans living with IBD.

As there are more than 66,000 U.S. veterans with IBD, the Foundation is proud to have developed information and resources to address their unique situations, including transitioning to care through U.S. Department of Veterans Affairs' (VA) healthcare system and advocating for their health needs. We recently welcomed Ray Mabus, 75th U.S. Secretary of the Navy and a Crohn's disease patient, who joined us in educating veterans about health resources available to them. You can watch Secretary Mabus share his personal story in [a video on our website](#).



Ray Mabus, 75th U.S. Secretary of the Navy.

Our Impact in Access to Care

34 states have passed **step therapy laws**

88,000 healthcare professionals use our **educational resources**

Fundraising and Donors

Special events and major contributions that support our crucial work

YOUR SUPPORT MATTERS

On behalf of everyone at the Crohn's & Colitis Foundation, thank you! Our efforts are fueled by our community of remarkable patients, caregivers, clinicians, researchers, volunteers, and supporters who each day inspire us to keep working hard for better treatments and cures. All year, you participate in our community events, encourage us with your stories of hope and resilience, raise funds for research and awareness of IBD, and make lives of people with living with IBD better. We invite you to continue your efforts and find your community of support through local events like our galas, Take Steps, Team Challenge, spin4 crohn's & colitis cures, and more.

Take Steps Gets a Fresh Look

A new Take Steps experience for you

Take Steps, our signature walk fundraiser, has long helped us raise money for a cure while empowering and inspiring patients to continue fighting against Crohn's disease and ulcerative colitis. For years we have welcomed patients and supporters to these family-friendly events—and, in the process, we've raised over \$114 million. In January, we kicked off a reimagined Take Steps, featuring a new look, new walk day activities, and experiences.

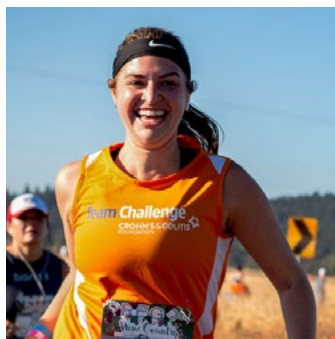
Join us at an **upcoming walk in your area**. Whether you are a patient, clinician, caregiver, or there to support a loved one, this reimagined Take Steps experience is designed to empower and celebrate all those impacted by IBD.



[Take Steps for IBD cures](#)



[Pedal with purpose at a spin4 crohn's & colitis cures event](#)



[Want to hike, run, or bike for cures? Fundraise with Team Challenges](#)



[Find Galas and Special Events](#)

