UNITING TO CURE: 2019 RESEARCH ACCOMPLISHMENTS

In 2019, the Foundation invested $28 million in research, funding nearly 250 multi-year and one-year studies—a total investment of $384 million since our inception.

LEVERAGING YEARS OF FOUNDATIONAL RESEARCH INVESTMENTS

MICROBIOME INITIATIVE
A multi-institutional project to identify, compare, and analyze how intestinal microbes and their metabolic byproducts play a role in IBD in hopes of one day developing cures.
- Discovered a type of fatty acid that shows an increase in the stools of IBD patients and could shift a healthy microbiome into an IBD-like state
- Demonstrated that two genetic mutations linked to IBD drive colonization of disease-causing bacteria in the gut and the production of inflammation-causing molecules

GENETICS INITIATIVE
A research initiative to study the genetic component of IBD and find gene pathways that may help in the design of new IBD medications.
- Created an unprecedented model, where “mini guts” are cultured in a petri dish and engineered to carry IBD gene variants using a cutting-edge gene editing technology. This will aid in the identification of new therapeutic approaches toward customized, precision medicine.
- Identified 30 new drug-like molecules that could decrease PAI-1, a protein that is elevated in many IBD patients

PEDIATRIC RISK STRATIFICATION STUDY
The largest, new-onset study completed on pediatric Crohn's disease patients.
- Centralized reading of radiology tests led to more accurate classification of complications in RISK-enrolled patients
- Used artificial intelligence (AI) to discover four additional genetic signatures that may predict complications at diagnosis and response to anti-TNF treatment
ACCELERATING THE PACE OF RESEARCH & CATALYZING CRITICAL RESEARCH IN NEW DOMAINS

FOUNDATION FUNDING SUPPORTED RESEARCH INVESTIGATING:

- Light-activated sealants that stick to wet surfaces and have potential to treat fistulas
- Wearable bracelet that can detect inflammation-associated signals in sweat
- Role of genes and microbes in the development of intestinal fibrosis using a new “guts-on-a-chip” model
- New method to detect viral exposures in the blood and their association with flare-ups in pediatric Crohn’s patients
- Blood test to predict, at the time of diagnosis with IBD, whether a patient is at high or low risk for aggressive disease
- Engineering of probiotic bacteria that may detect IBD-associated intestinal inflammation
- New biomarker to measure the relationship between higher psychological stress and frequency of flares in UC patients
- Ideas proposed by researchers to address how diet affects IBD, particularly at the individual patient level

INSPIRING & ENGAGING PATIENTS
Contributing data and biosamples to accelerate research

IBD PLEXUS®
The largest and most comprehensive data and research information platform in IBD that enables researchers from industry and academia to cut years off the research process, as we search for better treatments and cures.

- Over 70 sites contributing biosamples and/or data linked through IBD Plexus, with 15 medical centers newly added
- Increased data from SPARC IBD and IBD Qorus® cohorts by over 50%, to over 7,000 adult patients
- Grew biobank to 100,000 biosamples, a 30% increase from last year
- IBD Plexus was recognized as a modern registry by the FDA and was one of three organizations selected to participate in an FDA Real-World Evidence Program using the FDA MyStudies App. Using this open-source device and data storage system, we are piloting IBD PROdigy, a digital tracker, through our SPARC-IBD cohort.

IBD PARTNERS®
A patient-powered research network that connects patients and researchers, and allows patients to ask questions, propose research ideas, and share their experiences with IBD. This data is contributed to the IBD Plexus platform.

- Based on patient-reported data collected by IBD Partners, findings have been shared with the scientific community through 41 manuscripts and 52 abstracts to date.
UNITING TO CARE: 2019 EDUCATION, SUPPORT, & ADVOCACY ACCOMPLISHMENTS

In 2019, we made over 2 million connections through our education, support, and advocacy programs, a 40% year-over-year increase.

BUILDING RESILIENCE & EMPOWERING THE IBD COMMUNITY

EDUCATION

- **400,000** Facebook Live educational video views
- **340,420** views of online IBD education videos and webcasts (+13%)
- **243,860** interactions with the Clinical Trials Community educational resources (+39%)
- **35,000** connections were made with medical professionals through live and online education
- **11,000** patients and family members attended live education programs (+43%)
- **1,930** healthcare professionals reached through local live professional education programs (+36%)

NEW RESOURCES

- **37,000** engagements with mental health resources, including new videos that share young adults’ perspectives on mental health challenges in IBD
- **25,000** visits to the newly launched online resources designed to help everyone navigate health insurance options and financial assistance programs

SUPPORT

- **216,000** unique visitors accessed the Community website
- **12,000** inquiries from patients, caregivers, and providers answered through the IBD Help Center
- **9,100** patients and family members participated in in-person support groups (+9%)
- **2,000** constituents engaged through Facebook support groups
- **80** peer-to-peer matches made through the Power of Two program
INSPIRING & ENGAGING THE COUNTRY’S LARGEST IBD COMMUNITY

ADVOCACY

- **8,088** emails from the Foundation’s volunteers sent to legislators through the growing Advocacy Network volunteer list
- **210** state and federal legislators signed to public policy asks
- Passage of the **Safe Step Act** into law in Ohio, Washington, and Georgia
- Introduced a **federal step therapy reform bill in the U.S. Senate** for the first time (S.2546–Safe Step Act)

PEDIATRICS

- **38,000** unique views on the Teen Website (justlikemeIBD.org)
- **33,000** unique views on the Campus Connection website (+31%)
- **1,600** engagements on the pediatric transition self-assessment tool for teens (+20%)
- **1,181** pediatric patients attended Camp Oasis across 12 locations