

What is CCFA Partners?

CCFA Partners is an online research study designed to improve the quality of life for patients with inflammatory bowel diseases (IBD) through research and education.

Our goal is to follow IBD patients over time through this online registry for a better understanding of the issues they face. These issues include: how patients are functioning day-to-day, diet, treatments, and how these factors change over time.

CCFA Partners is purely a research initiative, not a fundraising effort. We only ask you to complete an online survey twice a year to update your health history. It is a convenient and simple way for you to make a contribution to the search for cures.

Am I eligible?

Participants must have been diagnosed with Crohn's disease or ulcerative colitis.

How do I register?

Registering is easy: visit CCFAPartners.org and click on the "Register" tab. We will ask you to provide detailed information about your disease history, treatment, and current symptoms. Completing this initial confidential survey should only take 20 to 30 minutes of your time. The survey can be done all in one sitting, or you can log off and return to complete it at a later time.

Once you are enrolled, we will ask you to update your medical information in a brief online survey every six months. We will also provide you with quarterly progress reports and relevant information about IBD. As an additional service, we may notify you about new research studies for which you might be eligible.



Register today:
www.ccfapartners.org

Do I have to answer every question?

No—all questions are optional. You don't have to answer any questions that you don't want to, and you can withdraw from the research study at any time. The survey questions are straightforward and are about your disease characteristics—the more answers you provide, the more we can understand how IBD is affecting you.

What do I get for participating?

You do not receive any compensation for participating. However, your involvement will lead us closer to finding cures. Research findings will be published on the CCFA Partners website, in peer-reviewed research journals, and presented at scientific meetings.

I have friends or relatives with IBD. Can they join?

If a loved one or friend has IBD, we encourage you to pass along the news about CCFA Partners. The more participants we have, the more useful our research results will be.

Is my information safe?

Although we collect your name, address, and email, we will not share any information without your permission. All information you provide to the CCFA Partners registry is stored in a safe, secure, password-protected location at the University of North Carolina, with extensive safeguards in place to prevent any loss of privacy.

How are CCFA and CCFA Partners different?

CCFA (the Crohn's & Colitis Foundation of America) is a non-profit, volunteer-driven organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and to providing resources for patients and medical professionals involved in the care of patients with IBD. For more information, visit ccfa.org.

CCFA Partners is a research initiative, sponsored by CCFA, that is designed as a comprehensive Internet-based registry to study thousands of patients with Crohn's disease or ulcerative colitis. It is an independent scientific research study governed by a team of experienced IBD investigators.

How will my information be used?

The information you provide will be analyzed by a panel of qualified and experienced IBD researchers. Analyses will look at things like quality of life, complications of disease, and how IBD patients feel when living with the disease. Our research team hopes to improve treatment outcomes and prevent complications. The information that you contribute is very important in enhancing the pace of progress in research, as well as identifying better treatments and ultimately the cures we need.

**For more information about
CCFA Partners and to join the
research study, please visit
CCFAPartners.org.**

Introducing...



We have expanded CCFA Partners to include children. Given that children are the fastest growing IBD patient subgroup and many children have severe disease, pediatric-focused research is critical.

To better understand this population, pediatric patients (17 years of age or younger) and their parents or caregivers are invited to participate in this special component of CCFA Partners—**CCFA Partners: Kids & Teens.**

Registration requires parental consent for all participants. Survey questions depend on the child's current age and may include topics such as medication use, disease symptoms, and quality of life.

For all patients, parents complete a portion of each survey. Child participation in surveys increases as children grow older. Younger children are encouraged to work with their parents to complete their surveys, while teens may work more independently if they choose.

Find the new "Kids & Teens" module at www.ccfapartners.org!



*Patients
helping patients...*

www.ccfapartners.org