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Development of CCFA Partners Kids & Teens: an Internet-Based Cohort of Pediatric IBD

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Background and Aims: In 2011, our group successfully launched CCFA Partners, an Internet-based cohort of adult patients with inflammatory bowel diseases (IBD) focusing on patient reported exposures, health behaviors, and disease outcomes. Here we report the development and early results of a pediatric IBD Internet cohort.

Methods: In partnership with the Crohn's and Colitis Foundation of America (CCFA), we recruited children (< 18 years of age) with self-reported IBD through email invitations to individuals on CCFA list and promotion on the CCFA website, social media, and other publicity mechanisms. After informed consent/assent, parents and their children completed surveys about demographics, disease characteristics, disease activity, treatments, health behaviors, quality of life, and other Patient Reported Outcome Measurement Information System (PROMIS) measures. Surveys were designed to be developmentally appropriate, with increasing levels of self-report based upon age. To the extent possible, previously validated survey instruments were used. Baseline characteristics of the cohort are summarized using descriptive statistics.

Results: In the first month, 419 individuals with self-reported IBD joined CCFA Partners Kids & Teens. The median age was 13 years (IQR 10-15, Figure 1); 177 (45%) were female. Age at diagnosis is shown in Figure 2. A total of 312 (74%) had CD, 96 (23%) had UC, and 11 (3%) had indeterminate colitis (IC) / IBD unspecified. Of those with CD, 150 (48%) were currently on biologics, 83 (27%) on thiopurines and 90 (29%) on 5-ASA. A total of 251 (81%) reported prior use of biologic, immunomodulator or corticosteroid therapies and 45 (14%) had prior CD-related surgery. For UC, 18 (19%) were currently on biologics, 25 (26%) on thiopurines and 28 (29%) on 5-ASA. A total of 63 (66%) reported prior use of biologic, immunomodulator or corticosteroid therapies and 18 (19%) had prior surgery for UC. For CD, the mean short CD activity index (CDAI) was 103 (sd 69), indicating quiescent disease. For UC, the mean Pediatric Ulcerative Colitis Activity Index (PUCAI) was 19 (sd 17), indicating mild disease. The mean IMPACT quality of life scores for CD and UC were 132 (sd 21) and 131(sd 25), respectively (IMPACT scores can range from 35 (poor) to 175 (best)). Mean (sd) of PROMIS t-scores for anxiety and depressive symptoms were 56.9 (8.7) and 57.1 (6.4), higher than population norms of 50 (10). Scores for children with active disease were significantly higher than children in remission, for both anxiety (64 versus 54.7, $p < .001$) and depressive symptoms (62 versus 55.8, $p < .001$).

Conclusions: CCFA Partners Kids & Teens is a novel, ongoing Internet-based prospective cohort study of pediatric onset IBD, with the potential for decades of follow up as participants transition from Kids & Teens to the adult CCFA Partners study upon their 18th birthday. Current work includes linkage of this patient-reported cohort to the CCFA Risk Stratification study, establishing a rich dataset of patient-reported data, provider-reported data, and biological samples that will help catalyze translational research. An open and transparent ancillary studies process has been developed to encourage use of this resource by the scientific community.

