

# resources

There are many great organizations that are here to support you. From initial diagnosis, to flares and remission, these resources can help answer a lot of your questions about life with IBD. Of course, your Dayton Children's IBD care team is always here to help, too.

## organizations and support groups

- Dayton Children's Hospital: [childrensdayton.org](http://childrensdayton.org)
  - **Research and quality improvement:** Dayton Children's Hospital is participating in multiple research and quality improvement projects regarding IBD patients. Some areas of research and quality improvement projects include:
    - Combined medications
    - Obesity in IBD
    - Body image
    - Timing between new diagnosis to starting treatment
    - New medication trials
    - Patient-reported-outcome (PRO) studies
  - **ImproveCareNow (ICN) partnership:** By being part of ImproveCareNow (more information below), you can be assured that you are receiving world-class care. A group of clinicians (GI doctors, surgeons, psychologists, and nurse practitioners), social workers, dietitians, researchers, and parent representatives meet several times a month to discuss IBD patients and provide input. ICN focuses on four interventions:
    - Population management
    - Pre-visit planning
    - Care protocols
    - Audit tools
  - **Parent Advisory Council:** Dayton Children's hosts a parent advisory council. This group shares feedback to affect change on everything from patient family education to overall hospital experience. Made up of parents of newly diagnosed kids to patients who are now in college, this is a great place to have your voice heard. We also have an IBD FACT (Family Action Collaborative Team). The group meets monthly. To join, contact a family partnership coordinator at 937-641-3306.
- Crohn's and Colitis Foundation (CCF): [crohnscolitisfoundation.org](http://crohnscolitisfoundation.org)
  - The Crohn's and Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's disease and ulcerative colitis, and to improving the quality of life in children and adults affected by these diseases.

- If you're interested in getting involved and connecting with our local community in person, the closest CCF chapter is the Southwest Ohio/Kentucky chapter, located in Cincinnati.
- CCF also has local support groups. Go to [crohnscolitisfoundation.org/community-support](http://crohnscolitisfoundation.org/community-support), then click "Find a Support Group".
- ImproveCareNow (ICN): [improvecarenow.org](http://improvecarenow.org)
  - ImproveCareNow is a collaborative community where clinicians, researchers, parents and patients are empowered to learn and continuously improve. The goal is to bring reliable, proactive IBD care for healthier children and youth. If you are interested in getting involved in ICN, visit: [improvecarenow.org/get\\_involved\\_signup](http://improvecarenow.org/get_involved_signup)
- Support Groups for patients who have had an ostomy: Go to: [ostomy.org/support-group-finder/](http://ostomy.org/support-group-finder/)
- Local Medical Legal assistance
  - Advocates for Basic Legal Equality, Inc. (or ABLE) is a local non-profit law firm that provides legal assistance. Visit them online at [ablelaw.org](http://ablelaw.org).

## websites

source	information/purpose	link
<b>MyMedSchedule.com</b>	Daily medication tracking	<a href="http://secure.medactionplan.com/mymedschedule/">secure.medactionplan.com/mymedschedule/</a>
<b>Crohn's and Colitis Foundation</b>	Asks you a few questions about your IBD care and support team. Then connects you with information and resources.	<a href="http://justlikemeibd.org/">justlikemeibd.org/</a>
	Managing the cost of IBD	<a href="http://site.crohnscolitisfoundation.org/living-with-crohns-colitis/managing-the-cost-of-ibd/">site.crohnscolitisfoundation.org/living-with-crohns-colitis/managing-the-cost-of-ibd/</a>
	Diet and Nutrition	<a href="http://crohnscolitisfoundation.org/diet-and-nutrition">crohnscolitisfoundation.org/diet-and-nutrition</a>
	The main page to access all of Crohn's and Colitis Foundation's resources	<a href="http://crohnscolitisfoundation.org/resources/">crohnscolitisfoundation.org/resources/</a>
<b>GI Kids</b>	Specifically review the "Plowing through the Paperwork" guide under PDF downloads	<a href="http://gikids.org/inflammatory-bowel-disease/ibd-resources/">gikids.org/inflammatory-bowel-disease/ibd-resources/</a>

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source	information/purpose	link
ImproveCareNow	IBD Accommodations Toolkit	<a href="https://improvecarenow.org/accommodations">improvecarenow.org/accommodations</a>
	Talking about IBD Toolkit	<a href="https://improvecarenow.org/talking_about_IBD">improvecarenow.org/talking_about_IBD</a>
	Body Image Toolkit	<a href="https://improvecarenow.org/pac_body_image_toolkit">improvecarenow.org/pac_body_image_toolkit</a>
	Resources from parents and patients based on what they've learned over the years	<a href="https://improvecarenow.org/tools">improvecarenow.org/tools</a>
	Mental Health Toolkit	<a href="https://improvecarenow.org/toolkits_and_guides">improvecarenow.org/toolkits_and_guides</a>

## phone apps

All apps are available on Apple and Android devices, unless noted next to the app name.

### My IBD Manager

Track and store relevant health information between clinician visits, like a food and medication log and pain ratings. This tool was produced by @ Point of Care and the American Gastroenterological Association (AGA).

### Doc4me

Helps adolescents and young adults search for adult IBD care doctors. The app also gives teens the opportunity to complete checklists for what to know and do to transition to an adult IBD doctor.

### Medisafe

Add prescriptions and doses and set reminders to take your medications and when you need to refill your medications. You can also download your progress report and send it to your care team as a PDF.

### GI Monitor

Another app to help patients track their symptoms, such as pain, meals, weight, etc. The data can be downloaded into reports to share with physicians.

### Poop Tracker (available on Android only)

Poop Tracker uses the Bristol stool scale to determine the quality of your poop and allows you to track and analyze your bowel movement data over time.

### **Complete (AbbVie, maker of Humira)**

Resources for managing treatment on HUMIRA are at your fingertips. This app can help you record the locations and dates of your injections, receive medication reminders, log your symptoms and more.

### **My Crohn's and Colitis Team**

MyCrohnsandColitisTeam is a social network and support group for those living with Crohn's or colitis. Get the emotional support you need from others like you, get practical tips to manage your life with Crohn's or colitis, and insights about treatment or therapies. MyCrohnsandColitisTeam is the only social network where you can truly connect, make real friendships, and share daily ups and downs in a judgment-free place.

### **Oshi**

Track your symptoms and lifestyle factors and get an overall wellness score to help you manage your IBD. You can also read articles about living with IBD, and ask questions to health care professionals and IBD experts.

### **myColitis**

Record your bowel movements, symptoms, meals, medications, moods, medical procedures and more. This simple and clean app will make tracking your data an easy habit to start and maintain. Simply tap an icon and fill in the blanks. Take control of your condition by using your data to share with your care team and to better understand your overall health. The app can also track bowel movement discomfort and calculating unique insights.

