

Inflammatory Bowel Disease (IBD)

We would like to give you a brief introduction to inflammatory bowel disease (IBD) and let you know what to expect over the next few days. We know you may be overwhelmed but we hope this information will help you.

What is inflammatory bowel disease?

There are two kinds of IBD:

- Crohn's disease
- Ulcerative colitis

The immune system causes chronic (meaning it lasts a long time) inflammation (swelling) which damages the gastrointestinal (GI) tract. Currently, there is no cure for IBD, but medications and surgery can help children and adults with IBD live full and active lives. It is important to know there is nothing you or your child did to cause IBD or could have done to prevent IBD from happening.

How is inflammatory bowel disease diagnosed?

There are multiple tests used to diagnose IBD.

- One of the tests is called an esophagogastroduodenoscopy, or EGD. We use a small scope with a light and a camera at the end of it to go into the mouth, down the esophagus, into the stomach and into the first portion of the small intestine.
- Another common test for IBD is a colonoscopy, or lower scope. During a colonoscopy, we use a longer scope, again with a camera and light, to enter the rectum and travel through the large intestine into the very end of the small intestine. During these tests, the medical team will take biopsies or small tissue samples from the intestines.
- Labs and imaging studies (tests that take pictures of your intestines) are also used to diagnose IBD.

How do you treat inflammatory bowel disease?

There are various medications available to treat IBD. All forms of IBD, except for mild ulcerative colitis, require immune suppressing medications. These medications help stop the immune system from causing damage to the GI tract. There are different ways to give these medications:

- Taken by mouth,
- Injected (a shot),
- Intravenous (IV) infusion (given in the vein)

Some patients may require surgery to repair or remove damaged parts of their GI tract. When you have a diagnosis, your GI medical team will talk to you about ways to treat your child.

Who will be taking care of my child?

We have a team of pediatric GI physicians (doctors) who take care of patients with IBD. Fellow physicians are fully trained pediatricians who are completing their GI training. They are supervised by an attending physician. Nurses, dietitians, and social workers will also be a part of your child's care.

Gastroenterology

What can I expect in the next few days?

Your biopsy results should be available in about 5-10 days. Your physician will discuss the results and treatment options with you at that time. They may need more testing done. Your child may need to have more labs drawn. These labs will check your child's immunization (vaccine) status for:

- Hepatitis B
- Varicella (chicken pox)
- Epstein Barr Virus (EBV or "mono")
- Tuberculosis (TB)

There are more imaging tests that may be needed:

- MRI enterography (MRE): an imaging test that is used to look for:
 - Inflammation-swelling
 - Abscesses-collections of pus
 - Fistulas-an abnormal opening or connection between the bowel and organs near the bowel
 - Strictures-an area of scar tissue that causes portions of the GI tract to be narrow
- MR pelvis (an MRI of the lower pelvis and perianal area): this imaging test looks at the pelvic area specifically for fistulas or abscesses
- Video capsule endoscopy (VCE or PillCam): A VCE or PillCam test allows us to see portions of the small bowel that are not reachable by the usual upper (EGD) and lower (colonoscopy) scopes.

After all the tests and labs, your child may need to see a pediatric surgeon if:

- large portions of their GI tract (or intestines) are narrow
- they have a fistula (an abnormal opening or connection inside the intestine)

Where can I find more information about IBD?

We encourage you and your child to learn more about IBD while you wait to hear from your physician. It is important to get your information from a good source. Here are some websites we trust and recommend:

1. Crohn's and Colitis Foundation: www.crohnscolitisfoundation.org
2. Children's Digestive Health Information for kids and parents: www.GIKids.org
3. ImproveCareNow: <https://www.improvecarenow.org>

Inflammatory Bowel Disease Program

Here is some information about our Pediatric IBD program. We want you and your family to feel comfortable with your child's care. We recommend that anyone who cares for your child is familiar with the information below.

- When you call the GI clinic be prepared to tell us exactly what symptoms your child is having. Give specific details about your concerns. Please have a list of current medications. Make sure we have your correct phone number so we can reach you.
- If your child is ill between 8:00 AM and 5:00 PM, call our office so you can speak with one of our nurses. Our nurses can provide support, notify your medical provider of your questions/concerns, and contact the emergency room (ER) if needed. If you cannot reach us and you or your child is seriously ill, please do not wait until you hear back from us; go to the ER right away!
- If you call before 12:00 PM with an urgent issue, we will make every effort to return your call by the end of the day. Calls that are not urgent will, generally, be returned within 1 to 3 business days.
- For medication refills, please call at least 5 business days before you will run out of your medication. Requests for refills should be made to the office during normal business hours (8:00AM to 4:30 PM).
- If you use a mail order service, please call at least 3 weeks before you need the refill so there is enough time for your medication to be mailed to you.
- If you need prior authorization from your insurance company, you may need to call at least a week before you need a refill.
- Please try to bring records of any outside ER visits, hospital admissions or other health information to your visits with us. The most important records to bring are the discharge summary and reports of any tests, such as endoscopy, CT, MRI, and blood tests.
- If you have an **urgent** question or concern related to your IBD care after 5:00 PM on a weekday or on the weekend or a holiday, call the hospital operator and ask for the gastroenterologist (GI) doctor on call.
- Important numbers:
 - Main hospital number: (323)-660-2450
 - GI nursing line: (323)-361-2777
 - IBD nursing line: (323)-361-3581