

2019 Annual Report

Helping Patients Today, Accelerating Breakthroughs For Tomorrow



Leadership Message

Improving the Lives of Patients

Prioritizing Impactful Research

Supporting Innovative Solutions

Funding the Future

Financials and Supporters

A Message from Our Leadership	pg. 2
Improving the Lives of Patients	pg. 4
Prioritizing Impactful Research	pg. 15
Supporting Innovative Solutions	pg. 19
Funding the Future	pg. 24
Financials and Supporters	pg. 28

We're meeting patients' most pressing needs right now while prioritizing research that promises to transform lives with potential new treatments, improved diagnostic tests, and other advances that will bring us closer to cures.

We Can't Wait



Michael Osso
President & CEO



John Crosson
Chair, Board of Trustees

A Message from Our Leadership

2019 was an exciting year of progress for the Crohn's & Colitis Foundation. As this Annual Report shows, we made great strides and saw tremendous advancements in IBD research; we introduced important new education programs for patients, caregivers, and healthcare professionals; and experienced important public policy wins. None of these achievements would have been possible without your support, our network of dedicated volunteers, and the collaboration of the IBD community as a whole. We are so grateful to each of you for your contributions.

While we want to recognize and celebrate the many accomplishments of 2019, we would be remiss if we did not acknowledge how much and how quickly our world has changed since the start of 2020. We entered the new year with great plans and optimism, fueled to continue the momentum of 2019. However, the onset and rapid spread of COVID-19 has changed the trajectory of everyday life, how people live, and how businesses, including non-profits like ours, are run.

While the country has been practicing social distancing for the greater good, the effects of closures and cancelled events have significantly impacted our ability to raise funds that will allow us to advance the important work you will read about in this report. While in-person events and gatherings have stopped, IBD has not, and during this crisis we have seen that our patients need us now more than ever. As the need for COVID-19-related resources grew, we quickly expanded our efforts to provide relevant education and support materials, while not losing sight of our commitment to the many long-term needs of our patients. As the headline of this Annual Report reads, we are *helping patients today, accelerating breakthroughs for tomorrow*.

Every endeavor we embark upon is driven by the shared urgency to get to cures as quickly as possible, combined with the need to provide education and support for the IBD community until we get there. In 2019, we continued to expand our research investments in areas that have the potential to get us to cures faster; we also increased education, support, and advocacy programs designed to build resiliency and empower patients to take charge of their care. In this report you will learn more about how we are:

Empowering and inspiring patients

- We meet patients where they are by providing education and tools they can use immediately to improve their quality of care and quality of life. In 2019, we launched a suite of financial management resources designed to help both young and older adults navigate health insurance options; and introduced new shared decision-making videos with guidance on effective communication between the patient and caregiver and their healthcare team.
- We continued to grow our Advocacy Network to support the passing of state-based step therapy reform legislation in Ohio, Georgia, and Washington, as well as the introduction of the first federal step therapy reform bill—S 2546, the Safe Step Act—in the U.S. Senate.

Accelerating the best research and catalyzing critical research in new domains

- We published *Challenges in IBD Research*, which sets our research agenda for the next five years to prioritize and address the unmet needs in IBD patients. Developed in partnership with over 100 stakeholders—scientists, clinicians, and patients—the document not only provides a roadmap for the Foundation, but also the IBD research community at large.
- We are funding the most cutting-edge research with the potential to be game-changing in terms of how patients are diagnosed, treated, and monitored, including: light-activated sealants that have the potential to treat fistulas; a wearable bracelet that can detect, through sweat, signals associated with inflammation; and a blood test to predict, at the time of diagnosis with IBD, whether a patient is at high or low risk for aggressive disease.

While we recognize that 2020 will be a much different year, the incredible progress made in 2019 shows us how much is possible with your support. We are hopeful that if we continue to work together, we will be able to share more great accomplishments at the end of 2020. Because IBD does not stop, and we just can't wait.



Michael Osso
President & CEO



John Crosson
Chair, Board of Trustees

Improving the Lives of Patients



We're Here for You

Making patients' lives better is central to our mission. We're committed to helping those who need assistance by addressing an array of patient needs.

When IBD patients and caregivers need help, we're ready and eager to respond. Those who seek information about how to manage their condition turn to our online education videos and webcasts or connect with us via social media. In 2019 alone, our Facebook Live educational videos had over 400,000 views! We also welcomed more than 9,000 patients and caregivers to in-person support groups and another 2,000 to Facebook support groups. Many others explored our brand-new suite of financial management resources designed to make healthcare more affordable and accessible and watched videos aimed at improving shared decision-making between patients and their providers.

Here are some of the many other ways we're working to meet the needs of everyone impacted by IBD:



The right medication at the right time



Health insurance coverage patients can count on



Better access to restrooms



Support and information to make surgery less daunting



Resources to relieve stress and become more resilient



Here are some of the many other ways we're working to meet the needs of everyone impacted by IBD:



THE RIGHT MEDICATION AT THE RIGHT TIME

How we're helping: By advocating in support of step therapy reform

Insurance companies often require patients to try and fail one or more insurer-preferred treatments before agreeing to cover the treatments originally prescribed by a patient's provider. This protocol is known as [step therapy](#), or "fail first," and when the insurer-preferred treatment is not in line with the provider recommendation, it can lead to delays in care as well as worsened health outcomes. In 2019, we made significant strides in reforming step therapy by passing bills on the state level and advancing legislation on the federal level that require health plans to provide a fast appeals process and to base their decisions on reasonable medical thinking. Our volunteer-fueled efforts led to the passage of step therapy reform acts in Ohio, Georgia, and Washington, bringing the total number of states that have passed similar legislation to 26.

After years of dedicated efforts on behalf of our patients, the Foundation celebrated another major victory when the Safe Step Act (federal legislation to reform step therapy) was introduced in the U.S. Senate in the Fall of 2019.

Brooke Abbott, pictured at left with Congressman Andy Levin, is a patient advocate who has experienced delays in receiving treatment for her IBD due to decisions made by her insurance carrier. She knows all too well why fighting for step therapy reform and other protections for people with IBD is so crucial. "I don't think healthcare is political; it's a basic need," she says. "It's so important that we give the power back to the healthcare providers. They can't do their jobs if a bureaucrat is tying their hands and holding them hostage."



HEALTH INSURANCE COVERAGE PATIENTS CAN COUNT ON

How we're helping: By defending protections for people with preexisting conditions

In 2019, a lawsuit challenging the constitutionality of the Affordable Care Act (ACA) moved to an appeals court. The plaintiffs in this case, known as *Texas v. Azar*, aim to undo the entire ACA—including the provision stating that no one can be denied health insurance because of a preexisting condition.

If the ACA is repealed, it would be devastating for those with chronic diseases, including IBD, because it risks leaving the most vulnerable people uninsured. That's why in April, the Foundation joined with 16 other national health organizations to submit a joint amicus brief to the Fifth Circuit Court of Appeals on *Texas v. Azar*. The brief urges the court to sustain the patient protections included in the ACA, such as prohibiting discrimination concerning preexisting conditions, prohibiting lifetime coverage limits, and allowing young adults to remain on their parents' insurance through age 26.

Texas v. Azar has since moved through the appeals process back to the original court, and the Foundation continues to monitor its progress. We will keep working to ensure Congress knows how vital patient protections are for everyone with IBD.

Here are some of the many other ways we're working to meet the needs of everyone impacted by IBD:

BETTER ACCESS TO RESTROOMS

How we're helping: By supporting restroom access legislation and providing tools patients can use to prove eligibility



Restroom access legislation, sometimes known as Ally's Law or the Restroom Access Act, is state legislation that gives people with IBD and other medical conditions (pregnancy, cancer, etc.) access to employee-only restrooms when a public one is unavailable. As proof of eligibility, patients can use the Foundation's "I Can't Wait" cards in the 17 states where the legislation has already been enacted. The Foundation supported volunteer-led efforts across the country to pass restroom access legislation. Last year, we created model legislation, videos, and other materials that are also available now on the [Foundation's website](#) so that volunteers can work to improve restroom access in their own states.



SUPPORT AND INFORMATION TO MAKE SURGERY LESS DAUNTING

How we're helping: By connecting patients with others who've been through it

Because the prospect of surgery can be frightening and overwhelming, the Foundation [website](#) now features videos of patients describing their experiences preparing for and recovering from surgery. These videos, which also include a wound ostomy nurse talking about surgical considerations, are crucial to easing fears by demystifying the process.

Meanwhile, our private Facebook [J-Pouch Support Group](#) grew by 151% in 2019; it now connects more than 400 participants from around the world. "There are a ton of scary stories out there on the internet. This group provides a place where patients can connect with others who understand what they're going through, from the comfort of their own home," says Jordan Wilson, ulcerative colitis patient and J-Pouch Support Group moderator.

Here are some of the many other ways we're working to meet the needs of everyone impacted by IBD:

RESOURCES TO REDUCE STRESS AND BECOME MORE RESILIENT

How we're helping: By providing a wide range of social and emotional support programs



In 2019 we launched a number of new mental health resources, including a video series about living with IBD that was created by members of our National Council of College Leaders, a group of college-age volunteers. These videos are available on our [Campus Connection website](#), which had 33,000 unique views in 2019.

Meanwhile, we continued running [Camp Oasis](#), our residential summer camp for kids with IBD that many participants and their parents have described as “life-changing.” For adults with IBD, we offer numerous [support groups](#) across the country, access to active online forums, and [Power of Two](#), our peer-to-peer program that connects patients by phone.

Patients Under Pressure

Who's at greatest risk for stress-induced flares?

Research suggests people with IBD are more likely to experience anxiety and depression, but the overall role stress plays in symptoms still remains unclear. However, new research funded by the Foundation now reveals a direct connection.

Emeran Mayer, MD, PhD, and Jenny Sauk, MD, gastroenterologists at the David Geffen School of Medicine at the University of California Los Angeles, studied 93 patients with ulcerative colitis who were in clinical remission and found that those who experienced higher perceived stress and anxiety were significantly more likely to experience clinical flares.



Study participants were given brain imaging tests, behavioral assessments, and autonomic nervous system testing, including a skin test to measure electrodermal activity (EDA)—which indicates sympathetic nervous system activation at the time of enrollment. Patients were given biweekly online questionnaires to assess clinical disease activity, stress and anxiety levels, and they provided stool and serum for microbiome and metabolomic analysis at three-month intervals for the duration of the study. The same tests were repeated whenever a patient reported having a flare.

Mayer, director of UCLA's G. Oppenheimer Center for Neurobiology of Stress and Resilience and principal investigator of the research project, and Sauk found that patients who were in remission and had higher EDA when the study began were more likely to experience flares during the rest of the study period. They also found that certain patients reported flaring, but their stools did not have higher levels of fecal calprotectin, an indicator of gut inflammation. "This suggests that imbalances in the autonomic nervous system could potentially contribute to these clinical flares. We will also evaluate whether higher EDA at baseline could contribute to increases in fecal calprotectin during follow-up," Sauk explains.

What it also suggests, adds Mayer, is that mindfulness-based stress reduction therapies could make a big difference in reducing clinical flares. "Two people may be exposed to the exact same stressor, but if one of them overreacts this person's brain sends signals to the gut immune system and microbiome that triggers a flare," he says. "If we can stop that process, we may be able to resolve their symptoms."

The group's research is still ongoing, with future plans to analyze brain MRIs on the participants as well as the bacteria, viruses, and fungi that make up their intestinal microbiomes and their metabolites. But Sauk is hopeful. "If we can find more physiologic markers that indicate someone is having more of a stress-related flare, we can potentially avoid a lot of extra testing and improve a patient's quality of life by working to alter a patient's physiologic reaction to perceived stressful stimuli," she says. "Anecdotally, patients report that stress makes their symptoms worse. We now have data to support that."

BUILDING RESILIENCY AND EMPOWERING PATIENTS

We are increasing support and education for our patients and caregivers in an effort to build resiliency and further empower them to take charge of their care.

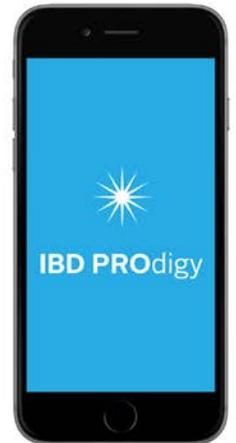
Drive Research Participation

In 2019, the Foundation hired its first-ever digital health and engagement professional. Emily Cerciello's goal is to make it as easy as possible for [patients to participate in research](#) and, in turn, increase the relevance and reliability of IBD studies.

Easy-to-use mobile apps are a top priority. "We want to build a broad, diverse network of patients interested in contributing to research," Cerciello explains. "And we want to make sure that the data we collect about IBD is representative of the patient population."

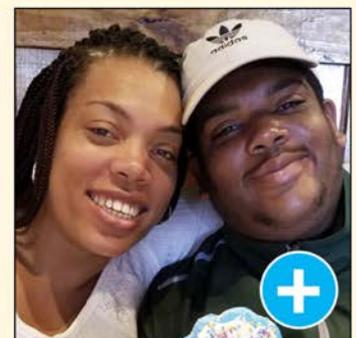
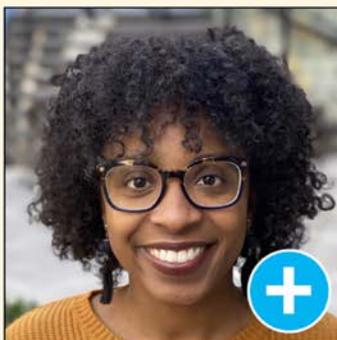
In an effort to enroll more diverse patients into research projects, the Foundation applied for and received grant support from the Patient-Centered Outcomes Research Institute (PCORI). This award is being used to enhance the diversity of IBD Partners, an online research study that enrolls patients directly, which is run by the Foundation and the University of North Carolina School of Medicine. IBD Partners promotes the incorporation of strong patient voices and values into research efforts.

In September, the Foundation was selected by the U.S. Food and Drug Administration to build IBD PROdigy, a digital tracker tool as part of IBD Plexus. IBD PROdigy makes it simple for patients to report their own symptoms and experiences via a mobile app. The IBD PROdigy app will launch in 2020 and initially be rolled out to participants in SPARC IBD, our longitudinal study of over 3,000 adult IBD patients.



We Understand Patients Because Many of Us are Patients

For many Foundation staffers, working to end IBD is more than a job.





“When I was diagnosed with IBD 18 years ago, I had to decide whether I would let it define me or if I would define the disease. I decided to dedicate my life to helping those with IBD.”

—**Caneka McNeil**, *East Area Education Director*



“I hope to work myself out of a job one day by doing my part to drive money toward research that will ultimately lead to cures for me, my daughter (who also has IBD), and the 3.1 million Americans like us.”

—**Derek Dodson**, *Central Texas Walk Manager*



“After struggling to convince my insurance company to cover various procedures, tests, and treatments for my IBD, I realized how important it is to have a focused and knowledgeable organization to pave the way for patients.”

—Eric Hope-Ross, Director, Project Management



“Because a large number of Foundation employees have a personal link to these debilitating diseases, we’re empathetic, passionate, and driven. As someone with IBD, I truly appreciate that the Foundation will continue to be at the forefront of cutting-edge therapies and research initiatives that will ultimately help me and my fellow IBD sufferers.”

—Joseph Cobucci, National Manager, Business Development



“I chose to work for the Foundation because it provided me with a sense of control and purpose in this fight against IBD. My daughter, Addy, was diagnosed with severe Crohn’s disease at the age of 8, and the Foundation has empowered and supported us nonstop. It gives me hope for my daughter and her future.”

—**Nicole Kittelson**, *National Business Development Manager*



“As someone living with IBD, I understand the difficulties of being a patient. For all those patients waiting for answers and a better way of life: We are fighting for you every day and won't stop until there are cures.”

—**Suzanne Fry**, *Manager, National Fundraising Campaigns & Volunteer Engagement for spin4 crohn's & colitis cures*



“I have IBD, yet if the Foundation’s leadership were not great stewards of the dollars raised I would not choose to work here. We will not stop working until everyone with IBD can be effectively treated and enjoy a healthy quality of life.”

—Linda Winston, Executive Director of the Upstate Northeastern NY Chapter



“The stigma around IBD often causes patients and caregivers to suffer in isolation, so I really value the Foundation’s efforts to build community. The organization has become a ‘part of the family,’ and when it wins and experiences progress, patients (including my son, Jaden, who has IBD) and caregivers do as well.”

—Chrissy M. Thornton, Executive Director, Maryland/Southern Delaware

INSPIRING AND ENGAGING PATIENTS AND CAREGIVERS

We bring together the largest community of IBD patients in the country, and we engage them in the fight against Crohn's disease and ulcerative colitis.

IN 2019 WE...



2 million

Had more than 2 million engagements with patients and supporters through our education, support, and advocacy programs, a 40% rise from 2018



59%

Increased our partnerships with hospitals and clinical practices by 59%, which enabled us to greatly expand our outreach to patients through their healthcare teams



11,216

Hosted 11,216 patients and family members at live education programs, a 43% increase from 2018



1,181

Welcomed 1,181 children with IBD to Camp Oasis and awarded 520 camp scholarships based on family need

Prioritizing Impactful Research

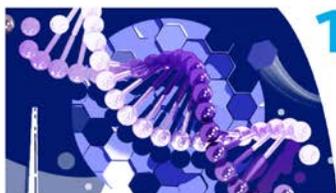


Up for the Challenge

The Foundation's 2019 update to *Challenges in IBD Research* highlights crucial scientific knowledge gaps and outlines our research priorities for years to come.

A substantial amount of time and money is required to push a scientific idea from inception toward reality—and even then a concept that initially seemed to have promise might not work. “Where should we put the Foundation’s investments? We look for a scientific rationale,” explains Andrés Hurtado-Lorenzo, PhD, vice president of translational research for the Crohn’s & Colitis Foundation.

That rationale is summarized in [Challenges in IBD Research](#), an in-depth report that the Foundation publishes about every five years after analyzing current knowledge gaps. The current version—which was conceived with input from 100 scientists, clinicians, and patients—was published in June 2019. As a result, the Foundation is now prioritizing research in five key areas:



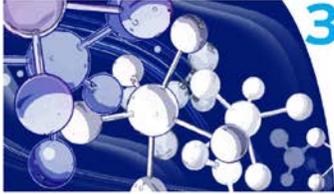
1 Preclinical research that sets the stage for later patient trials

We are currently funding a number of projects in this category, some of which build on our previous accomplishments. For instance, thanks to our Genetics Initiative, scientists know about a protein that helps maintain the connections between cells in the intestinal wall. Now we need to learn how these connections can be controlled and strengthened.



2 Environmental triggers

How could a person with IBD have an identical twin who doesn't also have the disease? The answer to this question lies with environmental factors that can turn genes on or off, and we need to know which ones are most significant. We're prioritizing research that will help us learn more about potential triggers including diet, viruses, tobacco, and psychological stress.

**3****Novel technologies**

The Foundation is currently funding research that uses bioengineering technology to track IBD in a noninvasive manner, such as a sweat-sensing bracelet that monitors internal inflammation. We're also using stem cell technology to create "mini guts" that researchers are studying to learn why certain patients develop fibrosis.

**4****Personalized (precision) medicine**

Predicting which patients will suffer serious complications (and are therefore likely to benefit from aggressive treatment) is largely a guessing game. We're supporting studies that aim to change that, including the Pediatric RISK Stratification Study. We're also supporting a clinical trial in the U.S. to determine whether a blood test that checks for a gene pattern can accurately predict which patients are most likely to have multiple relapses.

**5****Clinical research in real-world settings**

Pragmatic clinical research studies can allow clinicians to integrate research into their regular practice. These types of studies, which provide information collected during routine patient appointments, can be used to evaluate how well various treatments and interventions are working in the real world, after the clinical trials are over. They tend to be cost-effective, allow for easy recruitment of participants, and they can yield very important results.

CATALYZING CRITICAL RESEARCH IN NEW DOMAINS

We are leading the way with millions of dollars of research investment in critically important areas.

Keeping Clinicians Up-to-Date

People with Crohn's disease and ulcerative colitis count on their healthcare providers to stay abreast of the latest treatment guidelines and practices in a rapidly-evolving field. This year, the Foundation continued to expand its educational opportunities for providers so they can remain at the cutting edge of IBD care.

In 2019 the Foundation made 37,000 connections with medical professionals through live and online education opportunities—a 19% increase from 2018, says Orna Ehrlich, the Foundation's senior director for professional education and innovative programs. "We want to meet providers where they are," she says. "We know there are different learning styles and opportunities—maybe one individual can attend a meeting in person, but another only has time to access information with their phone. We use multiple channels to make sure we're reaching as many providers as possible."



Our largest in-person professional education event was the annual [Crohn's & Colitis Congress®](#)—a three-day meeting cosponsored by the American Gastroenterological Association that brought together IBD professionals from around the world. Local chapters also hosted regional events for providers seeking to earn continuing medical education credits closer to home.

Since many providers prefer to have quick online access to important research and clinical updates, the Foundation launched [Crohn's & Colitis 360](#) in May 2019. This online-only, open-access (free to view), peer-reviewed journal covers key aspects of caring for IBD patients and includes a lay summary for each article—so it's accessible to all. It features the latest research aimed at advancing prevention, treatment, and cures, and provides a forum for the dissemination of novel insights and innovations across key disciplines involved in IBD care.

Because providing the best care sometimes entails knowing how to manage insurance appeals and decisions, we also convened our first provider-payer roundtables—eight gatherings in different cities that brought providers and representatives from local insurance companies together to discuss ways to improve patients' access to quality care. Along the same lines, we launched a suite of practical tools to help providers navigate step therapy protocols that can potentially delay patient access to appropriate care. Our online [state-by-state guide](#) now enables healthcare providers to find information about local laws, and provides details on the updated state insurance appeals processes.

Advancing Surgical Research for Better Outcomes

When IBD patients must undergo an invasive procedure, we want to ensure that it's as safe and effective as possible, and that the risk of complications is minimized. One way we're making that happen is through the [Surgery Research Network](#) (SRN), a consortium of more than 60 research centers dedicated to collaborating on clinical studies of IBD patients who require surgery. Since the SRN's inception in 2017, all SRN members get to vote on which studies deserve funding each year. The sponsors of the winning proposals receive funds from the Crohn's & Colitis Foundation and the American Society of Colon and Rectal Surgeons to advance their research in collaboration with other SRN members.



"There is no real research home for IBD surgeons, and so they welcomed the opportunity that the Foundation provided to bring them together and fund projects focused on improving IBD surgery outcomes," says Caren Heller, MD, MBA, the Foundation's chief scientific officer. In 2019, one study we funded focused on developing a patient-centric definition of "j-pouch syndrome." This phrase refers to a complication some ulcerative colitis patients develop after having their colons and rectums surgically removed, yet there is currently no standardized definition. The Foundation worked with the surgeons to bring in more than 200 patients to provide input regarding what was important to them.

LEVERAGING YEARS OF MAJOR FOUNDATIONAL RESEARCH INVESTMENTS

Our multi-year, multi-million-dollar research investments in areas that are important to IBD are paying off.

IN 2019 WE...



30%

Expanded IBD Plexus[®], our massive information exchange platform, by increasing the biosample acquisition rate by 30% since 2018



80

Held our first IBD Clinical Research Strategy meeting, which included more than 80 participants from leading research and academic institutions, industry partners, and patient advocates



1,400

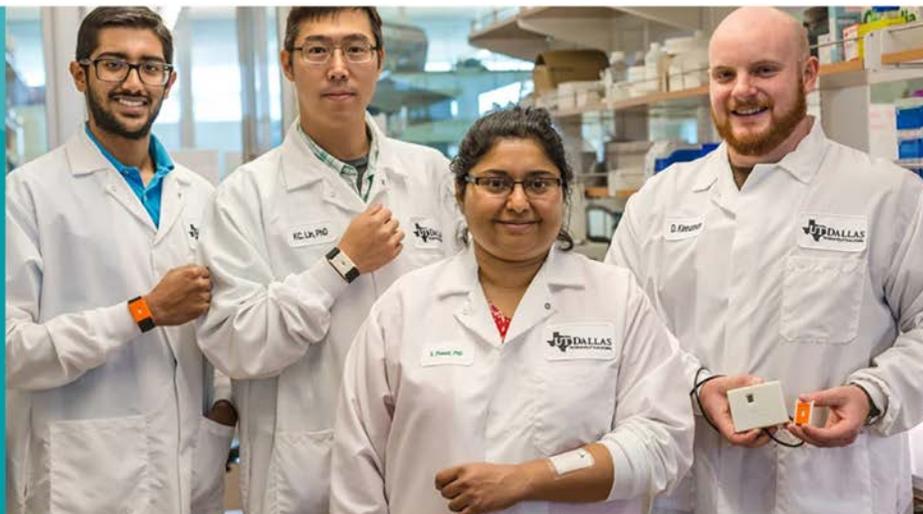
Hosted nearly 1,400 healthcare professionals and researchers at the 2019 Crohn's & Colitis Congress[®]



60

Supported colorectal surgeons at more than 60 research centers across the United States who are now exploring research questions related to IBD patients and surgery

Supporting Innovative Solutions



A Novel Approach

We're supporting cutting-edge technology that has the potential to transform the way IBD is managed.

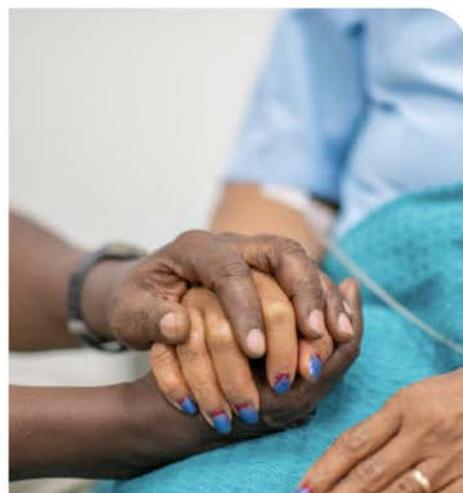
IBD care has improved significantly since the Foundation's inception in 1967, but there's so much more to accomplish. Patients need medications that control IBD more effectively, more noninvasive ways to monitor their individual conditions, and remedies for IBD complications that don't entail major surgery. The Foundation is currently supporting several projects that could redefine what it means to live with IBD.



Noninvasive monitoring



New treatments



Addressing complications





NONINVASIVE MONITORING

Our [Novel Technologies Initiative](#) is funding two projects involving biosensors. At the Massachusetts Institute of Technology, researchers, led by Tim Lu, PhD, are developing a small capsule that detects inflammation in the gut. If the project is successful, patients would ultimately be able to swallow the capsule and learn more about their current disease activity—perhaps reducing the current frequency of colonoscopies.

Meanwhile, at the University of Texas at Dallas, researchers led by Shalini Prasad, PhD, are making great progress in developing a bracelet that measures inflammatory biomarkers in sweat. In 2019 the team successfully proved that their prototype can accurately detect four inflammatory markers and that it can continue tracking levels for at least 24 hours. "In one year we engineered and validated the device by testing it on healthy humans," says Dr. Prasad. "Now we're ready for the next step, which is testing it on IBD patients."



NEW TREATMENTS

[IBD Ventures](#), the Foundation's venture philanthropy arm, is supporting multiple projects that have the potential to improve patient outcomes. Three of them are specifically focused on developing innovative new treatments.

At Vedanta Biosciences, researchers are refining a cocktail of beneficial bacteria designed to kick out harmful bacteria that have been linked to IBD flares.

Drugs designed to block enzymes associated with IBD and poor responses to current treatments are also in the works, thanks to IBD Ventures funding. At the Cleveland Clinic, researchers, led by Thad Stappenbeck, MD, PhD, are focused on blocking an enzyme called PAI-1 (plasminogen activator inhibitor) that is elevated in people with severe IBD.

At Johns Hopkins, a group of researchers led by Barbara Slusher, PhD, is working on blocking a different enzyme, GCPII (glutamate carboxypeptidase II), which is overactive in IBD patients. The group has already created a drug that's effective in animals; these researchers are now trying to formulate it for humans. "This drug might work in patients who don't respond to other therapies," says Slusher.



ADDRESSING COMPLICATIONS

Fibrosis (a buildup of scar tissue in the intestines) and fistulas (abnormal channels that connect the intestines to another internal organ or the skin) are notoriously difficult to treat. Two Foundation-supported projects could change that.

Launched in 2019, our Fibrosis Initiative is supporting scientists at Cedars-Sinai Medical Center who have figured out how to create "mini guts" in the lab using stem cells taken from IBD patients with and without fibrosis. By studying the differences, they hope to understand how certain genetic factors and dangerous gut bacteria come together to cause fibrosis. Eventually, they should be able to test potential new drug treatments on these mini guts before turning to human subjects.

Late in 2019, we reached an agreement to make an IBD Ventures investment in Tissium, a French company that manufactures medical-grade putty. The hope is that this compound will lend itself to plugging fistulas via a minimally-invasive technique (see "Revolutionizing the Treatment of Fistulas" for more information).

Revolutionizing the Treatment of Fistulas

Jeffrey Karp, PhD, is developing a medical-grade gel that has the potential to seal fistulas.

A large percentage of Crohn's disease patients will eventually develop fistulas, which are abnormal channels that can extend through the bowel wall into other organs or tissue and cause pain and potentially life-threatening infections that require emergency surgery. We are hoping a new putty-like gel, which was invented by Karp and colleagues and is being developed by the medical device company Tissium, can revolutionize fistula treatment.

"It draws on some of the principles of slug and snail secretions that enable adhesion to wet dynamic surfaces," says Karp, Professor of Medicine at Brigham and Women's Hospital in Boston. A Tissium product made from this gel is already approved in Europe for use in cardiovascular procedures.

Karp's hope that it will prove useful for fistulas is both professional and personal: His 11-year-old daughter, Jordyn, was diagnosed with ulcerative colitis six years ago. After her diagnosis, Karp struck up a close relationship with Scott Snapper, MD, PhD, her physician at Boston Children's Hospital. Intrigued by Karp's research, Snapper, a past chair of the Crohn's & Colitis Foundation's National Scientific Advisory Committee, invited him to a novel technologies workgroup sponsored by the Foundation. "I quickly realized the limitations of treating fistulas, and it occurred to me that this technology could offer a new option," Karp says.

Over the next couple of years, Tissium will work on tweaking the gel so that it can be applied to fistulas. "The hope is that it will not only seal a fistula hole but also serve as a scaffold on which new, healthy cells can grow," Karp explains. Although his daughter has made "incredible progress" and is currently in remission, Karp also knows that could change. "My mission is to do what I can to ensure that she, along with the millions of other patients living with IBD, lead full lives."



The Future is Personal

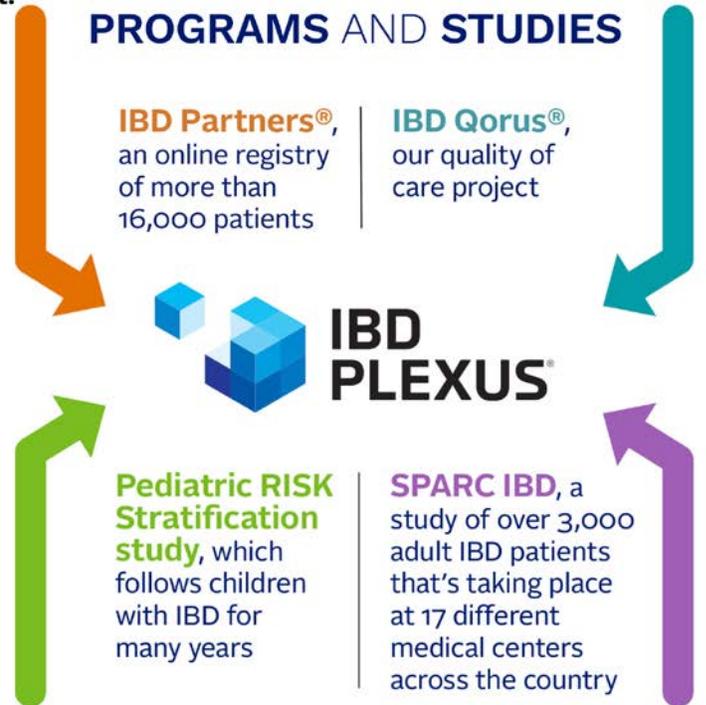
Precision medicine aims to find the best fit for each patient.

Years ago, cancer was treated as a single disease, but today scientists know there are many different types, even when it crops up in the same body part. Personalized (or precision) medicine—which entails homing in on each patient’s unique genetics, behavior, and environment—has transformed cancer care, and it’s now similarly poised to revolutionize the management of IBD.

The Crohn’s & Colitis Foundation aims to be at the forefront of this effort. Our first-of-its-kind research information exchange platform, IBD Plexus, is helping researchers better understand which factors drive Crohn’s disease and ulcerative colitis in different patients, so we can eventually develop novel drugs to target them. Since its inception in 2017, IBD Plexus has centralized almost 100,000 biosamples from thousands of patients along with their clinical data. “Harnessing the transformative power of the IBD Plexus platform, researchers have access to a critical mass of research-ready, multidimensional data to accelerate the development of new therapies that will keep IBD in remission longer, and better tools to help select the right therapy for the right patient,” says Angela Dobes, the Foundation’s vice president of IBD Plexus.

The Foundation studies that provide data to IBD Plexus researchers now include IBD Qorus, our quality-of-care initiative; the Pediatric RISK Stratification study, which follows children with Crohn’s disease for many years; SPARC IBD, our prospective adult research cohort; and IBD Partners, an online registry of more than 15,000 patients. SPARC IBD collects clinical data, patient-reported outcome data, and biosamples. “A key goal is to expand it so that it includes a very diverse patient population, which will help us understand what makes the disease different for each individual,” explains Cecile Norris, the Foundation’s senior research manager of SPARC IBD.

While developing new drugs is a major focus, there’s also powerful new evidence that tailoring a patient’s diet to their biological, clinical, and lifestyle characteristics can have a major impact. In 2019, the Foundation received a generous donation from Jonathan D. Rose, MD, PhD, chair of our Intestinal Pathology Research Program, to launch the Foundation’s new Precision Nutrition Initiative. In July, we issued a request for proposals focused on investigating the biological mechanisms underlying the individual patient’s personal response to different foods. This research is critical to advancing our understanding of diet in IBD and the emerging field of precision nutrition.



The Growth of IBD Qorus

Our national quality-of-care initiative, IBD Qorus, is a collaboration that brings together the voices of clinicians, researchers, and patients from all over the country. At each site—an academic center, community health clinic, or private health practice—patients and providers utilize IBD Qorus tools to track, measure, and evaluate data to improve patient care. Providers connect via monthly conference calls and all stakeholders join twice a year in-person meetings during which they review pooled data and information with the goal of identifying patterns about how care is delivered.

“The IBD Qorus collaborative is incredibly valuable and will help determine practice patterns that lead to improved health outcomes,” says Alandra Weaver, senior director for clinical quality and research innovation.

IBD Qorus is growing rapidly: Nearly 20 new sites have recently joined the initiative and there are plans to bring more sites into the program in 2020.



ACCELERATING THE PACE OF RESEARCH

We are accelerating research by breaking down traditional barriers to patients, data, funding, and collaborations.

IN 2019 WE...



Selected

Chose five new projects to fund through IBD Ventures, our venture philanthropy initiative that aims to advance new product opportunities that have the potential to address pressing unmet medical needs in patients



Collaborated

Had a partnership between Evotec, a drug discovery company, the Foundation's Genetic Initiative researchers, and the Foundation's scientific staff focused on developing a new treatment that would block the PAI-1 protein



Supported

Continued supporting the development of wearable and ingestible biosensors with the goal of providing noninvasive, patient-friendly means of detecting inflammation and imminent flares



Launched

Kicked off the brand-new Precision Nutrition Initiative, which focuses on investigating the biological mechanisms underlying individual patients' responses to different foods

Funding the Future



Raising Money to Change Lives

Every year we rely on volunteers to help us raise money via our signature fundraising events. Some key highlights:



Take Steps



Team Challenge



spin4 crohn's & colitis cures





TAKE STEPS

Our largest nationwide campaign not only raises crucial funds, but also connects and empowers the IBD community to help patients and caregivers feel less alone during their journey. [Take Steps](#) community walks are held all over the U.S. and help us raise money as well as awareness. Since its inception in 2008, more than 400,000 people have participated in Take Steps—which has enabled us to raise more than \$100 million in support of our mission. In 2019, we welcomed Olympic swimmer Kathleen Baker as our national Take Steps ambassador.



TEAM CHALLENGE

Our endurance program combines fitness training and a supportive community, empowering those affected by IBD to complete a run, walk, hike, cycle, or triathlon while raising critical funds to support the Foundation's mission. Since [Team Challenge](#) got its start in 2007, the program has raised over \$88 million and created an extended network of friends and family for all involved.



spin4 crohn's & colitis cures

A high-energy event that incorporates teamwork and fun to make an impact worth millions of dollars, [spin4 crohn's & colitis cures](#) participants form teams or ride solo and pedal with a purpose on stationary bikes. The Foundation's newest national fundraiser got its start in 2015, and has raised \$5.4 million since then. In 2019, we held 31 local rides, with additional riders creating their own events through our "ride where you live" option.

Biking to End IBD

After Michael Hoogsteden lost his wife, Wendy, to complications of IBD, he resolved to honor her memory and raise money by cycling across the country. We asked him to share his story:

Wendy came with a group of friends to make some jumps at the skydiving club where I was an instructor. I saw her from a distance and thought to myself, "I think I just met my wife." I hadn't even said hello yet. We started dating in May and married the next February.

At the time, Wendy was an occupational therapist. She had been living with ulcerative colitis since she was 21, but it was manageable. She became a skydiving instructor and we started competing nationally—we won a gold medal one year, bronze the next. In 1999, we went to Thailand to participate in setting the record for the largest number of skydivers in a free-fall. Then when she was about 31, she got a new diagnosis: Crohn's disease. Wendy got sicker and had to stop skydiving.

Wendy was an indescribable, unstoppable, powerful energy. She was always smiling and put a smile on everyone's face around her. She was just a beautiful person and a tremendous athlete—a competitive body builder, personal trainer, and cyclist.

We were married 21 years. Wendy died of complications of IBD in October 2018. I was so angry at the disease. I thought something must be done. Being a cyclist, I decided to parlay this thing I love into support of this person I love.

In October 2019, I embarked on a 42-day bicycling journey from Santa Barbara, California to Myrtle Beach, South Carolina. The trip raised \$75,000 for the Foundation through Team Challenge's [Race in Orange](#) program.

I spread Wendy's ashes in the Pacific, in the Atlantic, and in nine states along the way. It was cathartic, challenging, exhilarating, liberating. It helped me through some very dark times. Along the way, I'd get an email that someone else had made a donation, or I'd see something that would remind me of Wendy. It gave me comfort that I could do this for her, reach this goal of hers to travel across the country.



Passionate Partners, Powerful Results

Our volunteer-fueled special events generate excitement as well as much-needed funds.



Every year IBD patients, caregivers, and other supporters join forces to create a wide variety of local fundraisers. In 2019 alone, more than 100 special events were held across our 39 chapters, generating nearly \$19 million for the Crohn's & Colitis Foundation.

While Foundation staffers play a role in these events—which include galas, golf outings, fishing tournaments, bocce ball competitions, and football games that take place in NFL stadiums—volunteers are the heart of these unique fundraisers. “They really hinge on volunteers who have a strong commitment to fighting IBD and are connectors who bring together others with similar interests for the cause,” says Kristin Kaplan, the Foundation’s senior vice president of special events and volunteer engagement.

The largest annual special event is a women's luncheon and fashion show that generated \$1.8 million in 2019 for the Foundation and has been taking place in New York for the past 26 years.

“Many of our most unique ideas come from volunteers,” says Kaplan. Fishing enthusiasts in the Florida Keys, for instance, spearheaded a now-annual event that raises more than \$800,000 each year. Meanwhile, football fans join together at four NFL stadiums (in Detroit, Seattle, New Jersey, and Minnesota) to play round-robin tournaments and raise money for IBD in the process. “It’s our job to take something they’re really passionate about and help turn it into a fundraiser,” says Kaplan.

IN 2019 WE...



Financials and Supporters



Donor Spotlight: Dr. Jonathan Rose

Philanthropist Jonathan D. Rose, MD, PhD, is a steadfast champion and friend to the scientific research community, supporting a diverse array of research projects at leading institutions across the country. Earning his MD from Rush Medical University, PhD in Biochemistry and Molecular Biology from the Medical College of Ohio at Toledo, and Masters in Forensic Sciences from National University, Dr. Rose's professional and academic experiences are impressive in both breadth and depth.

A true scholar with a passion for learning, in addition to his exceptional academic accomplishments, Dr. Rose's interests in technology and science have led him to receive numerous certifications and credentials in medical research, patient care, fire science, forensics, private investigations and security consulting, and medicolegal forensics.

As Chair of the Crohn's & Colitis Foundation's Intestinal Pathology Research Program, Dr. Rose provides valuable support to the Foundation's research program. Indeed, Dr. Rose recently made a major commitment to advancing IBD research with a meaningful grant to help the Foundation launch a comprehensive, multi-institution research program to explore the role of diet's impact on IBD.

Central to all patients with IBD is how they manage their diet and food intake while living with a disease that affects their gastrointestinal tract. Yet, just as Crohn's disease and ulcerative colitis are highly individualized diseases, how one patient reacts to a particular food or diet may be very different from another patient's experience. The need to understand how diet affects disease, particularly at the individual patient level, is a critical gap in the IBD field's understanding of the disease, and an area of opportunity to make a significant impact on patients' quality of life.

We believe the outcomes will provide evidence to inform and streamline human diet trials, and ultimately guide the development of personalized nutrition for IBD disease management. Our ability to launch this robust research program would truly not be possible without Dr. Rose's visionary support and leadership.



The need to understand how diet affects disease, particularly at the individual patient level, is a critical gap in the IBD field's understanding of the disease, and an area of opportunity to make a significant impact on patients' quality of life.

More than 80 cents of every dollar the Crohn's & Colitis Foundation spends goes to research, education, or support services.

+ 2019
Research
Awards

+ 2019 Friends
of the
Foundation

+ Corporate
Supporters

+ 2019 Planned
Giving:
Founders
Society

+ Board of
Trustees

+ Financials



2019 Research Awards

The Crohn's & Colitis Foundation is pleased to acknowledge the following investigators for their excellence in research approaches to advancing our knowledge of IBD.

Research Fellowship Award for Research Excellence

Nitesh Shashikanth, PhD

Brigham and Women's Hospital
Boston, MA

Competition between pore forming and barrier forming claudins in Inflammatory Bowel Disease

Lloyd Mayer Career Development Award

Sarah Short, PhD

Vanderbilt University Medical Center
Nashville, TN

GPX1 in colitis and colitis-associated dysplasia

The Crohn's & Colitis Foundation is pleased to acknowledge the following donors whose gifts were designated in support of individual researcher awards.

Ethel Wilson Bowles and Robert Bowles Memorial Fund

Uma Mahadevan, MD

University of California, San Francisco
San Francisco, CA

Pregnancy and Inflammatory Bowel Disease And Neonatal Outcomes (PIANO) Registry: Long-term Outcomes of In-Utero Biologic Exposure

Flowerree Foundation

Stephan Targan, MD

Cedars-Sinai Medical Center
Los Angeles, CA

A personalized intestinal fibrosis model combining patient specific iPSC-derived human intestinal organoids and small microengineered Chip technology

F.M. Kirby Foundation

Lei Zhou, PhD

Joan & Sanford I. Weill Medical College of Cornell University
New York, NY
IL-2-dependent regulation of intestinal health and inflammation

F.M. Kirby Foundation

Wenhan Zhu, PhD

UT Southwestern Medical Center
Dallas, TX
Precision targeting Enterobacteriaceae during gut inflammation ameliorates colitis and colorectal cancer development

Roddenberry Foundation

Timothy Lu, MD, PhD

Massachusetts Institute of Technology
Cambridge, MA
An ingestible bacterial-electronic monitoring system for inflammatory bowel disease

Linda Tallen & David Paul Kane Educational and Research Foundation

Ronen Sumagin, PhD

Northwestern University
Chicago, IL
Neutrophil-driven inflammation leads to carcinogenesis in IBD

The Leona M. and Harry B. Helmsley Charitable Trust has been a visionary supporter of Crohn's disease research and the Crohn's & Colitis Foundation, providing significant support in 2019 to IBD Plexus® and IBD Qorus®. The Helmsley Charitable Trust also supported the following awards:

Rana Al-Sadi, PhD

University of New Mexico
Albuquerque, NM
MMP-9 modulates intestinal epithelial tight junction barrier and intestinal inflammation

Ashwin Ananthkrishnan, MD, PhD

Massachusetts General Hospital
Boston, MA
Microbiome predictors of response to anti-TNF and anti-integrin therapy in inflammatory bowel diseases

Rajatava Basu, PhD

University of Alabama at Birmingham
Birmingham, AL
IL-1-mediated regulation of the Th17 developmental program and its role in IBD

Samuel Bertin, PhD

University of California, San Diego
La Jolla, CA
TRPA1 and TRPV1 ion channels as novel therapeutic targets in inflammatory bowel disease

Jennifer Dotson, MD, MPH

The Research Institute at Nationwide Children's Hospital
Columbus, OH

The effect of provider bias and patient/family hardships on healthcare disparities in pediatric inflammatory bowel disease

Mark Frey, PhD

Children's Hospital Los Angeles
Los Angeles, CA

Suppression of pro-inflammatory macrophage activity by ErbB4

Melanie Gareau, PhD

University of California, Davis
Davis, CA

The microbiota-gut-brain axis in pediatric IBD

Akihito Harusato, MD, PhD

Georgia State University
Atlanta, GA

IL-36-mediated regulation of chronic and acute intestinal inflammation

Shinya Ito, MD

The Hospital for Sick Children
Toronto, ON

Assessing the drug exposure risk of infants breastfed by women with inflammatory bowel disease

Hiroko Kitamoto, PhD

University of Michigan
Ann Arbor, MI

Gut dysbiosis increases the risk of clostridium difficile infection in patients with inflammatory bowel diseases

Frits Koning, PhD

Leiden University Medical Center
Leiden, Netherlands

Identification of Crohn's disease-specific immune signatures through high-resolution multiparameter analysis of the intestinal immune system

Yelizaveta Konnikova, MD, PhD

Brigham and Women's Hospital, Inc.
Boston, MA

High dimensional immunophenotyping and functional assessment of intestinal tissue in VEOIBD

Pawan Kumar, PhD

Stony Brook University
Stony Brook, NY

IL-17 receptor signaling and intestinal host defense

Sila Kurugol, PhD

Boston Children's Hospital
Boston, MA

Motion-robust quantitative MR imaging markers for assessment of inflammation and fibrosis in Crohn's disease

Nayden Naydenov, PhD

Virginia Commonwealth University
Richmond, VA

Inhibition of protein translation initiation and disruption of the intestinal epithelial barrier in IBD

Jodie Ouahed, MD

Boston Children's Hospital
Boston, MA

The influence of genetic variants on the antiinflammatory response to interleukin 10: relevance to very early onset inflammatory bowel diseases

Olga Sarmiento, PhD

Mayo Clinic
Rochester, MN

EZH2 prevents IBD by silencing critical T cell gene networks responsible for the production of pathogenic FOXP3+ cells

Siddharth Singh, MBBS

University of California, San Diego
La Jolla, CA

Impact of obesity on disease course and treatment response in inflammatory bowel diseases

Ryan Ungaro, MD

Icahn School of Medicine at Mount Sinai
New York, NY

Assessing predictors of response to anti-tumor necrosis alpha therapy in early inflammatory bowel diseases patients

Qun Wang, PhD

Iowa State University of Science and Technology
Ames, IA

Targeted delivery of intestinal stem cells to treat inflammatory bowel diseases

Shiyan Yu, PhD

Rutgers University–Newark
Newark, NJ

Role of Paneth cell lysozyme in modulating microbiota colonization and IBD pathogenesis

Friends of the Foundation

The following individuals and foundations have made important and significant contributions to the Crohn's & Colitis Foundation in support of our mission programs. We are deeply grateful to them for their extraordinarily generous gifts.

Visionaries

Lisa and Matt Chanoff
Ellen and Daniel Crown
The Leona M. and Harry B. Helmsley Charitable Trust
The Manners/Coole Foundation in memory of Joanne Melhuish
Carole and Ira Pittelman
Janet and Elvin Price
Jonathan D. Rose, MD, PhD
Liliane and Edward Schneider and Family
Heidi and Chris Stolte
Michelle and Howard Swarzman
Anonymous (1)

Innovators

Marcy and Arthur Falcone
Jenanne Owen Charitable Remainder Unitrust
Molly Porter Drolla Burke Charitable Remainder Unitrust

Pioneers

E. Alan Boettcher CRAT
Ellie Carmody, MD and Daniel Stone
Ann and Jay Davis
Ellen and David Horing
Wilbur May Foundation
Anonymous (1)

Champions

Gwen and David Baker
Rolf Benirschke Legacy Foundation
David R. Clare & Margaret C. Clare Foundation in memory of Margaret Lynne Clare
Cathy and Alessandro DiNello
The Dodson Foundation
The Dorfman Foundation
Kenneth Dunst
Patty and Alex Funderburg
Michael J. Gaughan
Joe Gugger
Robin Kaplan Memorial Fund
Mary Lou and Don Kortz
Kulynych Family Foundation I, Inc.
The Leavitt Family Foundation
Barbara and Matthew LePage
Edward D. & Anna Mitchell Family Foundation

Mary L Riordan Revocable Living Trust DTD 10/27/00
Roddenberry Foundation
Dulcy and Jerry Rosenberg
Ilene Schwartz
Trudi and Christopher Seiwald
Bonnie and Andrew Stern
Linda Tallen & David Paul Kane Educational and Research Foundation
Sara Tayeb-Khalifa and Family
James A. Vaughn Family Trust DTD 4/11/1970
Ali and Alan J. Vaynerchuk
Hannah and Karl Voskuil
Jodi and Charles Yellen
Anonymous (3)

Friends

The Steve M. Agin Memorial Fund
Bonnie and Charles Alter
Monica and Scott Anderson
Rachelle and Howard Balaban
Lisa and Arvinhd Balakrishnan
Louise and Leo L. Benatar
Margot and Michael Benstock
Angela and Robert Biggar
Judi and Phil Bounsall
Ethel Wilson Bowles and Robert Bowles Memorial Fund
The Brewer Family Foundation
Bright Funds Foundation
Nancy and Howard Brown
Johanna and Ryan Caplan
Zane and Brady Carruth
Children's Foundation
Children's Hospital of Philadelphia
Marilyn Chinitz and Piero Pozzi
Becky and Chris Collette
Sally E. Connolly
The Leon and Toby Cooperman Family Foundation
Kitty and Ander Crenshaw
Crohn's Disease Research, Inc. (Dr. Ira and Anita Shafran)
Carolyn and John Crosson
Randi and Joel Cutler
The Derfner Foundation
Donnini-Rudolph Family Foundation
Stephanie and Patrick F. Doyle Family
Peter C. Dozzi Family Foundation
The Samuel R. Dweck Foundation and the Elno Family Foundation
Leshia and Tom Elsenbrook
Linn and Jonathan Epstein
Finkelstein Family Foundation
Flowerree Foundation
Carol E. Ford

Gordon Ford
Allyson and Bill Fox
Frankel Health and Research Foundation
Fulk Family Foundation
Galashiels Fund Limited
Lauren and Steven Geduld
Rollin M. Gerstacker Foundation
Greg Gilbert
The Gillman Family
Tim Goedecker
Lisa and Douglas Goldman Fund
Steven G. Goodman
Joan Hartl
Hellman Foundation
The Herrick Family
Robert B. Hinton, Jr.
Rochelle and David Hirsch
The Stanley and Anita Hirsh Trust
Hittman Family Foundation
Helene Houle
Alissa and Joel Isaacson
Estate of Joseph Russell Iverson
Penny Bursch-Johnson and Dan Johnson
Lisa and Norman Judah
Sandra and Jeffrey J. Justin
Brigitte and Bashar Kalai
Marcia and Ned Kaplin
Judi and Joey Karas
The Louis J. and June E. Kay Foundation, Inc.
Karen and Steven Kay
Susie and Michael Kerr
Susan and Eugene Kestenbaum
Maryellen and Richard Keyser
F.M. Kirby Foundation
Jackie and Arnold Kling
Koret Foundation
Jill and Kurtis Krentz
Kritchman Family Foundation Inc
Virginia and David Lebioda
Stefanie and David Levenson
Bryna Lithman and Arthur J. Epstein
The Luke and Meadow Foundation
Allison and Howard Lutnick
Sari Mass and David Orentreich
Ashley OConnor McCready and Mike McCready
John P. McGovern Foundation
Hannah and Cal McNair
Diane and Stanley Miller
Marcia & Mark Miller Family Foundation
Eve and Stephen Milstein

Marcia Rolfe-Mishaan and Richard Mishaan
Pam and Jeff Mittleman
Tammy and Joe Monk
The Elizabeth Morse Charitable Trust
David and Linda Moscow Foundation
Juliet Moser and Ben Darnell
The Donald R. Mullen Family Foundation, Inc.
Jennifer and Chris Murphy
Patricia and Grib Murphy
Nagin Family Foundation & Francine and Laurance Nagin
Bobbie Nau
Elyse and Michael Newhouse
Alvaro Noboa
Diane and Robert Noelke
Northwell Health
NYU Langone Health
Pauline Arama-Olsten and Stuart Olsten
Elizabeth and Rob Orgel
Lauren and Nick Oschman
Pamela and Edward Pantzer
Patriarch Family Foundation
Gail and Berndt Perl
Lauren and Joseph Pizza
Gary Podell
Colleen and Jim Polk
Gerald T. Proehl
Robert Van Pulley and Family
The Stewart J. Rahr Foundation
Research Foundation of the American Society of Colorectal Surgeons
Phyllis and Sidney Rodbell
Wendell & Doris Rogers Foundation
Carolyn and Marc Rowan
Dora and Steve Rubin
Lauren and Mark Rubin
Tina Hoffman and Geoff Schechter
Lisa and Mark Schneider
Sara and Greg Seifert
Ellen and Steven Shapiro
Cynthia and Bruce Sherman
Karen and Gary Singer
Iris Smith
Gillian and Robert Steel
Elisabeth Straus
Joshua Stumpf
Michele Sweetwood
Flora L. Thornton Foundation
Carmella and Peter Tully
Stephanie and Michael Van Daele
Mary and Tim Walsh
Cathy and Allan Weiss
Tanya Zuckerbrot and Anthony Westreich
Rebecca and Terry Wiler
Faith and David Workman
Adam Yenser
Anonymous (6)

Corporate Supporters

The Crohn's & Colitis Foundation is proud to recognize the generosity of corporations around the world for supporting programs in research and patients and professional education as well as a host of events in communities nationwide. We thank these companies for joining with us in the battle against inflammatory bowel diseases.

Visionaries

AbbVie
Eli Lilly & Company
Gilead Sciences, Inc.
Janssen Biotech Inc.
Takeda Pharmaceuticals U.S.A., Inc.

Innovators

Allergan Plc
Boehringer Ingelheim Pharmaceuticals, Inc.

Pioneers

Celgene Corporation
Genentech, Inc.
Pfizer, Inc.
UCB, Inc.

Champions

Amgen, Inc.
Arena Pharmaceuticals, Inc.
Mortenson Construction
Poo~Pourri
UnitedHealth Group

Friends

Abrams, Fensterman, Fensterman, Eisman, Formato, Ferrara, Wolf & Carone, LLC
AMAG Pharmaceuticals, Inc.
Bank of America
Barnett Capital
BB&T Now Truist
BioBidet
BNY Mellon
Bristol-Myers Squibb Company
Capital Digestive Care
Centene Management Company
Daiichi Sankyo, Inc.
DiaSorin
Dietz & Watson
The Durst Organization L.P.
Edmunds GovTech
Gotham Technology Group, LLC
Insperity

Intercontinental Real Estate Corporation

MeetingAdvice

Meijer, Inc.

MNGI Digestive Health

Nephroceuticals

OWYN

OptumRx Inc.

Parametric Portfolio Associates

RC Andersen, LLC

Seres Therapeutics, Inc.

Shire Plc

Squatty Potty, LLC

Sublimity Therapeutics, Inc.

Texas Digestive Disease Consultants

UPMC

Valero

Media Partners

Outcome Health

Reach MD

Planned Giving: Founders Society

The Crohn's & Colitis Foundation greatly appreciates the generosity and foresight of individuals who have included the Foundation in their estate planning. If you have made estate plans that include the Foundation and would like to share with us, please contact Susan Carriker, director, national advancement & planned giving, at 252-597-5085 or scarriker@crohnscolitisfoundation.org.

Isabel B. Anderson
 Amber and Andrew Backhaus
 Anushree Bag
 Lois Bailey
 Arnold Baker
 Kevin Barnes
 Gila Belsky and Alexander Modell
 Grace Benedikt
 Wendy and Philip Bentlif
 Mary E. Berry
 Alicia and Tim Blank
 Marilyn and Dave Blood
 Susan and John Borzenski
 Judi and Phil Bounsall
 Mikel and Bryce Breitenstein
 Jill Brenneman
 Larry Britsman
 Dona M. Browne
 Rona Budovitch
 Lander Burr
 Joan Canfield
 Patricia Carney
 Susan and Daniel Carr
 Krista Castell
 Bob Checchio
 Jennifer Christensen
 Dennis Ciccone
 Laura Clifford
 Allison Coffey and Michael Ogrysko
 Alex Cohen
 Sue Cohn and Scott Weinstein
 Becky and Chris Collette
 Ellen M. Collins
 Phil Conley
 Michelle Covington
 Laura Cridlebaugh
 Gerald Croan
 Carolyn and John Crosson
 Clara and Brian Cruden
 Betsy and Phil Culberson
 Marcia Greenburg Davis

Mary Louise Davis
John Dayton
Martha and Dale Delano
Vera Deutsch
Cathy and Alessandro DiNello
Kathryn Dins
Rhondell and Glenn Domilici
Virginia and Kenneth Dunst
Georgette Edkins
Irene and Bernard Eizen
Karen English
Mary Jane Evans
Karen M. Findora
Amy Finkelstein
Alan B. Finn
Dean Fiorelli
Pattie Moxham-Fisher and Michael Fisher
Elise Foland
Evelyn Fox
Martha S. Frank
William Frankenstein
Mary and Timothy Franklin
Linda Fraser
Michele Freadman
Diane Froot
Brenda Fudell
Patty and Alex Funderburg
Arlene Galbert
Gary Garfield
Robert B. Garman
Deborah and Vance Gibbs
Annette and Leonard Gilman
Deborah P. Goldberg
Diane and Donald Goldfarb
Steven G. Goodman
Mona M. Gordon
Randi R. Gordon
Miriam Gottlibb
Julie Grable
Martina Gramer
Debbie and Greg Greenberg
Lorri Greif
Marlene Gronholz
Fanny Gruszecki
Paulette and Donald Gutt
Jill and Michael Hainkel
Bruce Hartzmark
Mary Sue and Robert Hawk
Daniel L. Hawkins
Barbara L. Heidecker

Paula and Gary Hilbert
Deanne Hill
Ralph D. Hillman
Herbert Hirsch
Hanna L. Hombordy
Nancy and William Homeyer
Celia J. Honig
Michele Kissous-Hunt and Daniel Hunt
Dan Johnson
Wendy Johnson
Sharon and Sanford Kahn
Dawne and Mark Kaufman
June E. Kay
Millicent Kellner
Beth King
Michael Klein and Jeffrey Ward
Steve R. Koonin
Mary Lou and Don Kortz
Julie and Michael Koss
Jill and Kurtis Krentz
Eric A. Landau
Renee Landau
Gloria Langos
Patricia Lapedus
Robert M. Levi
Helen Levin
Shelly and Ronald Levy
Michael Libys
David Linemeyer
Lucia A. Loding
Adeline Luckman
Juanita and Roger Ludke
Judith Ludwig Levine
Harvey S. Luterman
Rusty Maddox
Theodora Mahoney
Marc Marasco
Margaret Marasco
Carolyn Martin
Thomas G. Martin
Patti M. Masarek
Nancy J. McNabb
Henry J. Meyer
Jacquelin Mittal
Shelby Modell
Tammy and Joe Monk
Cynthia and John Monter
J. Roger Morrison
Martha Morrison
Ann Moslowitz

Philip S. Muller
Charles R. Munsey
Joan and Mark Murray
Barbara and Robert Murray
Marcy and Jeremy Nanus
Barbara and Bob Nieder
Rose Marie Nilsson
Agnes E. Nixon
Debra and Peter O'Connor
Jeana and Paul Ogren
Maria Oliva-Hemker
Annclaire Oscar
Carole A. Ostroff
Sarah-Katharine Owen
Gilbert Pallen
Renee F. Parente
Gilbert B. Pauley
Santos G. Perez
Neil Pessin
George Pierson
Christine Pitt
Kathryn Pizza
Mark Plostock
Christine Pollock
Robert Van Pulley
Rex H. Rathbun
Rosalyn C. Richman
Mary L. Riordan
Carol and Seymour Roberts
Robin M. Roger
Mona J. Rosenberg
Marc Rosen
Joan and Steve Rosenfeld
Susan and Joel Rosh
Warren Ross
Cynthia Roth
Carol and Arnold Rudoff
Aimee and Frank Russomano
Selma P. Ryave
Carolyn W. Sampson
Judy and Richard Saphir
George J. Saunders
Linda Saunders
Deborah Schenker
Lisa and Mark Schneider
Ronald M. Schwartz
Frank Scottie
Sally and Larry Sears
Carol and Robert Sexton
Lanie and Gary Sinderbrand

Susan Sivitz
Betty Smith
Judith A. Smith
George W. Smyth
Kim and Scott Snapper
Sheldon Sokol
Pip Spandorfer
John S. Spiecker
Pam A. Staats
Sylvia D. Steinbrock
Bonnie and Andrew Stern
Rebecca and Eric Stone
Beverly Taubel
Jane and Kenneth Thomas
John B. Thompson II
Julie Townsend
Jeff Tupper
Lawrence Vandervoorn
Salvatore Varveri
Kathryn Vaughan
Helene and Joseph Victor
Sara Jane and Martin Victor
Cynthia and Bruce Wagner
Laura I. Walker
Rene Warren
Judith and Arie Weissman
Bob Whitehold
Ray Whitaker
Marilyn and John Whitcher
Nancy A. Wiltgen
Linda Windsor
John W. Wine
Barbara Wolfe Stern
Mark S. Yanocho
Jodi and Charles Yellen
Phoebe and Charles Yochim
Anonymous (5)

2019 Board of Trustees

Officers:

John Crosson
Board Chair
Los Angeles, CA

Brent Polk, MD
NSAC Chair
Los Angeles, CA

David Rubin, MD
NSAC Chair-Elect
Chicago, IL

Andrew Stern, Esq.
Secretary
Sea Girt, NJ

Robert "Van" Pulley
Treasurer
McLean, VA

Michael Osso
President & CEO (non-voting)
New York, NY

Robert Territo
COO/CFO (non-voting)
Middletown, NJ

Co-Founders:

William Modell (deceased)
Shelby Modell
Long Island, NY

Irwin Rosenthal (deceased)
Suzanne Rosenthal (deceased)
Long Island, NY

National Trustees:

Amber Backhaus
Minneapolis, MN

Noël Brown
New York, NY

Jason Burr
Oneonta, NY

Christopher Collette
Excelsior, MN

The Hon. Ander Crenshaw
Jacksonville, FL

Alessandro DiNello
Birmingham, MI

Alex Funderburg
Charlotte, NC

Paula J. Hilbert
Basking Ridge, NJ

Michele Kissous-Hunt, PA-C
New York, NY

Donald Kortz
Cherry Hills Village, CO

Joseph Monk
Bloomington, IL

Mark Murray, PhD
Seattle, WA

Marcy Beth Nanus
Upper Saddle River, NJ

Maria Oliva-Hemker, MD
Baltimore, MD

Jennifer O'Neill
Pleasantville, NY

Joel Rosh, MD
Morristown, NJ

Cynthia Roth
Morgantown, WV

Frank Russomano
Ambler, PA

Eric Stone
San Francisco, CA

Troy Vollertsen
McLean, VA

Jodi F. Yellen
New York, NY

Crohn's & Colitis Foundation, Inc.

STATEMENT OF FINANCIAL POSITION

As of December 31, 2019, with summarized comparative information for 2018

	2019	2018
ASSETS		
Cash and cash equivalents	\$ 3,100,451	\$ 12,365,023
Pledges receivable, net	13,001,335	9,849,767
Bequests receivable	521,377	270,432
Prepaid expenses and other assets	4,344,565	4,315,901
Investments	20,238,195	17,450,761
Reinsurance contracts	228,669	240,848
Charitable remainder trusts	1,664,654	50,444
Fixed assets, net	2,175,003	2,039,912
Total assets	\$ 45,274,249	\$ 46,583,088
LIABILITIES AND NET ASSETS		
LIABILITIES		
Accounts payable and accrued expenses	\$ 4,791,819	\$ 5,219,133
Research grants payable	25,547,248	27,522,249
Deferred rent	335,932	378,307
Deferred revenue	5,552,232	4,167,778
Reinsurance contracts	228,669	240,848
Total liabilities	36,455,900	37,528,315
Commitments (Note 8)		
NET ASSETS (DEFICIT)		
Net assets without donor restrictions	(5,307,069)	(2,111,482)
Net assets with donor restrictions	14,125,418	11,166,255
Total net assets	8,818,349	9,054,773
Total liabilities and net assets	\$ 45,274,249	\$ 46,583,088

The following information has been derived from our audited financial statements. For a complete copy of the audited financial statements and report from our independent certified public accountants, please visit <https://www.crohnscolitisfoundation.org/about/our-financials>

Crohn's & Colitis Foundation, Inc.

STATEMENT OF ACTIVITIES

For the year ended December 31, 2019, with summarized comparative information for 2018

	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	2019 Total	2018 Total
OPERATING CONTRIBUTIONS, GRANTS AND OTHER INCOME AND SUPPORT				
Contributions and grants:				
Contributions and grants from individuals, foundations and corporations	\$ 13,463,518	\$ 19,934,671	\$ 33,398,189	\$ 35,888,955
Contributed services and airtime	7,996,354	-	7,996,354	8,140,353
Special events revenue	36,083,192	-	36,083,192	36,311,942
Less: Costs of direct benefits to donors	(7,316,025)	-	(7,316,025)	(7,616,317)
Net special events revenue	28,767,167	-	28,767,167	28,695,625
Federated campaigns	1,184,804	-	1,184,804	1,355,181
Bequests	2,473,718	-	2,473,718	651,559
Total operating contributions and grants	53,885,561	19,934,671	73,820,232	74,731,673
Other income:				
IBD Plexus membership revenue	4,765,830	-	4,765,830	4,330,414
Program service fees	509,670	-	509,670	503,862
Investment return designated for operations	1,119,881	-	1,119,881	302,943
Federal grant revenue	581,443	-	581,443	418,583
Royalties	416,509	-	416,509	312,439
Other	869,326	-	869,326	952,494
Total other income	8,262,659	-	8,262,659	6,820,735
Total operating contributions and other income	62,148,220	19,934,671	82,082,891	81,552,408
Net assets released from restrictions	16,975,508	(16,975,508)	-	-
Total operating contributions, grants and other income and support	79,123,728	2,959,163	82,082,891	81,552,408
OPERATING EXPENSES				
Program services:				
Research	29,510,518	-	29,510,518	28,728,120
Health professional education and public information	39,319,124	-	39,319,124	38,589,063
Total program services	68,829,642	-	68,829,642	67,317,183
Supporting services:				
Management and general	10,189,131	-	10,189,131	9,918,401
Fundraising	4,871,325	-	4,871,325	4,741,895
Total supporting services	15,060,456	-	15,060,456	14,660,296
Total operating expenses	83,890,098	-	83,890,098	81,977,479
Changes in net assets from operating activities	(4,766,370)	2,959,163	(1,807,207)	(425,071)
Non-operating activities:				
Investment return, net of amounts designated for operations	1,564,130	-	1,564,130	(1,093,293)
Changes in remainder trust valuations	6,653	-	6,653	(3,721)
Total non-operating activities	1,570,783	-	1,570,783	(1,097,014)
Changes in net assets	(3,195,587)	2,959,163	(236,424)	(1,522,085)
Net assets, beginning of year	(2,111,482)	11,166,255	9,054,773	10,576,858
Net assets, end of year	\$ (5,307,069)	\$ 14,125,418	\$ 8,818,349	\$ 9,054,773

The following information has been derived from our audited financial statements. For a complete copy of the audited financial statements and report from our independent certified public accountants, please visit <https://www.crohnscolitisfoundation.org/about/our-financials>



Learn more at crohnscolitisfoundation.org

The Crohn's & Colitis Foundation is the leading non-profit organization focused on both research and patient support for inflammatory bowel disease (IBD). The Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life for more than 3 million Americans living with IBD. Our work is dramatically accelerating the research process through our database and investment initiatives. We also provide extensive educational resources for patients and their families, medical professionals, and the public.