**DISCUSSION TOPICS**

*Please note that these are subject to change!*

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**UNDERSTANDING THE EMERGING ADULT WITH IBD:**

This session will serve as a kickoff for the subsequent roundtable discussions. It will provide a preview of the themes for this series, introduce the challenges of AYAs with IBD, and aim to create more global awareness surrounding this patient demographic.

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**CARE FOR YOUNG ADULTS WITH IBD LIVING WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES (IDD)**

In a study published in the Journal of Autism and Developmental Disorders, scientists found that children with autism were 67% more likely than their peers to have IBD. From both a treatment and a care-coordination perspective, this session will cover best care practices for young adults with IDD and IBD.

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**BODY IMAGE & DISORDERED EATING:**

Disordered eating is increasing in recognition as it pertains to IBD, but it is an issue that affects almost every young adult IBD patient we have worked with and body image dissatisfaction is associated with IBD-related side effects such as steroid treatment, fatigue, disease activity, and surgery. Furthermore, there has been a shown correlation between impaired body image and poor quality of life, which is one of the many reasons we feel it is important to shed light on this issue.

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**MEDICAL TRAUMA & BEHAVIORAL HEALTH:**

Developing or coping with a chronic illness as a young adult can result in detrimental mental health implications. Traumatic experiences that result from one’s condition may lead to developmental crises that can have a lasting impact on an individual’s quality of life. In the case of IBD, experiencing an accident or the urgency to use the restroom in front of peers is just one example of a socially traumatic experience. Acute, unplanned hospitalization can trigger chronic stress responses. Additionally, coping with difficult procedures and treatments may result in post-traumatic stress. Effective communication between a patient and provider may be difficult, but may result in decreased adherence and hopelessness experienced by patients.
According to one study, fear of infertility is very common in people with IBD, particularly those who reported previous surgery. IBD patients also experience concerns about the heritability of IBD, risk of congenital abnormalities, and medication teratogenicity. Despite this, sexual health and family planning are under-discussed with younger patients, or are discussed solely with parents at times of treatment decisions. It is critical to address these topics more proactively. This session will also cover surgery and sexual health, and will also touch on topics of care coordination and how providers can help to proactively encourage these discussions.

This session will address the importance of recognizing adverse childhood events and their impact on IBD. The prevalence of at least one ACE was 74.2% in young people with IBD. This session will discuss the unique challenges of working with AYAs with IBD who have experienced abuse or significant life events in childhood. A major premise of this session will also include working with AYAs with IBD who come from families of lower health literacy backgrounds. It will also discuss strategies to empower and meet their needs.

Fatigue is one of the most complex and common symptoms of IBD, occurring in over 50% of IBD patients. This session will also discuss common comorbidities with IBD and malignancies. We hope this session will encourage proactive screening for malignancies and appropriate education for young adult IBD patients.

Discussion Topics
Please note that these are subject to change!
Young adult patients with IBD face difficulties when transitioning from pediatric to adult providers. Pediatric providers do not consistently implement formal transition and transfer of care programs, and adult providers lack the information and resources to holistically treat young adult patients. The session will cover core topics such as the Socio-ecological Model of Adolescent and Young Adult Transition Readiness, and provide resources such as those found at Got Transition. This session will be geared toward adult GI providers and will discuss best practices to build trust and compassion, as well as strategies for fostering effective transitions, even in situations where time is limited.

**DISCUSSION TOPICS**

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**HIGHER EDUCATION, THE WORKPLACE, & FINANCIAL CHALLENGES:**

Individuals diagnosed with IBD during childhood or adolescence face a lifetime of illness, the impact of which has not received adequate attention. The financial burden of a chronic illness alone can be massive. Twenty-three percent of chronically ill patients interviewed by the Harvard T. Chan School of Medicine reported being unable to pay for basic necessities like food and housing. People diagnosed with Crohn’s disease between the ages of zero and eleven years old could incur an average cost of over $700,000 during their lifetime. This is compounded by the fact that an early illness can lead to fewer years of education, more joblessness, and lower pay. This session will cover how to best advocate and share knowledge about accommodations and resources for AYAs with IBD.

**WHAT ADULT GI PROVIDERS SHOULD KNOW ABOUT YOUNG ADULTS WITH IBD:**

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**LGBTQ+ & OTHER INTERSECTING IDENTITIES:**

Microaggressions experienced by sexual and gender minorities (SGM) and racial/ethnic minority identifying individuals affect health-related behaviors, service utilization, as well as mental and physical health. Adolescence and young adulthood is a period of rapid change and discovering and exploring one’s own identity. This session will cover how providers can best open dialogue for SGM and other racial/ethnic minorities; It will also cover cultural humility and building trust and open communication with young adult patients.
Young adults with chronic conditions such as Crohn’s disease are **363% more likely** to attempt suicide. Per the study, peer support is recommended to reduce isolation and the burden of chronic illness for the individual. Peer support has often been thought of as valuable but has not been identified as essential for AYAs with IBD. It should be recognized as a critical intervention to promoting disease acceptance and self-management. This session will discuss various peer support interventions and how providers can engage and promote patients to gain peer support from other AYAs with IBD.

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