ISSUE NO. 7—Summer 2023 VOLUME 4

# IBD Digest

The IBD and Behavioral Health study team is excited for summer—warm weather, cookouts, and family vacations are what we think about when we think of this time of year. However, we know that shaking up your routine can sometimes come with challenges, such as worries about eating foods that might not be a part of your normal diet or managing your medications. Here are some tips provided by members of our clinical study team about ways to make sure your summer plans are nothing but smooth sailing.

From Therezia Alchoufete, MS, RD, LDN, Lead Dietitian, UPMC Total Care – IBD

- **Stay hydrated:** Bring enough water if travelling by car or take a reusable water bottle so you can fill it up if going through airports. Sometimes, an oral hydration solution might be needed; talk to your dietitian about over-the-counter options you might be able to pack in your travel bag.
- **Pack your go-to protein snacks:** Protein will help you to stay satisfied throughout travel, and packing snacks you already know are well-tolerated can ease any stress when searching for foods along the way.
- **Check in with your dietitian:** Get an individualized plan for eating on the go and ask any questions you may have before your trip.

From Dr. Ben Cohen, MD, Co-Section Head and Clinical Director for Inflammatory Bowel Disease, Cleveland Clinic

- **Think ahead with medications**: For patients on biologics, it's good to think ahead about the timing of your doses as it relates to when you will be away. It's usually better to get a dose early rather than one late, but make sure to talk to your doctor.
- **Consider any required vaccinations**: If traveling to areas where vaccinations may be required, it's important to see a travel medicine doctor and let them know if you are on immunosuppressive drugs. This may mean you can't get certain live virus vaccines.

From Dr. Eva Szigethy, MD, PhD, Professor of Psychiatry, Pediatrics and Medicine, University of Pittsburgh

- **Get adjusted to new time zones as soon as possible**: Mental wellness can be best maintained by switching to a new time zone as soon as possible and consolidating sleep to the "new" nighttime.
- **Make time for mental wellness**: It is important to listen to your brain and body for signs of exhaustion and take breaks, especially if you're planning a rigorous schedule. Meditation can be a great way to do this.

### STUDY PROGRESS

As of **May 18**, 2023, we have enrolled

**593**

participants across the three study locations!

We are **60%** of the way to our goal.

### REMEMBER!

Participants are asked to complete questionnaires at three points:

- Upon enrolling in the study
- Six months after enrolling
- One year after enrolling

You will be paid $20 each for the initial and six-month questionnaires and $40 for the final questionnaire.

## Study Findings: Young Adults With IBD

Last summer, we shared some findings from the telephone interviews we conducted with selected study participants when they first enrolled in the study. Our interviews included a few questions that we only asked our young adult patients between the ages of 18 and 30. Many patients in this age group have recently experienced a transition in their health care—moving from the pediatric providers they saw as a child to adult doctors. The study team specifically wanted to know more about this experience so we could learn how doctors, health systems, and insurers can make the transition as seamless as possible and help young people with IBD get set up for success in managing their disease over their lifetime. The study team plans to share this information with clinical teams at each of the study sites so they can take this information into account for their own practices, and also share with other providers via published papers, conference presentations, and other types of outreach. Below are some of the main themes from these interviews.

**Provide logistical support for care transitions.** Finding a new doctor, especially if the patient already had a good relationship with their pediatrician, was a concern for several patients. Some specifically asked for help in learning how their health insurance worked, including how to find in-network providers and determine what medicines would be covered. Others suggested that pediatric GI doctors help their patients to begin looking for adult providers while the patient is a teenager to make the process easier.

**Provide education and resources to support life with a chronic medical condition, such as a long-term treatment plans.** Many young adults who were diagnosed as children wanted to know more about how having IBD would impact their health as they grew older. One specific area patients wished their doctors would discuss with them or direct them to resources for was how IBD would impact their future plans to have children. Others talked about how they wanted a "refresher course" from their doctor about IBD, since many of the specifics had been explained to their parents if they were diagnosed as children.

**Understand and address both the mental and physical impacts of living with IBD.** Some patients described having IBD during their formative years as traumatic. They specifically discussed the need for more mental health services to be incorporated into their care, but also for their GI doctors to understand and empathize with their experiences.

**Deliver comforting, clear, and personalized care**. Some patients reported experiences where their pediatric doctors did not believe them about their experiences and level of pain. Others talked about doctors who would only talk to their parents about their treatment, leaving the patient feeling excluded. Many requested that their doctors take the time to connect, listen, and trust that the patient knows their own experiences best.

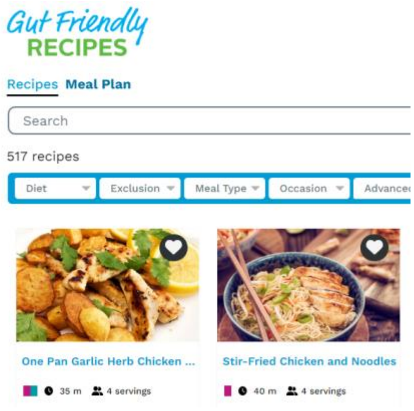
## New Crohn's & Colitis Foundation Resources

The Crohn's & Colitis Foundation is a great resource for patients living with IBD. This nonprofit organization has played an important role in IBD research, professional education, and patient advocacy for more than 50 years. Below, we highlight two of their newer resources designed to help you with living a happy, healthy life.

**We Can't Wait restroom finder app**

Planning on taking a summer vacation? The We Can't Wait app is a free app available for download on both Android and Apple devices. Users of the app can search on a map for available public restrooms, which can help alleviate stress related to travel when visiting somewhere new. Search "We Can't Wait" in your device's app store for more information.

**Gut Friendly Recipes database**



Looking for a new recipe for a summer cookout? The Gut Friendly Recipes site has more than 500 recipes developed and approved by dietitians who specialize in treating IBD patients. Users can sort and filter recipes based on type of meal, foods to avoid, and specific types of diets that may be recommended by your dietitian. You can register for a free account and browse, save favorites, and create a meal plan at: crohnscolitisfoundation.org/gutfriendlyrecipes.

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TIPS

## Finding a New Doctor: Making Smooth Care Transitions

Whether you're a young adult looking to transition to adult care, moving to a new location and in need of a new primary care physician, or just need to connect with a new provider for whatever reason, changing doctors can be a nerve-wracking experience. In the health care system, this is an example of a "care transition" or "transitional care." A smooth care transition is important for many reasons—patients with chronic medical conditions who experience gaps in their care during this period are more likely to have difficulties maintaining their medication regimens or tracking new progressions in their disease, to experience flares, and to need hospitalization or emergency medical services.[1,2] Below are some tips on that can help you prepare for a smooth care transition no matter what your situation.

*Understand what your health insurance covers.* If you have health coverage, your insurer can provide you with information about what exactly your plan covers, including any copays or deductibles you may owe after visiting providers. These may change depending on what type of specialist you're seeing—for example, different plans may have different levels of coverage for seeing a primary care physician versus a specialist (like a gastroenterologist) or a mental health provider (like a therapist). Many plans offer discounts or lower costs for visiting "in-network" providers. An easy way to find someone in-network is to search through your health insurance online portal. When you've found a new provider, it's important to call their office and make sure that your specific plan is accepted. If you are a UPMC Health Plan member, you can search for providers, review your benefits, and get help from our knowledgeable staff by visiting upmchealthplan.com or myupmc.com.

*Ask for help and references.* A great first place to start your search for a new healthcare team is by asking your current doctor for references. Be sure to check with your insurance plan that any referrals or recommendations for a new healthcare team are in-network providers. Many providers, like the staff members in the UPMC Total Care clinic, are members of national organizations and have colleagues throughout the country. Since they know your history and medical needs, they can often connect you with a great team in a new area. You can also check with support groups, like the regional ones offered through Crohn's and Colitis Foundation, to learn about their experiences with providers in your new area.

*Be prepared for your first appointment.* To help you get established with a new provider, it's important that they have your most up-to-date information about your medical history. Most new offices will have you fill out forms allowing them to access medical records from your previous provider. However, this process can sometimes take a while, so it's important that you attend your first appointment with a list of important information to cover. This can include current (and potentially previous) medications, allergies, surgical history, and any other information relevant to your care.

*Remember that the first time isn't always the charm*. Sometimes you won't always connect with your new doctor, and that's OK! Don't be afraid to seek a second opinion or a new doctor altogether if the first person you see isn't a good fit.

1. Cohen-Mekelburg S, Saini SD, Krein SL, et al. Association of continuity of care with outcomesin US Veterans with inflammatory bowel disease. *JAMA Network Open*. 2020 Sep;3(9):e2015899
2. van den Brink G, van Gaalen MAC, DE Ridder L, et al. Health care transition outcomes in inflammatory bowel disease: a multinational Delphi study. *Journal of Crohn's and Colitis*. 2019 Sep;13(9):1163-1172

## Contact

If you have any questions, please contact a member of the research team at **412-208-5235** or email us at **IBDStudy@upmc.edu**. We can help you:

- Address concerns about your Vincent Payment Card.
- Update your contact information.
- Resolve issues you may be having with the RxWell® app.
- Schedule a time to complete your follow-up questionnaires.