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### **An Update on the CCFA Partners Internet Cohort Study**

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**Background and Aims:** Most observational studies of inflammatory bowel disease (IBD) rely on administrative data and/or medical records of subjects followed at tertiary care centers. Yet, many research questions require data captured directly from the patient such as diet, adherence, quality of life, and other patient-reported outcomes. To address this gap, in June 2011 we developed an internet-based cohort of patients with IBD in collaboration with the Crohn's and Colitis Foundation of America (CCFA). In this abstract, we present the current status of this project.

**Methods:** We established the CCFA Partners cohort of adults with IBD by recruiting through the CCFA email roster and various promotional activities developed with the assistance of the CCFA marketing department including the foundation website, social media outlets, newsletters, chapter events, and paid advertising. Respondents complete a baseline survey that includes questions about disease history, medication use, disease activity, quality of life and other patient reported outcomes, and health behaviors including adherence and prevention. Participants are invited to complete follow-up surveys every 6 months. Quarterly emails are used to inform participants about the status of the cohort, and deliver educational messages. Engagement of and collaboration with the IBD scientific community was actively sought through the development of an open and transparent ancillary studies process.

**Results:** As of August 26, 2012, 11743 individuals with self-reported IBD have joined CCFA Partners. The median age was 43 years (IQR 18-91), 8282 (71%) were female. A total of 7345 (63%) had CD, 4101 (35%) had UC, and 297 (3%) had indeterminate colitis (IC) / IBD unspecified. Of those with CD, 2769 (38%) were currently on biologics, 1796 (24%) on thiopurines, and 2559 (35%) on 5-ASA. Of patients with CD, 92% have used biologic, immunomodulator or corticosteroid therapy at some point in their illness and 51% have had one or more CD-related operations. For UC, 661 (16%) were currently on biologics, 808 (20%) on thiopurines, and 2580 (63%) on 5-ASA. Of patients with UC, 88% have used a biologic, immunomodulator or corticosteroid at some point for their illness, and 16% have had surgery for UC.

A total of 4385 subjects have completed  $\geq 1$  follow-up survey (48% of eligible participants), 1889 have completed  $\geq 2$  follow-up surveys, and 4385 participants (34%) remain active in the cohort (have completed a follow-up survey in the last 6 months). We have received a total of 12 applications by external investigators for ancillary studies; 9 have been approved and are underway. Topics include the effects of sleep, depression, and menstruation on disease activity, an evaluation of health literacy, and the use of the CCFA Partners cohort to screen and recruit subjects for independent studies. Two validation studies are currently underway, including a link to a multi-center IBD registry and a medical record review of random sample of the cohort. A pilot project to collect DNA from selected members is also underway.

**Conclusions:** CCFA Partners is a novel, ongoing internet-based prospective cohort study. As enrollment and long-term follow-up continue to accrue, this cohort will be a valuable resource for clinical and translational research. Continued validation studies and efforts to collect and bank biospecimens will add additional value to this cohort.