







## Working Together for Better Outcomes

IBD Qorus™, the Crohn's & Colitis Foundation's national quality of care initiative, enables physicians to provide their patients with the best possible care while simultaneously testing ideas that could eventually help people with IBD all over the country.

Qorus sounds like "chorus," and that's no accident: IBD Qorus is a collaboration that brings together the voices of clinicians, researchers, and patients. Nearly 30 academic centers, community health clinics, and private health practices are participating across the country, and the program continues to grow. By the end of 2020, we expect to have more than 60 participating centers.

### Here's how it works:

-  Enrolled patient is notified about an upcoming doctor's appointment.
-  Patient logs into their dashboard to complete a pre-visit questionnaire, which allows them to share information about current symptoms and primary concerns.
-  During the appointment, doctor and patient review the dashboard together, using it to guide them as they discuss any changes, reassess the current medication regimen, and make decisions about treatment plans.
-  Doctor enters information about each patient, which is then pooled into a database containing details of thousands of patients.
-  Participating doctors connect via monthly conference calls and in person twice a year to review the pooled information and to discuss how to improve the care they provide to patients. 

### FOUNDATION IMPACT

#### 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.



## The Power of Strong Partnerships

IBD Qorus brings doctors and patients together for better care. Here are two stories:

**Clinician: Gastroenterologist John Betteridge, MD, director of IBD services at Regional GI in Lancaster, PA**

How I use IBD Qorus: Every month, our team participates in a conference call for clinicians and researchers involved in the program, and twice a year we meet in person. Whenever we connect, we talk about what we want to improve, brainstorm how to do it, and discuss how to implement it in our practices.

The biggest impact: Using IBD Qorus has already helped keep patients out of the emergency room. During one of the provider calls, we came up with the idea of creating high-risk patient lists. In my practice, we focused in on the five highest-risk patients—we call them the "high five"—and now they get a phone call from a nurse every week to see how they're doing. If they're having any problems, we talk about making proactive changes, rather than waiting for them to show up in the ER.


**Patient: Emily Keith, Crohn's disease patient in Portland, Oregon**

How I use IBD Qorus: The main way I engage in IBD Qorus is through a pre-visit survey that's emailed to me before an upcoming appointment. That way, when I walk into my doctor's office, he already has a good idea of what I'm experiencing.

I also really appreciate that I can log in to the IBD Qorus dashboard and add any questions, comments, or concerns I have, including those that aren't directly

related to my current symptoms. That's especially important to me right now because I've been symptom-free for about a year.

The biggest impact: Before IBD Qorus, my doctor would just ask me if I was having any symptoms; I'd say no, and that would be the end of the conversation. Now that I'm encouraged to bring up additional comments and questions, we have more meaningful interactions about the future of my care.

We're having more in-depth conversations, and I've become more optimistic about my future as someone with Crohn's. It's very empowering. 

## Help Us Change Lives

The innovative projects described in this edition of *Under the Microscope* are just a few of our endeavors designed to accelerate the pace of research and uncover new treatments and cures for IBD as quickly as possible. While our ultimate vision is a world without Crohn's and colitis, we're equally committed to helping patients who are struggling with the physical and emotional toll of living with IBD right now, but we can't do any of it without your help.

**Help to create a better tomorrow for those suffering from IBD by making a gift to the Crohn's & Colitis Foundation today. To make a contribution to the Foundation, please visit [crohnscolitisfoundation.org/microscope](http://crohnscolitisfoundation.org/microscope).** 



Learn more at [crohnscolitisfoundation.org](http://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.


### Fast Facts about IBD Qorus

- Uses sophisticated population health tools to track symptoms, medication response, and complications in adults with IBD.
- Generates tools, such as high-risk patient lists, that physicians can use right away to provide better care.
- Allows clinicians to consult and brainstorm with a network of other providers dedicated to improving care for IBD patients.

## Join the Founders Society

The Founders Society honors those who strengthen the vision and commitment of the Crohn's & Colitis Foundation by including the Foundation in their estate planning. As a member of the Founders Society, you will be listed in our Annual Report and receive privileged information and updates about our mission advancement and research progress. We invite you to join the Founders Society today.

**If you're interested in making a planned gift or have questions regarding planned giving and the Founders Society, please contact Allison Coffey at [acoffey@crohnscolitisfoundation.org](mailto:acoffey@crohnscolitisfoundation.org).** 



# Under the Microscope

GROUNDBREAKING RESEARCH AND SUPPORT FOR PEOPLE WITH IBD


CROHN'S & COLITIS FOUNDATION

FALL 2019

## A Roadmap for the Future

### Driving New Research and Meeting Patients' Needs

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## Focusing Our Efforts

The Foundation's 2019 update of *Challenges in IBD Research* highlights key knowledge gaps and outlines priority research areas to target.

Every few years, in an effort to identify areas of research that could advance us more quickly toward our mission, we develop a detailed report called *Challenges in IBD Research*. The latest version appears in the supplement to the May 2019 issue of *Inflammatory Bowel Diseases*, the Foundation's peer-reviewed journal for healthcare professionals.

The new report is a highly researched document developed with input from approximately 100 stakeholders, including scientists, clinicians, patients, and caregivers.

"*Challenges in IBD Research* provides direction so that we can focus efforts to drive the continuum from new discovery to optimal care for all patients," says Caren Heller, MD, MBA, chief scientific officer for the Foundation. "This not only influences our funding priorities for the next few years, it also influences priorities for independent researchers." Here's a look at the five key areas we have identified:

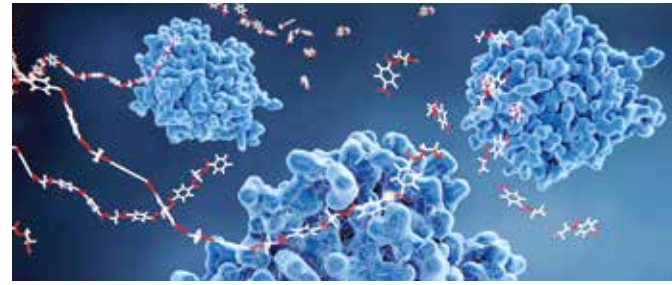
### 1 Laboratory research that sets the stage for later patient trials

Before scientists can develop new treatments, they must first understand more about why inflammatory bowel disease occurs and how it progresses. Laboratory research has the potential to answer crucial questions, such as:

#### **What mechanisms are responsible for maintaining the architecture of the intestinal wall?**

The cells of the intestinal wall are joined together by junctions that are supposed to keep out bacteria and viruses, but those junctions are compromised in people with IBD. We need to know why.

Thanks to the Foundation's Genetics Initiative, scientists recently discovered the function of a gene that produces a protein that helps to maintain the integrity of these junctions. Now they're aiming to learn more about how these junctions are controlled. "The goal isn't just to improve symptoms, but to actually restore the intestinal wall," says Andrés Hurtado-Lorenzo, PhD, senior director of translational research for the Foundation.



#### **Why do 50% of patients develop complications like fibrosis?**

Scientists believe that there are specific genetic mutations and defective proteins that, together with environmental factors, may explain how the disease will progress in a patient. The Foundation is currently funding work that uses stem cell technology. This technology will transform blood samples from patients into three-dimensional "mini guts." Through this, we can learn more about who is most likely to develop fibrosis (a buildup of collagen-containing scar tissue in the intestines that can lead to strictures).

### 2 Environmental triggers

Your genes do not provide the full story when it comes to IBD. For instance, if one identical twin has IBD, there's only a 50% chance that the other will also develop it. Meanwhile, IBD seems to be occurring in geographic areas where it used to be very uncommon. To find out why, we need to know the following:

#### **Which environmental factors are most important?**

We are currently funding research to investigate the impact of diet, psychological stress, and tobacco use on IBD. We are also learning more about the impact of exposure to certain viruses.

#### **What happens when someone susceptible to IBD is exposed to an environmental trigger?**

Exposure to tobacco, for instance, may cause changes in your gut microbiome, but how do those shifts lead to an increased risk of IBD? We need to understand the mechanisms at cellular, microbial, and molecular levels to be able to develop preventive and therapeutic approaches.

### 3 Novel technologies

In the not too distant future, you might be able to wear a bracelet that tells you what's going on in your intestines or swallow a "hydrogel" pill that is programmed to deliver medicine directly to sites of inflammation in your gut (instead of traveling through your bloodstream). These are some of the innovative

engineering approaches that have the potential to change how IBD is managed.

The Crohn's & Colitis Foundation is supporting projects that use cutting-edge bioengineering technology to answer some important questions:

#### **How can we learn about the status of a patient's disease without making them undergo an invasive procedure?**

"Sometimes patients feel well, but if you look inside the intestines, there's a lot of damage," says Hurtado-Lorenzo. At the moment, the only way to reliably know what's going on in the gut is to do an invasive colonoscopy. Biosensors could change that. In addition to the above-mentioned bracelet, the Foundation is funding research into a biosensor capsule that patients would swallow. Such a capsule could detect inflammatory substances that reflect the health status of your gut.

#### **How can doctors tell whether narrowing in the intestines is fibrosis?**

If inflammation alone is causing the narrowing, it might be addressed with medication; if fibrosis is to blame, surgery is often needed. But right now there's no reliable, minimally-invasive way to determine the root cause. The Foundation is funding research to evaluate whether photoacoustic imaging—which uses a combination of lasers and sound waves—can be effectively used to distinguish between fibrosis and narrowing caused only by inflammation.

### 4 Personalized medicine

Treatment is not one-size-fits-all; at the moment, predicting who will respond well to a treatment is largely a guessing game. In order to offer a more personalized approach, we need answers to the following questions:

#### **Which genetic mutations or other biological characteristics suggest that a patient would benefit from one drug rather than another?**

This type of personalized approach is already being employed in other diseases. If it can be applied to IBD, it would dramatically improve patient outcomes.

#### **How can we predict whether a newly-diagnosed patient is likely to face complications?**

If you knew that frequent flares or fibrosis were on the horizon, it would make sense to immediately start treatment with a more powerful drug. The flip side is that if the course of a patient's disease is likely to be

mild, it would be wiser to stick to gentler, less expensive treatments with fewer side effects. The Foundation has provided funding to PredictImmune to carry out an observational trial in the United States to see whether a blood test that checks for a gene pattern can accurately predict, at the time of diagnosis, which patients are most likely to have multiple relapses. We are also continuing to fund the Pediatric RISK Stratification Study, in order to identify factors that can be used to predict who will develop serious complications requiring surgery.



### 5 Clinical research in real-world settings

So-called pragmatic studies can move research along faster and at less cost than traditional clinical trials, in part because participants don't have to meet highly restrictive criteria. "Pragmatic trials allow clinicians to do studies in their clinical practice—in the real world," says Alandra Weaver, director, quality of care & clinical research programs.

In the next few years, pragmatic trials may help us to gain insight into:

#### **How can we provide better pain management for people with IBD?**

Do we need better drugs, or just a different approach? Pragmatic trials can be used to determine whether assigning patients to a team of healthcare providers—a gastroenterologist, pain management specialist, and mental health professional—would improve patient outcomes.

#### **How many people actually have IBD?**

In an effort to better grasp the current incidence and prevalence of IBD, the Foundation is using funding from the Centers for Disease Control and Prevention (CDC) to analyze insurance claims data, as well as analyzing patterns of care in newly diagnosed patients using data from Improve Care Now and from the Foundation-supported Study of a Prospective Adult Research Cohort in IBD (SPARC IBD).

## A Patient-Centric Approach

Each of the five working groups that developed the current *Challenges in IBD Research* included at least one patient representative. Texas resident Ashley Guillory explains why she got involved and what she got out of it.

Since being diagnosed with ulcerative colitis about five years ago, I've gained a greater appreciation for the benefits of including the patient perspective in scientific work. I was assigned to the *Challenges* working group that focused on novel technologies, and I appreciated having a unique opportunity to help IBD clinicians and researchers understand more about what living with IBD is really like.

In our working group, I realized that there was a disconnect between how experts and patients view certain symptoms and medication side effects. Personally, I suffer with anemia a lot—I feel very tired, experience a lot of brain fog, and have a hard time getting through the work day. A doctor would want to resolve the underlying problem, but it can take weeks or months after increasing iron supplements to notice a difference, and I want to feel better now.

The best part of working on *Challenges* was learning about the cutting-edge work that's being done in this field. There are so many new avenues being explored for testing, disease monitoring, and medication delivery, and, as a patient, that's really exciting. I know the concepts being investigated today aren't going to be available to help me tomorrow, but they very well might in 10 years.

### FOUNDATION IMPACT

**Leveraging Years of Major Foundational Research Investments**  
Our past research investments in important areas, such as genetics and the microbiome, are paying off.

### Fast Facts about Challenges in IBD Research

- An in-depth Foundation report establishing our funding priorities for the next five years. It has been issued periodically since 1990.
- Identifies key gaps in IBD research and potential ways to address them.
- The version published in 2019 includes input from 100 stakeholders, including patients, caregivers, scientists, and clinicians.
- Serves as a research roadmap for the IBD community at large and covers adult and pediatric research from the bench to the bedside.

### FOUNDATION IMPACT

#### **Accelerating the Pace of Research**

We are speeding up the development of breakthroughs by supporting unique projects and innovative solutions that have the potential to change the lives of people with IBD.