

S013 IBD Registries: Triumphs and Challenges

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Accurate delineation of the natural history of pediatric IBD is crucial to the evaluation of current and emerging therapies. While clinical trials provide some data in this regard, they often involve only limited numbers of patients (especially children) and their stringent guidelines often do not mirror actual clinical practice. To address these concerns xx pediatric IBD natural history registries have been developed in North America and Europe that to a variable extent prospectively record important clinical, laboratory, genetic, serologic, and demographic data at diagnosis and at follow-up visits. These registries vary in size and number of participating centers but collectively follow thousands of patients. Important observations on the safety and efficacy of corticosteroids, immunomodulators, and biologic agents have been published from these registries. Long-term data (>10 years) must await several more years of registry operation. These registries face constant challenges in adequate funding and investigator and research coordinator time in an era of increasing clinical demand. Nonetheless their continued operation is essential to understanding the natural history of pediatric IBD.

Session : Clinical Session 1 – Specific Care for Pediatric IBD (part II)