



FALL/WINTER 2022 IMPACT REPORT

Improving Patient Lives As We Work Toward Cures



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A Message from our Leadership

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

We've had good news from people who turn to us for help. More than 75% of patients connected with the Foundation stated that we had a positive impact on their patient journey, according to our 2022 Tracking Study. They also reported better symptom control than non-Foundation-connected patients.

We are proud to present our latest Impact Report, which we publish three times a year, to share our most recent achievements and progress towards our mission to improve the quality of life for people living with inflammatory bowel disease (IBD), evidenced by the survey results mentioned above.

Nearly one in 100 Americans live with IBD. It is often a painful and challenging journey for many patients, some of whom feel isolated and reluctant to share their diagnosis with family and friends. Many know little about this disease when they are first diagnosed and don't know where to turn.

The Crohn's & Colitis Foundation is here to help support patients throughout their journey and assure them they are not alone. As we search for cures, we also invest in improving patients' lives and supporting them through the challenges they face, whether it's chronic pain, stress, or the need for information and a network of support.

In this report, learn how patients are at the center of our research agenda and how we are addressing the issues that are most important to them so that they can live better and be confident that we are moving closer to discovering cures.

Learn about the impact of our caring community of staff and volunteers who provide daily support, education, and resources for people with IBD and their caregivers. Discover the many new programs we now offer to inform and connect patients with a community of support — no matter where they are on their IBD journey.

Last year, we invested \$63 million in our mission, the most in Foundation history. Your support fuels our work and our unwavering commitment to creating a better future for you, your loved ones, and all those affected by Crohn's disease and ulcerative colitis.

With warmest regards,



Michael Osso
President & CEO

A handwritten signature in black ink, appearing to read "Michael Osso".



Brent Polk, MD
Chair, Board of Trustees

A handwritten signature in black ink, appearing to read "Brent Polk".

Impact Profile

Mike Weinberg of Atlanta, Georgia

I started experiencing symptoms of ulcerative colitis when I was 11. At that age, I couldn't imagine what it could be, but my father definitely did. I didn't know it at the time, but my dad had been living with ulcerative colitis since he was in his 20s.

Adolescence is the worst time to have to deal with a disease like ulcerative colitis. It's not a disease you want to talk about, and I suffered in silence. Food was the enemy to me and I became extremely thin. And, unfortunately, the medications weren't great at the time.

Like my father, I really kept my disease hidden for a good part of my adult life. What personally changed for me was when my son, Aaron, was diagnosed at age two and a half. That was really devastating for me because I knew what was in front of him because I've been there. I knew I wanted to provide my son with as much support as I could. That was when I became more open about my disease, and surprisingly people were very understanding and supportive.

Shortly after Aaron was diagnosed, my wife and I became active with the Crohn's & Colitis Foundation. She attended education events and came back with information about the disease, current treatments, and new treatments that would be coming out. It was actually fascinating to see that there were much more information and programs out there than there were for me.

When Aaron was older, we learned about Camp Oasis, which I was very excited about, but like most kids he didn't know at first if he wanted to go. It turned out to be transformational for him. He attended for ten years and made many deep friendships.

The Foundation has driven research and development opportunities that have changed our lives. There are so many more treatments available for me and my son than there were for my father. Aaron spent his childhood in the hospital at least once a year and couldn't do much. Thanks to new medications, he was able to start gymnastics and today he is a nationally ranked gymnast.

The Foundation has given us a community which is huge for many of us dealing with this disease. The number one thing the Foundation has given us is hope for my son and not just him but for all kids and adults living with IBD.



Mike Weinberg was diagnosed with ulcerative colitis at age 11.

Advancing New Therapies

Research to uncover new treatments and bring us closer to cures

Putting Patients First

Research that strives for breakthroughs that matter most to people with IBD.

The Crohn's & Colitis Foundation is dedicated to finding cures for Crohn's disease and ulcerative colitis, known collectively as inflammatory bowel disease (IBD), and we're as committed to investing in research and programs designed to improve the quality of life of patients and help them achieve remission. Patient needs are our top priority when we set our research agenda and allocate our funding. In 2021, more than 200 research projects were funded by the Foundation.

We are investing in research to understand more about the chronic abdominal pain patients live with, harnessing the power of stress management, and understanding how diet influences both symptoms and disease activity.

“We work with members of the IBD community, including patients and caregivers, to identify the research areas that have the greatest potential to improve patient quality of life.”

Andrés Hurtado-Lorenzo, PhD,
Vice President, Translational
Research & IBD Ventures.

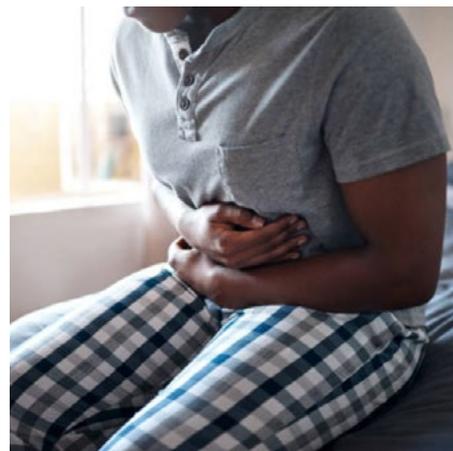
Tackling Chronic Abdominal Pain

New initiative aims to uncover root causes and new treatments.

Up to 50% of people with IBD struggle with abdominal pain that's chronic, meaning that it lasts for three months or longer. Sometimes, the pain persists even when there's no evidence of intestinal inflammation visible during an endoscopy.

To solve the mystery of what's causing such pain, and explore effective remedies to alleviate it, we launched the Chronic Pain in IBD Initiative. To kick off the initiative, we held a workshop that enabled patients, gastroenterologists, neurobiologists, and pain specialists to connect, share experiences, and identify key research gaps. We then solicited research proposals from scientific investigators worldwide and, early this year, awarded three three-year grants of up to \$900,000 each.

We are now supporting important new pain-related research at Johns Hopkins University in Baltimore, Maryland; Queen Mary University of London in the United Kingdom; and McMaster University in Canada.



Pain-related research could help IBD patients struggling with chronic abdominal pain.

Understanding the Impact of Stress

Scientists are clarifying the mechanisms that explain the mind-body connection.

Patients often report that psychological stress contributes to worsened physical symptoms. We are working to understand exactly how the two are connected as well as pinpoint which patients are most likely to benefit from specific stress-management techniques.

We are currently funding research at the University of Alabama at Birmingham that aims to determine whether being exposed to high levels of stress in early childhood translates to more severe disease in preteens and teens with IBD.

At the University of California, Los Angeles, we are supporting scientists who have demonstrated that adult ulcerative colitis patients with high stress reactivity (meaning they exhibit a stronger reaction to stressors) are more prone to disease flares.

Outcomes of this research were published in the July issue of *Clinical Gastroenterology and Hepatology*. That group is now attempting to learn about the pathways by which gut bacteria might influence stress reactivity through the brain and vice versa.



Jennifer Pollock, PhD, presenting at the Foundation's Voices of Progress research event.

“The Crohn’s & Colitis Foundation funding was the spark that started my research into the field of early life stress and colitis.”

—Jennifer Pollock, PhD, University of Alabama at Birmingham

Matching Patients to the Right Diet

What to eat? The answer likely varies from patient to patient.

Our Precision Nutrition Initiative aims to provide the knowledge needed so patients can tailor their diets, based on their unique biological, clinical, and lifestyle characteristics, to feel better and minimize their flares. This program was made possible through a generous donation from Johnathan D. Rose, MD, PhD, Chair, Crohn's & Colitis Foundation's Intestinal Pathology Research Program.

We are supporting precision nutrition research at the University of California, Los Angeles; the University of Calgary in Canada; the University of California, San Diego; and the University of Glasgow in Scotland. At Glasgow University, researchers are working to identify dietary triggers of flare after food reintroduction in children with Crohn's disease who have reached remission on enteral nutrition (a liquid diet that's provided via a feeding tube). They are also studying whether these children can remain in remission by transitioning to a solid diet plan called CD-TREAT.

In total, we are currently funding four clinical studies related to precision nutrition, **an investment of over \$3.6 million** into research in this crucial area.



Konstantinos Gerasimidis, PhD, presenting at the Foundation's Voices of Progress research event

“The role of the Foundation in driving this work has been critical. There are very few research opportunities on the role of diet in the management of patients with IBD. This is a gap that the Foundation has filled.”

—Konstantinos Gerasimidis, PhD, University of Glasgow

Improving Quality of Life and Driving Toward Remission

Initiatives to inform and support clinicians, patients, and caregivers

Connecting Clinicians, Optimizing Patient Outcomes

Our quality-of-care initiative is striving to keep patients out of the emergency room and move them into remission.

IBD Qorus®, our flagship quality-of-care initiative, was founded in 2015 with the goal of improving the standards of care delivered to adults with IBD. What began as a simple idea — to promote shared decision-making between patients and their providers — has evolved into a nationwide collaboration of IBD healthcare providers tracking care delivery performance to foster the exchange of ideas and improve patient outcomes.

“IBD Qorus can be described as a think tank of physicians sharing and learning best practices from one another,” says Alandra Weaver, Associate Vice President, Clinical Quality & Research Innovation for the Crohn’s & Colitis Foundation. “Clinicians are gathering data while treating patients as part of their regular practice and then collectively reflecting on their experience and learning from each other.”

The benefits have been powerful. After analyzing patient data and engaging in brainstorming sessions, IBD Qorus clinicians devised an **Urgent Care Toolkit** as part of a comprehensive module within the collaborative, with support from The Leona M. and Harry B. Helmsley Charitable Trust. This straightforward guide, which emphasizes identifying patients who are at the highest risk for hospitalization and expanding urgent care appointment availability, has already led to a **22% decrease in emergency room visits, a 21% decrease in hospitalizations, and a 50% decrease in opioid use** among patients in practices that have implemented it ([reference](#)).

Other IBD Qorus efforts include testing and adherence to a **treat-to-target** strategy as part of routine IBD care to improve remission rates; this research is being supported by a **\$6.3 million grant** from the Patient-Centered Outcomes Research Institute (PCORI).

“IBD Qorus® can be described as a think tank of IBD physicians, sharing and learning best practices from one another.”

Alandra Weaver, Associate Vice President, Clinical Quality & Research Innovation for the Crohn’s & Colitis Foundation

IBD Qorus: The First-Ever Adult IBD Quality-of-Care Initiative

More than 50 participating IBD centers across the U.S.



More than 5,000 patients enrolled across 27 states.



The ability to gather data while treating patients has led to the publication of more than 17 manuscripts and 23 scientific abstracts that are changing how IBD is managed across the country.



Supporting Patients Every Step of the Way

Our education and support programs bolster patient and caregiver confidence, increase knowledge, and provide a community.

It's not uncommon for people who are diagnosed with IBD to feel a sense of isolation and embarrassment, but it doesn't have to be that way. Whether someone is newly diagnosed with Crohn's disease or ulcerative colitis or has been struggling with it for some time, they will find a caring community when they participate in one or more of our many programs.

"The Foundation's education and support programs provide patients and caregivers with tools they can use to navigate their disease journey," says Catherine A. Soto, Senior Director, Patient Education & Support. "When patients come to us seeking answers about their concerns or challenges, we want them to know they have come to a trusted space, where they can get the resources and answers they need."

The Foundation offers support programs that span from local support groups to topic-specific **Facebook groups** that provide safe spaces for people who share similar backgrounds or experiences. We currently offer groups for those with fistulas, people who have a j-pouch, and veterans.

We also foster connection through **Power of Two**, our peer-to-peer mentoring program. Through this program, patients create a profile and then identify a match from a list of trained volunteers who are open to sharing their personal experience of living with Crohn's disease or ulcerative colitis.

Our **Crohn's & Colitis Community website** also serves as a place where patients can engage and share experiences in a forum.

Making a Difference Digitally

2 million engagements with patients and caregivers in 2021.



75% of patients who connect with the Foundation say we had a positive impact on their patient journey.



100+ support groups virtually and through our local chapters.



[Find a support group in your area](#)

Educating Patients and Caregivers

Navigating life with IBD requires trustworthy information. We're here to help.

Empowering and educating people directly impacted by Crohn's disease and ulcerative colitis is at the core of our mission. Every year, more than 12,000 personal connections are made through our **IBD Help Center**, which is available via phone (888.MY.GUT.PAIN), email (info@crohnscolitisfoundation.org), and **live chat**. Patients can turn to this resource for information, guidance on programs, support services, and much more.

Throughout the year, we host Facebook Live events, which can be viewed in real time or later on demand, covering topics such as urgency, complementary medicine, traveling with IBD, and the mind-gut connection. In total, we had more than **190,000 views of these video chats** since 2021.

In addition, we now offer educational resources for **veterans with IBD** and **Spanish speakers**.

Through our **MyIBD Learning programs**, we educate and share the latest information on IBD treatments, research, and resources that can improve participants' quality of life. Currently, we offer a combination of online and in-person regional programs that cover everything from disease basics and research and treatment updates to pregnancy and IBD, diet and nutrition, and the impact of IBD on mental health.



MyIBD Learning programs provide the latest information to more than **10,000 patients and caregivers each year.**

Spreading the Word About IBD

We're educating the public in an effort to reduce the stigma of IBD and encourage anyone with symptoms to seek help.

Our **Spill Your Guts** public service announcement (PSA) campaign — in English, and now, in Spanish as well — is educating the public about IBD and encouraging people with symptoms to seek help from a healthcare professional.

Our PSAs are airing on more than **150 TV stations across the U.S.** We are also running a series of radio PSAs, including 30- and 60- second spots recorded by Peter Sagal, host of NPR's "Wait-Wait-Don't Tell Me," in which he recounts his fondness for his beloved uncle who struggled with Crohn's disease.

[Listen Here](#)

96% of people who recalled seeing our public awareness campaign said that it helped them understand IBD better.



Spill Your Guts PSAs are airing on stations across the country.

Making Memories, Forging Connections

Camp Oasis provides kids with IBD with a traditional camp experience in a supportive environment.

We proudly run **Camp Oasis**, our summer camp for children with IBD. Featuring outdoor adventures, land and water sports, and leadership training for older campers, the program is known for leaving a positive, indelible mark on those who participate.

“Our data shows 99% of campers report favorable outcomes from camp and close to 70% describe it as life-changing each year,” says Becky Johnson Rescola, Vice President, Education & Community Engagement.

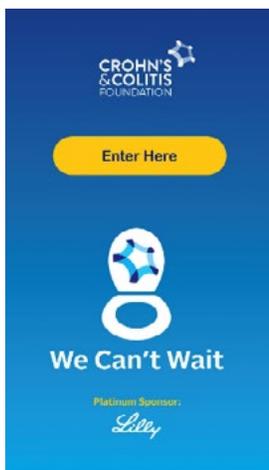
In summer 2022, we were thrilled to re-open Camp Oasis as a residential experience after having to pivot to a virtual model earlier in the pandemic. We welcomed nearly 600 campers back in person and an additional 185 campers who participated in our virtual CampOasis@Home program.



Camp Oasis offers children with IBD a unique opportunity to connect with each other in an enriching environment.

“Camp opened up [my son’s] world to a supportive community. Nothing made my heart smile more than hearing him talk about how he met friends and felt support.”

Parent of Camp Oasis participant



Find a Restroom — Stat!

Our free app helps patients locate bathrooms on the go. Urgent need for a restroom is an unfortunate part of life for many people with Crohn’s disease or ulcerative colitis. Our new “We Can’t Wait” app identifies publicly-accessible restrooms as well as sympathetic establishments that will let IBD patients access employee-only facilities. The app, which can be **downloaded via Google Play or the App Store**, now includes data on **more than 48,000 restrooms across the country**. More than 24,000 people have downloaded it to date.

Improving Access to Care

Breaking down barriers to optimal care for everyone with IBD

Fighting for Medical Nutrition Coverage

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

Sometimes, food *is* medicine. That's certainly the case for children with mild-to-moderate IBD who must be on a liquid formula diet (enteral nutrition) in order to let their gut heal and inflammation subside. Some adult IBD patients who are experiencing severe flares also use enteral nutrition because it works well for them without causing side effects. The problem: Insurance companies rarely pay for it for IBD patients.

The federal Medical Nutrition Equity Act would change that. If enacted into law, this bill would ensure that private insurance, Medicaid, and other payers are required to cover this medically-necessary therapy if it is prescribed for a patient with a digestive disease or an inherited metabolic disorder.

Enteral nutrition isn't a supplement; it's the person's entire diet, says Cassie Ray, Director of Advocacy for the Crohn's & Colitis Foundation. Generally, a pediatric patient who requires enteral nutrition will use it exclusively for 8-12 weeks, then transition to partial formula for up to six months. And the formula costs up to \$80 per day.

To subsist entirely on enteral nutrition, patients may drink formula every hour or two, but that schedule is challenging as well as unappealing for someone with abdominal pain who has little appetite. In such cases, formula is best given through a nasogastric tube, which provides a slow and steady supply of it through the nose and into the stomach to assure adequate nutrition. However, since formulas are often sold over-the-counter, and because most patients are able to take some things orally, insurance companies often treat enteral nutrition like any other food or supplement rather than a medication.

Ensuring that everyone who needs enteral nutrition can access it is crucial, especially for growing children. "It increases weight gain, muscle mass, and bone health, while allowing them to achieve remission," says Ray. "Sometimes, when families can't afford the formula, physicians have to resort to giving the children steroids, biologic medications, or even surgery because they have to control the underlying inflammation."

The Crohn's & Colitis Foundation has been working since 2019 to get the Medical Nutrition Equity Act passed by Congress. From meeting with legislators, mobilizing volunteers, and literally knocking on doors, we won't back down until all patients who would benefit from medical nutrition have access to it.

Help us achieve this important goal by [sending a message to your legislators now.](#)



The Medical Nutrition Equity Act would ensure everyone who needs enteral nutrition can access it.

Fundraising and Donors

Special events and major contributions that support our crucial work

In 2021 alone, the Crohn's & Colitis Foundation invested \$63 million in our mission, the most in Foundation history. Of this amount, more than \$32 million was directed to 200+ research projects, bringing the number of projects we have supported since our inception to more than 2,500 and our total investment in research to almost half a billion dollars.

Platinum
Transparency
2022

Candid.

We've Gone Platinum!

We are proud to announce that the Foundation earned the **2022 Platinum Seal of Transparency from Candid (formerly GuideStar)**. Candid is the most comprehensive source of information about IRS-registered nonprofit organizations, and Platinum is its highest seal of recognition. The Seal confirms our commitment to being transparent about our goals, strategies, capabilities, and achievements.

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 and encourage us with your stories of hope and resilience, and your commitment to raising funds for research and awareness of IBD and to making the lives of people living with IBD better.

We encourage 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.



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



[Take Steps for IBD cures](#)



[Find Galas and Special Events](#)



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