Inflammatory Bowel Disease in Children
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What is inflammatory bowel disease?

Inflammatory bowel disease (IBD) describes conditions that cause inflammation in the gastrointestinal (GI) tract. Two of the most commons types of IBD are Crohn's disease and ulcerative colitis. Crohn's disease may involve inflammation in any part of the GI tract (from the mouth to the anus). Ulcerative colitis affects only the large intestine (colon and rectum). In about 15 percent of cases when inflammation is only in the large intestine, it may not be clear whether it is because of Crohn’s disease or ulcerative colitis and may be labeled as indeterminate colitis.

Crohn's disease and ulcerative colitis may share similar symptoms, including the following:

- Persistent diarrhea
- Abdominal pain or cramps
- Rectal bleeding
- Fever and weight loss
- Fatigue
- Joint, skin or eye irritation
- Growth problems

There has been evidence of a genetic link to IBD, with about 20 percent of patients having a family member with the disease and with most family members with IBD following similar progressions of the disease.
It may be helpful to note your child’s particular diagnosis and the location(s) of your child’s inflammation.

**Date of Diagnosis:** ____________________________

**Date of Endoscopy/Colonoscopy:** ____________________________

**Date of Imaging (UGISBFT, CT, MRE, other):** ____________________________

**Diagnosis:**
- □ Crohn’s Disease
- □ Ulcerative Colitis
- □ Indeterminate

**Disease Locations:**
- □ Esophagus
- □ Stomach
- □ Duodenum
- □ Jejunum
- □ Ileum
- □ Colon
  - ○ Total colon
  - ○ Right colon
  - ○ Transverse colon
  - ○ Left colon
  - ○ Sigmoid colon
  - ○ Rectum
- □ Small intestine alone
  - □ Gastroduodenal
    - □ 5%
  - □ Distal ileum
    - □ 35%
Managing IBD

IBD affects every child differently. It can be controlled with treatment but not cured. Treatments can lead to remission (absence of or minimal symptoms). It is important to take treatments as directed to prevent a flare-up of symptoms.

Treatments may include the following:

• Dietary adjustments
• Probiotics
• A variety of prescription medications and medication types, summarized in the table below
• Colectomy or surgical bowel resection (surgically removing areas of bowel with uncontrolled disease)

These medications can be expensive and are not always covered by your insurance; however, programs associated with many IBD drugs can help pay for treatment. Ask your child’s doctor about assistance programs for IBD medications.

<table>
<thead>
<tr>
<th>Class of Drugs</th>
<th>Generic Name (Trade Name)</th>
<th>Indications (Use)</th>
<th>Route of Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biologic therapies</td>
<td>• Adalimumab (Humira)</td>
<td>For people with moderate-to-severe IBD. Effective for maintaining remission and for tapering off steroids.</td>
<td>Intravenous infusion or injection</td>
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<tr>
<td></td>
<td>• Certolizumab (Cimzia)</td>
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<tr>
<td></td>
<td>• Infliximab (Remicade)</td>
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<td></td>
<td>• Natalizumab (Tysabri)</td>
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<td>• Vedolizumab (Entyvio)</td>
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<td></td>
<td>• Ustekinumab (Stelara)</td>
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<tr>
<td>Class of Drugs</td>
<td>Generic Name (Trade Name)</td>
<td>Indications (Use)</td>
<td>Route of Delivery</td>
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<tr>
<td>Immunomodulators</td>
<td>• Azathioprine (Imuran, Azasan)</td>
<td>For use in people who have not responded adequately to aminosalicylates and corticosteroids. Useful for reducing dependency on corticosteroids. May take up to three months to work.</td>
<td>Oral, intravenous or subcutaneous injection</td>
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<td>• 6-Mercaptopurine (6MP) (Purinethol)</td>
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<td></td>
<td>• Methotrexate</td>
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<td></td>
<td>• Cyclosporine (Neoral, Gengraf, Sandimmune)</td>
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<td>Corticosteroids</td>
<td>• Budesonide (Entocort EC)</td>
<td>For mild-to-moderate Crohn’s disease and moderate-to-severe UC. Also effective for short-term control of flares.</td>
<td>Oral, rectal or intravenous</td>
</tr>
<tr>
<td></td>
<td>• Prednisolone (Orapred, Prelone, Pediapred, Medrol)</td>
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<td></td>
<td>• Prednisone (Deltasone)</td>
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<td>Aminosalicylates</td>
<td>• Balsalazide (Colazal, GIAZO)</td>
<td>For mild-to-moderate IBD and for the maintenance of remission and prevention of relapse of IBD once remission is achieved.</td>
<td>Oral or rectal</td>
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<tr>
<td>(5-ASA)</td>
<td>• Sulfasalazine (Azulfadine)</td>
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<td></td>
<td>• Mesalamine (Apriso, Asacol HD, Canasa, Delzicol, Pentasa, Rowasa)</td>
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<td></td>
<td>• Olsalazine (Dipentum)</td>
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<tr>
<td>Antibiotics</td>
<td>• Ciproflaxin (Cipro, Proquin)</td>
<td>For treatment of infections of IBD, such as abscesses.</td>
<td>Oral or intravenous</td>
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<tr>
<td></td>
<td>• Metronidazole (Flagyl)</td>
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Medication Log

Throughout the course of your child’s life, you may find that your child’s prescription medications for IBD will change. Sometimes the medications your child takes are no longer helpful, or a new drug comes along that works better than what your child is currently taking.

It is important to take all of the medications that are prescribed. While they may not always be easy-to-swallow pills, your child’s IBD doctor has prescribed these medications for a reason, so you should always make sure that your child takes all of his or her current medications at the recommended doses.

On page 9 is a chart to help you keep track of your child’s IBD medications. You can use this chart to remind you of all the medications that your child is taking when you visit the doctor or to track what (if any) medications your child has taken that have not worked. Use it any way you like; it is for your benefit.
<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage</th>
<th>Date Started-Date Ended</th>
<th>Side Effects (If Any)</th>
<th>Helpful?</th>
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Commonly Performed Tests

Throughout your child’s treatment for IBD, he or she will have a variety of lab tests to look for indicators as to whether his or her IBD is being sufficiently treated. Most tests will be run by taking a blood sample, although other tests (such as urine or stool) may be used as well. The following table summarizes common blood and stool tests that may be conducted as part of your child’s IBD treatment.

<table>
<thead>
<tr>
<th>Test</th>
<th>Descriptive Name</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>CRP</td>
<td>C-reactive Protein</td>
<td>Helps to diagnose inflammation (non-specific)</td>
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<tr>
<td>ESR</td>
<td>Erythrocyte Sedimentation Rate</td>
<td>Helps to diagnose inflammation (non-specific)</td>
</tr>
<tr>
<td>CBC</td>
<td>Complete Blood Count</td>
<td>Helps to diagnose anemia, infection, inflammation</td>
</tr>
<tr>
<td>Electrolytes</td>
<td>Sodium, Potassium, Chloride, CO2</td>
<td>Helps to diagnose dehydration</td>
</tr>
<tr>
<td>Liver Function</td>
<td>Liver Enzymes</td>
<td>Helps to diagnose medication side effects, PSC (primary sclerosing cholangitis)</td>
</tr>
<tr>
<td>Vitamin B12</td>
<td></td>
<td>Helps to diagnose anemia, nutritional status</td>
</tr>
<tr>
<td>Vitamin D</td>
<td></td>
<td>Helps to diagnose bone mineral status</td>
</tr>
<tr>
<td>Calprotectin</td>
<td>Stool Protein</td>
<td>Helps to diagnose active intestinal inflammation</td>
</tr>
<tr>
<td>TPMT</td>
<td>Thiopurine methyltransferase</td>
<td>Determines safety and starting dose of azathioprine or 6-MP</td>
</tr>
</tbody>
</table>
In addition to these lab tests, imaging tests (X-rays) may be conducted to evaluate the condition of your child’s digestive tract. Your child’s doctor will provide you with specific details and instructions before these tests, and you should not hesitate to ask any questions you may have. These tests include the following:

- **Upper Gastrointestinal Series (UGI):** Exam of the upper and middle sections of the GI tract. This test uses a barium contrast that your child will need to drink before the test.

- **Small Bowel Follow-through (SBFT)/Small Bowel Series (SBS):** A series of X-rays taken every 15-30 minutes. This test uses a barium contrast that your child will need to drink before the test. This test may take a half day or so to complete.

- **MR Enterography (MRE):** Special type of MRI performed with both oral and IV contrast material to produce detailed images of the small intestine.

- **CT Enterography (CTE):** Special type of CT performed with oral and IV contrast to produce detailed images of the small intestine.

- **Capsule Endoscopy:** Your child will swallow a capsule with a tiny camera attached. The camera (pillcam) takes pictures as it moves through the digestive tract, and the images are transmitted to a computer that is worn on a belt. Your child’s physician will later download and review the images. The capsule exits the body with stool after it makes its way through the digestive tract.
**Vaccination Concerns**

One common concern of many patients is the safety of receiving vaccinations for certain infections and diseases. Since IBD is an autoimmune condition, drugs often are used to decrease activity of the body’s immune system. For this reason, the body may have difficulty fighting off infection when immunosuppressant drugs are being used for treatment.

Vaccination is a process in which the body is exposed to a small amount of an infection-causing agent so that it will make antibodies. Antibodies are a type of protein that the body uses to fight off the infectious virus or bacteria.

Vaccines can be given as either killed or live viruses. IBD patients using immunosuppressant drugs and their family members should avoid live vaccines because exposure to the live agent actually may cause the infection if the immune system is not capable of forming sufficient antibodies.

Some examples of live vaccines that should be avoided when taking immunosuppressant drugs include the following:

- **Measles, mumps, rubella (MMR)**, which typically is given at age 1 and again at ages 4-6
- **Varicella (chicken pox)**, which typically is given around age 1

If your child will be starting a new immunosuppressant drug, it is best to consult a doctor about administering a vaccine before starting the immunosuppressant. Fortunately, most IBD patients already have received the majority of necessary vaccines before their IBD diagnosis.

Different travel destinations have different requirements for vaccination. The recommendations and requirements for vaccination for travel to all areas of the world can be found at [http://www.cdc.gov/nip/](http://www.cdc.gov/nip/).
Dietary Considerations for IBD

Some parents worry that something in their child's diet has caused him or her to have IBD, but no evidence suggests that this is the case. On the other hand, evidence does suggest that diet can help improve the condition. Typically, no major restrictions are placed on a child’s diet: Individuality is the key. Many people do not have any obvious sensitivity to foods, whereas other people may.

Keep a food journal if your child is not tolerating certain foods and then speak with your child’s healthcare team about your concerns. Some dietary adjustments that can be made include low-fiber, low-salt, low-dairy and high-calorie diets for a variety of purposes. Consult with your child’s doctor about dietary changes to ensure that these choices are safe, given your child’s IBD condition.
**Enteral Therapy for IBD**

Enteral therapy is a non-medication treatment option for some children with IBD. This requires a child to drink 90-100 percent of their total calorie needs in the form of Pediasure or another formula. Sometimes a temporary nasogastric (NG) tube is placed to allow the formula to be administered if he or she cannot drink it all.

**Surgery for IBD**

Crohn’s disease and ulcerative colitis are lifelong illnesses. While treatment with medication is the first therapeutic option, some patients also may require surgery.

Elective surgery may be performed if symptoms fail to respond to medication or if complications develop. Elective surgery also may be recommended if a physician suspects an elevated risk of colorectal cancer, which is a risk associated with IBD.

Immediate surgery may be required for some complications associated with IBD, including …

- Sudden, severe ulcerative colitis
- Perforation of the colon
- Intestinal obstruction or blockage
- Excessive bleeding in the intestine
- Fistula
- Abscess
- Toxic megacolon
In addition to keeping track of the medications that have been used to treat your child’s IBD, you will need to maintain a record of the other diagnostic and treatment procedures performed over the history of your child’s life with IBD as well as any other related health events that may occur. Some procedures worth noting are endoscopies, colonoscopies and surgeries, and events such as related diseases or hospitalizations. The chart below is a helpful tool for maintaining a history of the various procedures that your child may have undergone for IBD.

<table>
<thead>
<tr>
<th>Date</th>
<th>Healthcare Providers</th>
<th>Procedure/Event Type</th>
<th>Outcome</th>
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<tbody>
<tr>
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Contact Information for IBD Team

IBD is a condition that your child will have for the rest of his or her life; therefore, it is helpful to maintain good communication and relationships with your child’s care providers. Below, you will find information that will help you stay in contact with your child’s care providers.

These providers may not be able to help your child in an emergency situation. If your child experiences any sudden or severe symptoms, the best course of action is to call 911 or go to an emergency room.

Children’s Hospital of Greenville Health System
Pediatric Gastroenterology
200 Patewood Drive, Suite A140
(864) 454-5125
(864) 241-9201 Fax
ghschildrens.org/pedsgastro

MyChart

MyChart is GHS’ free online patient portal. By opening a proxy account, you can communicate with the care team and see key parts of your child’s medical record such as test results, medication lists, office visit summaries and follow-up instructions, and hospital stay summaries, all through your own MyChart account. If you have more than one child, you can access all of their accounts through your own MyChart account once you have set up proxy access.

Ask about setting up a MyChart account for your child and a proxy account for yourself at your next doctor visit. To request a MyChart account for yourself or for more information about MyChart, visit ghs.org/mychart.
When to Call

It is important to know that there are many signs and symptoms that your child’s IBD could be flaring up or be in an active inflammation state. If any sudden or severe symptoms arise and you are fearful for your child’s health, go to an emergency room or call 911. There are a multitude of other, less severe symptoms that should prompt you to call your doctor such as the following:

- Temperature above 101 (especially if on prednisone or biologics such as Remicade, Humira, Cimzia, Entyvio, Stelara, Azathioprine, 6-MP or methotrexate and the fever cannot otherwise be explained)
- Stomach pain/cramps worse than usual and not going away
- Weight loss or significant change in appetite
- More than usual number of bowel movements each day
- Change in consistency of bowel movements
- Waking at night to have bowel movements
- Blood (red or dark black in color) in bowel movements or increased amount of blood
- New pain around the anus or rectum
- Vomiting
- Fatigue that does not go away
- Rashes, especially on lower parts of the legs
- Swelling or pain in joints
- Changes in vision or eye pain
- Very loud bowel sounds (louder than normal bowel sounds)

If any of the above symptoms persist or you feel that a new symptom that your
child is experiencing could be related to IBD, please call our office at (864) 454-5125. The pediatric nurse will want a description of your child’s symptoms to address your concerns; therefore, please be prepared to answer questions concerning the following:

- Stool changes, frequency and form of stools, presence of blood
- Pain
  - Location
  - How often it occurs
  - How long it lasts
  - What makes it better
  - How it rates on a scale of 1 (mild) to 10 (severe)
- Fever
- Vomiting
- All medication that your child is taking (prescriptions and over-the-counter or herbals)
Special Considerations and Accommodations for IBD

For many patients, IBD can interfere with their ability to perform at work or school. It is possible for your provider to complete a Section 504 letter, a Family and Medical Leave Act (FMLA) request or an Exceptional Family Member Program (EFMP) form to request accommodations or special considerations for you or your child to help minimize the effects of IBD on his or her day-to-day life. If you are interested in having one of these special considerations, you should discuss it with your child’s physician. Please allow the care team approximately one month’s notice to complete the request.

Trusted Resources

With such an abundance of information on the internet, it is possible to find misleading or misconstrued information about IBD. To avoid misinformation, we encourage the use of these sites:

• The Children’s Digestive Health and Nutrition Foundation (CDHNF): cdhnf.org
• Crohn’s and Colitis Foundation: CCFA.org
• Empowered by Kids: empoweredbykids.com
• Starlight and Starbright Programs: starlight.org, starbrightworld.org
• North American Society for Pediatric Gastroenterology, Hepatology and Nutrition: naspghan.org
• Kids IBD: kidsibd.org
• GIKids: gikids.org
• IBD University (IBDU): ibdu.org
• You and IBD: youandibd.com
• I’ll be Determined (CCFA): IBDetermined.org

IBD can be controlled with treatment but not cured. It is important to take treatments as directed to prevent a flare-up of symptoms.
ImproveCareNow

Your child’s GI doctor is a member of ImproveCareNow (ICN). ICN is a large international network of doctors who are collecting information on their patients with IBD so that they may improve patient care. Your doctor or nurse will talk with you about whether this is something that you would like to be a part of and, if so, you will be asked to sign a special consent form. By choosing to participate in ICN, you are helping us to achieve the best possible outcomes for patients with IBD.

ImproveCareNow also offers a variety of tools and resources for families living with an IBD diagnosis. Use the following sites to stay connected with the ICN community:

- ICN Homepage: improvecarenow.org
- Facebook: facebook.com/ImproveCareNow
- Twitter: twitter.com/ImproveCareNow
- Youtube: youtube.com/user/ImproveCareNow
- LOOP blog: improvecarenowblog.org
- Circle publication subscription: improvecarenow.org/subscribe
- ICN Exchange: improvecarenowexchange.org
Nondiscrimination Statement

Greenville Health System (GHS) does not discriminate on the basis of race, color, national origin, sex, sexual orientation, gender identity, age or disability in its health programs and activities.

GHS provides appropriate aids and services, including qualified interpreters and written information in various formats, for people with disabilities. GHS provides language assistance services, including translated documents and oral interpretation, to people whose primary language is not English. All services are timely and offered for free. Those needing these services should call (864) 455-7000.

GHS has designated its Diversity Coordinator to ensure compliance with these services. Any person who believes someone has been discriminated against may submit to the Diversity Coordinator, within 60 days of becoming aware of the alleged discrimination, a written complaint with the name and address of the person filing the grievance, as well as the problem or action alleged to be discriminatory.

Complaints may be filed at diversity@ghs.org or 701 Grove Road, Greenville, SC 29605, attn. Diversity Coordinator. Individuals may file a complaint in court or with the U.S. Department of Health and Human Services, Office of Civil Rights, by mail at 200 Independence Ave. SW, Room 509F, HHH Building, Washington, DC 20201, by phone at 1-800-368-1019 or online at https://ocrportal.hhs.gov/ocr/office/file/index.html.

Language Assistance Information

Si usted habla español, tenemos a su disposición servicios gratuitos de asistencia lingüística. Llame al (864) 455-7000. (Spanish)

如果您说中文，傳譯服務可免费提供服务。您可以拨打。（864) 455-7000 (Chinese)

Neu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Goi số (864) 455-7000. (Vietnamese)

한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. (864) 455-7000 번으로 전화해 주십시오. (Korean)

Si vous ne maîtrisez pas bien la langue anglaise, des services gratuits d’assistance linguistique sont disponibles au numéro suivant (864) 455-7000. (French)

Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa (864) 455-7000. (Tagalog)

Если Вы говорите на русском языке, то Вам доступны бесплатные услуги переводчика. Звоните (864) 455-7000. (Russian)

Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: (864) 455-7000. (German)

분명 매 한국어를 하시는 분, 번역 서비스를 무료로 이용하실 수 있습니다. (864) 455-7000. (Korean)

إذا كنت من الناطقين باللغة العربية، تناح خدمات المساعدة اللغوية. اتصل على الرقم 455-7000. (Arabic)

Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para (864) 455-7000. (Portuguese)

注意事项：日本語を話す場合、言語支援サービスは無料でご利用できます。(864) 455-7000 までお電話ください。(Japanese)

Якщо ви розмовляєте українською мовою, ви можете звернутися до безкоштовної служби мовної підтримки. Телефонуйте за номером (864) 455-7000. (Ukrainian)

अगर आप हिंदी बोलते हैं, तो आप के लिए नं: शुल्क भाषा सहायता सेवाएँ उपलब्ध हैं। (864) 455-7000 पर कॉल करें! (Hindi)

نهائية لغوية مكملة للمصلحة تدعم فهم المرضى باللغة الأصلية للغة العربية، (864) 455-7000، (Cambodian)