

Clinical Trials Community eNewsletter

Summer 2020



From the Desk of the Clinical Trials Community

Greetings Clinical Trials Community! We hope your summer has been great so far, and we hope you've been finding ways to safely have fun!

The COVID-19 pandemic has made a global impact on clinical trials participation, including disruptions and delays. Trial challenges may have arisen in your area due to social and physical distancing guidelines, site closures, and travel limitations, to name a few. If you are a clinical trials participant, you may have questions and concerns about how COVID-19 impacts your participation. It's important that you speak with your healthcare team about any fears you have or if you are considering discontinuing your participation in your trial. We are here to provide you with helpful [information](#) and a [discussion guide](#) with some questions to ask your doctor and research coordinator.

Even though clinical trials may have been disrupted, participation in clinical research is still possible. [IBD Partners](#) is a partnership of the Crohn's & Colitis Foundation and the University of North Carolina at Chapel Hill that brings patients and researchers together to better understand IBD. Patients are involved in every part of the process from deciding survey questions to choosing priority topics for research. This online registry is used to gain a better understanding of how things you do affect your disease activity. If you choose to enroll, you will be asked to complete a baseline survey to learn more about your health and then you will be contacted a few times per year by email to update your health information. Find out more about IBD Partners.

As states and local communities begin relaxing stay at home orders, patients with IBD and caregivers of patients may be wondering how to safely return to activities of daily life. Our COVID-19 Resource Center has information about [how to safely return to work, school, and other aspects of daily life](#). You can also find information about IBD medications, surgery, and managing the emotional impact of the pandemic by [visiting our website](#).

Surviving Summer with IBD

Rachel is a Crohn's disease patient and a member of the Crohn's & Colitis Foundation's National Council of College Leaders. She recently shared how living with Crohn's disease has forced her into a love-hate relationship with summer. As a newly diagnosed kid, she passed on many of her favorite summer activities but now she is much more open about her disease and worries less about making plans in the summer. Despite the coronavirus pandemic, Rachel is looking forward to coming up with creative ways to stay busy and have fun. Check out Rachel's [blog post](#) to learn more about her story and her summer plans.

Ambassadors Spotlight: Get to Know Mary!



Did you know there are different types of IBD clinical trials you can enroll in? Mary is a Clinical Trials Ambassador from New Hampshire who participated in an iron infusion clinical trial. After being diagnosed with Crohn's disease, she developed anemia. After speaking with her gastroenterologist, she decided to enroll in this trial. Mary's piece of advice to anyone considering a clinical trial is to "not be afraid to ask questions." [Read more about Mary's experience.](#)

Get to Know Jennifer!

Jennifer is a Clinical Trials Ambassador from Ohio. She was diagnosed with Crohn's disease as a teenager. As a college student, she experienced many symptoms and had her first major surgery at 20-years-old. When things didn't get better, Jennifer's doctor suggested a clinical trial as an option. Jennifer says, "Participating in a clinical trial opened my eyes to other possibilities and I became more aware of the advancements being made in research." [Learn more about Jennifer's journey.](#)



Phrase of the Quarter: Clinical Research

Clinical research helps find new and better ways to detect, diagnose, treat, and prevent disease by studying people, data, or samples of tissues. Clinical trials are a type of clinical research, which you may be familiar. Completing internet-based studies, such as surveys or questionnaires, and donation of biosamples are other forms of clinical research.

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