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**CCFA Launches Development of World's Largest Research Database for
Crohn's Disease and Ulcerative Colitis:
First Ever Multi-Dimensional Knowledge Platform to Integrate
Scientific, Medical and Patient Data**

- *More than 40,000 patients to participate*
 - *\$17.5 million lead funding committed by Helmsley Charitable Trust*
- *Deloitte Consulting LLP, Thermo Fisher Scientific will host major components*

New York, NY—The Crohn's & Colitis Foundation of America (CCFA) announces a three-year, \$17.5 million grant from The Leona M. and Harry B. Helmsley Charitable Trust to establish an integrated knowledge platform designed to centralize and aggregate patient information – with linked biosamples – across multiple research efforts. The new initiative, called IBD Plexus, is designed to speed progress toward precision medicine through novel research, leading to better diagnostics, treatments and, ultimately, cures for Crohn's disease and ulcerative colitis, also known as inflammatory bowel diseases (IBD).

IBD Plexus (named for its complex network of parts) involves every IBD stakeholder, including academic and industry researchers, patients of all ages, and clinicians and other healthcare providers. The initiative forms and nurtures collaboration and cooperation among stakeholders, and is powered by their common drive toward better care, treatments and a cure.

James Lewis, MD, MSCE, Professor of Medicine and Clinical Epidemiology at the University of Pennsylvania, led a two-year discovery and planning process to conceptualize and design IBD Plexus, based on a "research exchange" model. "We have seen breakthrough discoveries in IBD, but progress toward identifying effective, personalized treatments and potential cures has been slow," he explained. "There is a strong and growing demand from both the medical and patient communities for new therapies that will keep IBD in remission, better tools to help select the right therapy for the right patient, and practical ways to reduce variability in the quality of care for individual patients."

The multi-component IBD Plexus includes a biobank; registries to capture clinical, patient-reported, and biosample data (genetic, genomic, microbiomic, etc.); and a large data management platform to house, organize, aggregate and disseminate data for research. Within three years, databases will be combined or built with clinical information on more than 40,000 Crohn's and colitis patients, along with genomic and microbial profiles from 7,000 patients who will be followed over time.

“We are extremely grateful to the Helmsley Charitable Trust for their vision and generosity,” said CCFA’s Chief Scientific Officer, Caren Heller, MD, MBA. “IBD Plexus provides the infrastructure and capacities to dramatically shift the paradigm, and facilitate and accelerate IBD research.”

“This project embodies the Helmsley Charitable Trust’s commitment to establishing close and productive partnerships with the organizations that offer the greatest potential to impact the areas that we support,” said Helmsley Charitable Trust trustee Sandor Frankel. “We are thrilled at the prospects of what this important new research platform can achieve in advancing therapies, care and the path to a cure for those with IBD.”

“Today’s advances in information technology and the lower cost of genomic sequencing are providing new tools with which to investigate and cure IBD. We’re proud to be supporting the scientists, clinicians and patients who will link and study data for insights into the causes of Crohn’s disease. With IBD Plexus, the field will have the highly powered, sophisticated tools it needs to get to a cure, and until then better treatments and patient care,” said Jim O’Sullivan, Program Director for the Helmsley Charitable Trust’s IBD and Crohn’s Disease Program.

IBD Plexus utilizes new technology that enables scientists, researchers, clinicians and patients to capture, organize and *share* large amounts of data on individuals with IBD, and – critically – to link and mine this data for insights into the causes of and potential treatments and a cure for, Crohn’s disease and ulcerative colitis. Currently, data gathering activities occur sporadically and are uncoordinated and unsustainable, as the data itself most often lies in a silo that is inaccessible to others.

“In isolation, when not linked to each other, these various data types are of limited value in helping to increase our understanding and develop better treatments and cures for IBD,” elucidated Scott Snapper, MD, PhD, Director of Boston Children’s Hospital’s Inflammatory Bowel Disease Center, and Chairman of CCFA’s National Scientific Advisory Committee. “However, brought together in an organized and comprehensive way and analyzed using sophisticated bioinformatics technology, this pool of data should yield extraordinary new opportunities for IBD research as well as for patient disease management and care, and, ultimately, cures for IBD.”

CCFA has selected Deloitte Consulting LLP to develop IBD Plexus’ big data management and analytics platform, in close collaboration with stakeholders across the research community. “Deloitte’s collaboration with CCFA involves a new way of thinking about, and engaging in, research into disease and patient care,” said Beth Meagher, Federal Strategy Leader, Deloitte Consulting LLP. “IBD Plexus will serve as a model for other organizations.” Nitin Mittal, Life Sciences and Healthcare Analytics Leader, Deloitte Consulting LLP, added, “Our work with CCFA will demonstrate the power of data analytics and data-driven insights in accelerating research. Utilizing Deloitte’s “ConvergeHEALTH Miner” suite of analytics, we are striving to enhance innovation and create strategies to advance initiatives and programs that improve patient health outcomes.”

IBD Plexus' biobanking services are being provided by Thermo Fisher Scientific, a leader in critical biologic material management, through its Fisher BioServices brand. Fisher BioServices operates an extensive network of biobanking facilities, and manages hundreds of millions of samples worldwide. "We employ cutting-edge biobanking solutions and information technology for leading research and therapy development organizations worldwide," said Dennis Barger, vice president and general manager, BioServices, for Thermo Fisher Scientific. "We are pleased to participate in CCFA's IBD Plexus, and join in their grand vision of delivering personalized medicine to patients. Our services will enable a global network of researchers to accelerate effective treatment development and discovery of a cure for IBD."

Crohn's disease (CD) and ulcerative colitis (UC) are painful, and thus far medically incurable chronic illnesses that belong to a group of conditions known as inflammatory bowel disease (IBD). It is still unclear why people get IBD, there is no known cure yet, and the incidence of IBD is increasing at an alarming rate in nearly all parts of the world. An estimated 1.6 million Americans (and approximately 5 million people worldwide) suffer from IBD.

About CCFA

The Crohn's & Colitis Foundation of America (CCFA) is the largest voluntary non-profit health organization dedicated to finding cures for Inflammatory Bowel Diseases (IBD). CCFA's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults who suffer from these diseases. The Foundation works to fulfill its mission by funding research, providing educational resources for patients and their families, medical professionals, and the public, and furnishing supportive services for those afflicted with IBD. CCFA has funded more than \$250 million in research. In the past five years, researchers have made significant inroads in the study of genetics, as well as the gut microbiome. For more information, visit www.ccfa.org, call 888-694-8872 or email info@ccfa.org.

About the Helmsley Charitable Trust

The Leona M. and Harry B. Helmsley Charitable Trust aspires to improve lives by supporting exceptional nonprofits and other mission-aligned organizations in the U.S. and around the world in health, selected place-based initiatives, and education and human services. Through its IBD and Crohn's Disease Program, the Trust has allocated nearly \$160 million to institutions in the United States, Canada, Europe, and Israel. Across the program, nearly 100 Helmsley-funded investigators are working to understand both how human genetics and the gut microbiome can cause and exacerbate IBD and bring those insights into the development of new treatments and a cure. For more information, please visit www.helmsleytrust.org.