



Inflammatory Bowel Disease (IBD)

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Children's Hospital
New Orleans
LCMC Health

Inflammatory Bowel Disease (IBD)



Thank you for trusting Children's Hospital of New Orleans with your child's IBD care.

We promise to make sure your child is receiving the highest quality, up-to-date treatments. We look forward to partnering with your child and your family to work as a team to get their IBD into remission.

What is IBD (Inflammatory Bowel Disease)?

IBD is a group of inflammatory gastrointestinal diseases, a term traditionally used for Crohn's Disease and Ulcerative Colitis (UC). Inflammation is a reaction from the body that causes localized redness, swelling, and usually pain. They affect men and women of all ages, but many patients are diagnosed as children. Currently, we do not know why some people get IBD, but sometimes there is a family member with the illness as well. It is also believed that an over-active immune system plays a big part in the inflammation in the GI tract as well as the environment and bacteria in the gut.

Crohn's Disease can involve the entire GI tract, anywhere from the mouth to the anus, potentially causing ulcers and inflammation. Multiple different areas can be involved with healthy parts of GI tract in between. UC affects only the colon at the inner layer.



What are the symptoms of IBD?

The symptoms of IBD will depend on your child's individual case including their disease diagnosis of UC or Crohn's, where their disease is located, and the degree of severity (how serious it is).

Most common symptoms:

- Abdominal pain
- Diarrhea - with or without blood
- Rectal bleeding
- Decreased appetite
- Weight loss

Crohn's Disease can also have some additional symptoms:

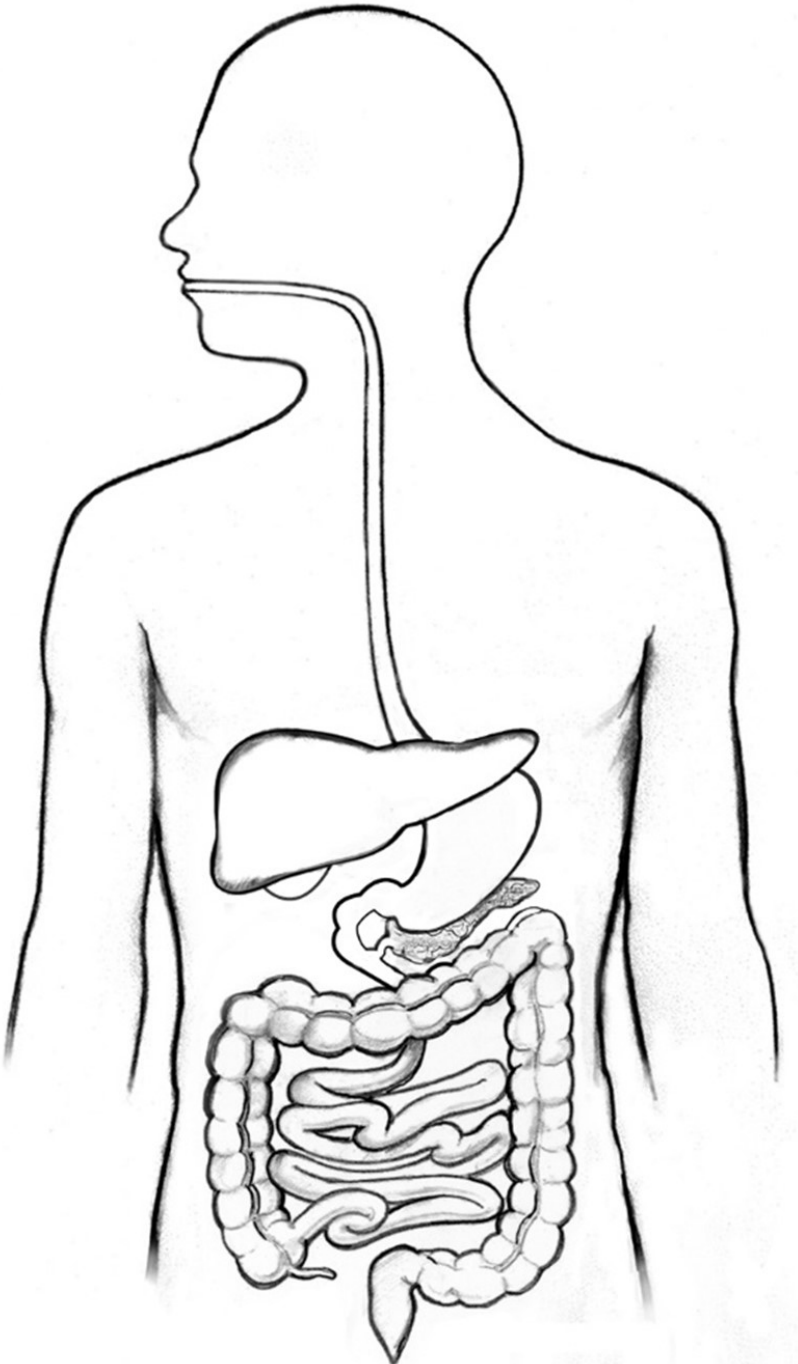
- Fevers
- Joint pains, sometimes with swelling
- Eye pain
- Mouth sores
- Rashes
- Growth problems



Where is my disease?

Diagnosis: ☐ Crohn's Disease ☐ Ulcerative Colitis ☐ Indeterminate Colitis

Location: _____



How is IBD diagnosed?

Due to IBD symptoms overlapping with other illness, diagnosis may take a long time. The process involves several tests in addition to your child's reported symptoms:

- **Lab work:** Blood and stool studies are done which will often show inflammation. Sometimes blood counts can also be low.
- **Imaging:** Magnetic Resonance Imaging (MRIs) or computed tomography (CTs) can help show inflammation and areas of infection or fistula tracts. It also allows us to see the small intestine where our endoscopy cannot reach.
- **Endoscopy:** This is a procedure done under anesthesia that allows your gastroenterologist to see the inside of the bowel and take biopsies (tiny tissue samples) for testing. This test will often reveal inflammation, ulcerations, swelling, or areas of bleeding and irritation
 - The biopsies will be looked at under a microscope by a pediatric pathologist to get a better idea of your child's disease on a microscopic level
- **Note:** This step is required to be diagnosed with IBD

All of these tests will be repeated from time to time after diagnosis to monitor disease activity and response to treatment. We will go over your testing timeline at your visits so that you and your child will be prepared and comfortable with the plan.

Is there a cure?

At this time, IBD does not have a cure and is seen as a chronic, but very treatable, illness. There are many treatments designed to help your child achieve remission (being symptom-free). In some cases, UC can be cured with surgery. You and your child's care team will work together to create a treatment plan to manage symptoms and make them healthy and happy again. Achieving remission is our goal in your child's care so that they can live a healthy, meaningful life.

What treatments are available?

Each child's care is unique and planned exclusively for them. It will likely be a combination of medications and dietary treatments to decrease inflammation, improve symptoms and help in growth/nutrition.

Medications for IBD can be given orally (by mouth), topically (rectal enemas), injection (shots), or intravenously. Your child's care provider will work with you to determine the best medications for them. We will discuss all side effects and safety/monitoring issues with you in detail. Some of these medications will require regular blood work to make sure the medication is working properly. The medications can take several weeks to months to start working, so short-term medications like steroids may also be given for quick relief of symptoms.

Exclusive Enteral Therapy (EEN) is another effective treatment that can work alongside medications or, in some cases, as a primary (main) treatment. Your child will replace most foods with formula which can drunk or given through a nasogastric tube if unable to tolerate drinking. This treatment plan allows the GI tract to heal/rest while improving nutrition over several weeks to months.

Surgery is available in some cases for children that have very severe disease or fail to respond to other treatments.

Often your child receives a combination of therapies. Their plan depends on their disease, location, severity, and response to treatment (measured by their lab work, endoscopies, and symptoms).

My treatment plan: _____

What else do children need checked with IBD?



Growth (height and weight)



Nutritional status



Vaccinations



Bone density



Eye health



School accommodations (504 plan)

Who is on my child's care team?

At Children's Hospital, we use a multidisciplinary approach to IBD care. This means that we have a team of people involved in your child's care playing different roles from unique areas of expertise. At any given visit, you may meet with one or all three of these members. These team members include:



Pediatric Gastroenterologist

Your primary doctor will manage the "big picture" of your child's care – focusing on the medical side and directing treatment plans. They will also perform procedures like endoscopies, order laboratory tests and prescribe medications.

- We also have a dedicated IBD Nurse Practitioner and GI registered nurses



Pediatric Psychologist

At CHNOLA we know that that IBD not only causes physical symptoms, but also affects children and families emotionally as well. We have a psychology care team that specializes in pediatric health and chronic illness to meet with your family and child at visits to help with emotional adjustment to illness, stress related to disease management, and behavioral strategies for pain management.



Registered Dietitian

Healthy nutrition is a vital part of IBD care. CHNOLA has a full-time registered dietitian to meet with your child to assess growth and caloric intake with practical home recommendations for each patient. If EEN therapy is recommended, the dietitian will assist in guiding families to get started, getting formula, and transitioning back to healthy diet after therapy is complete.

At Children's Hospital, we also have many other pediatric specialists available for referral and consultation as needed by your child's treatment plan.

When do I need to call my doctor?

You can expect to see the GI team every 3–4 months for follow-ups. While every patient has a different treatment plan, there are a few general symptoms that your IBD team needs to know so that we can determine any next steps.

Please call the office or message your provider if:

- Fevers (temperature >100.4)
- Bloody stools (poops)
- Diarrhea
- Vomiting
- Severe belly pain
- Losing weight
- Not able to take food or fluids by mouth (getting dehydrated)
- Any new or concerning symptoms

How do I contact the office to speak with my team or make an appointment?

We are available 24 hours a day, 7 days a week.
There are several ways to reach our team:

Phone: 504.896.9534

For urgent problems after hours, on weekends, or holidays, please call the main hospital at 504.899.9511 and ask to speak to the GI physician on-call.

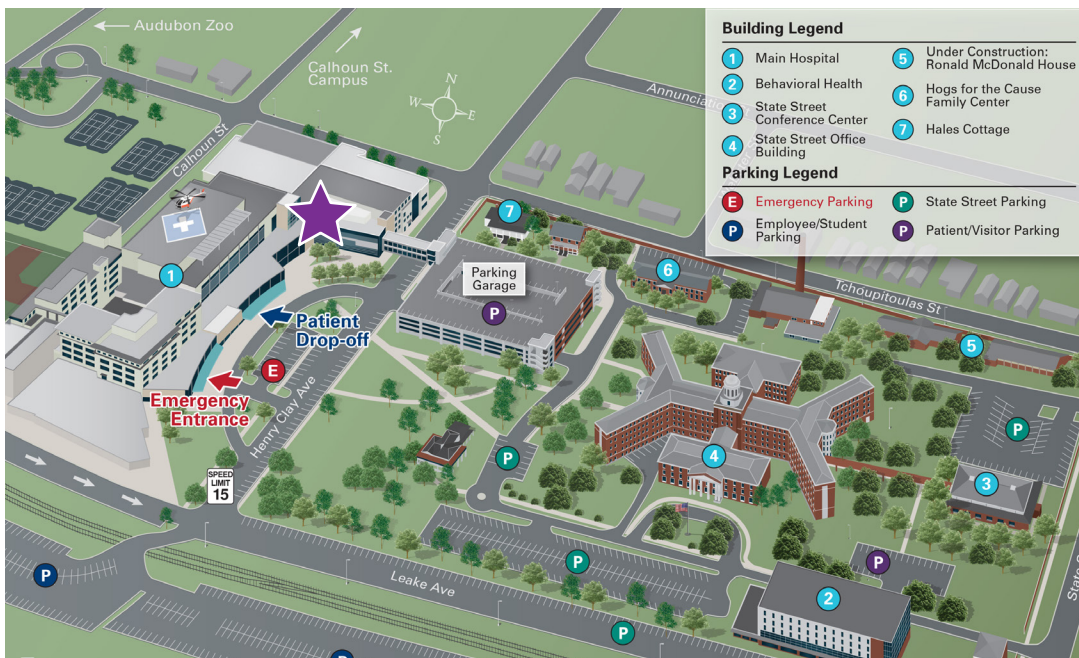
Epic MyChart Patient Portal

You will get access to your child's Epic profile during your visits to access test results as well as the ability to message your care team

In-person appointments

Children's Hospital Department of Gastroenterology

200 Henry Clay Ave, ACC
1st floor Multidisciplinary Pods
New Orleans, LA 70118





For additional information on our Children's Hospital Gastroenterology group or regarding Inflammatory Bowel Disease in children, these are **excellent internet resources:**

chnola.org/our-services/gastroenterology-hepatology-nutrition/

improvecarenow.org

crohnscolitisfoundation.org/youth-parent-resources

crohnscolitisfoundation.org/what-is-ibd/newly-diagnosed/pediatrics

Please contact our office with any questions or needs

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