



Boston
Children's
Hospital

Until every child is well™

Inflammatory
Bowel Disease
Center

IBD

Your Guide to Inflammatory Bowel Disease

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What is IBD?

Inflammatory bowel disease (IBD) is a term that describes several different conditions that cause inflammation (pain, swelling, irritation and ulcers) in the digestive tract. Signs of inflammation include vomiting, diarrhea, rectal bleeding and stomach pain. Children with IBD may lose weight or struggle to keep weight on, may feel tired or not grow as quickly as their peers.

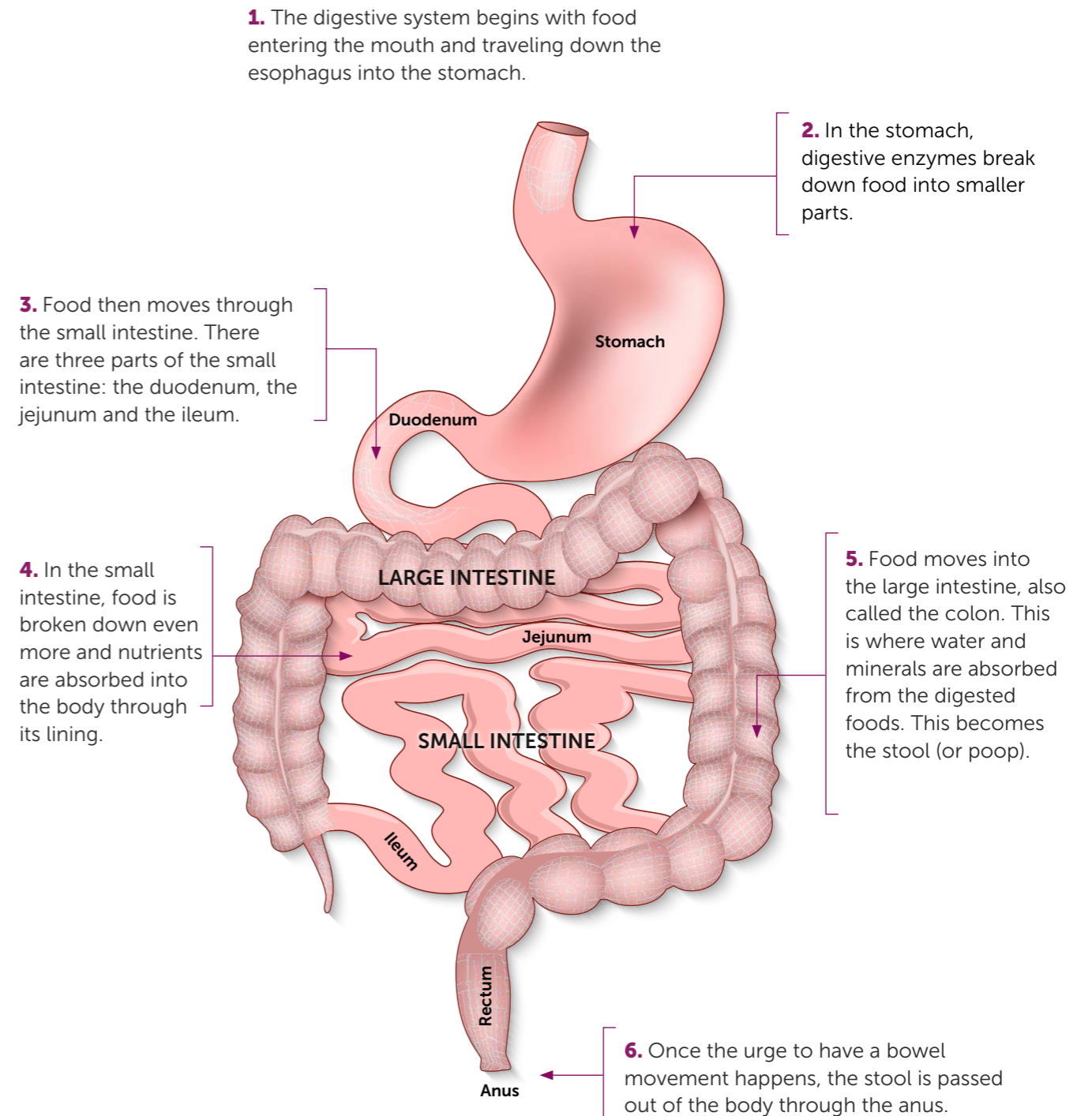
The two most common types of IBD are called Crohn's disease and ulcerative colitis. However, sometimes, it isn't always clear what form of IBD a child has, and this is called indeterminate colitis. Other types of IBD can also occur in young children, including IBD associated with immune deficiency syndromes.

Crohn's disease usually affects the terminal ileum, which is the part of the small intestine that connects to the large intestine. However, it can affect any part of the digestive tract including the mouth, esophagus, stomach, small intestine and large intestine. Active symptoms of Crohn's disease, also known as flares, may include diarrhea, rectal bleeding, abdominal pain, tiredness or weight loss.

Ulcerative colitis causes intestinal swelling and is usually limited to the inner lining of the large intestine (colon, rectum or both). For this reason, ulcerative colitis patients tend to experience abdominal cramps and diarrhea with bleeding as their main symptoms.

Although there is no cure for Crohn's disease or ulcerative colitis, most patients with these conditions can be effectively treated with medications, nutritional therapies and in some cases, surgery.

THE GI TRACT



What causes IBD and how is it diagnosed?

While we don't know the exact cause of IBD, we know it occurs when a child's immune system (the cells of the body that protect against infection) reacts against his or her own intestine. This is similar to other diseases caused by a faulty immune system, including asthma, diabetes and rheumatoid arthritis.

The first step in treating IBD is to figure out whether or not your child has Crohn's disease, ulcerative colitis or another type of IBD. To do that, a doctor will take a careful medical history and perform a physical exam. Some other tests might also be needed, such as:

Scope procedures

- An upper endoscopy looks inside the esophagus, stomach and the beginning of the small intestine. The doctor will pass a long, flexible tube with a light on the end through the mouth and esophagus and into the stomach and small intestine. As the doctor passes the tube, he or she looks at these areas and may take small samples of tissue, which are called biopsies.
- A colonoscopy also uses a thin, flexible tube with a light and camera lens at the end to examine the inside of the large intestine and the end of the small intestine. As the doctor passes the tube through the rectum, he or she looks at the areas of the large intestine and the end of the small intestine, and also may take biopsies.

Both of these scope procedures are performed under sedation as a day procedure.

Imaging

- CT and MRI scans can be used to detect inflamed or narrow areas of the small or large intestine, as well as visualize other abdominal organs.

Blood work

- Providers will test your child's blood to help diagnose IBD and to see how well treatment is working. These are the most common blood tests used for IBD and what the results can mean.

BLOOD TEST	WHY IT'S USED IN IBD
Hematocrit	<ul style="list-style-type: none">• measures the number of oxygen-carrying red blood cells• low levels can indicate anemia
White Blood Cell Count (WBC)	<ul style="list-style-type: none">• measures the number of white blood cells• elevated values reflect infection, inflammation or severe stress on the body or may be the result of medications such as corticosteroids
Platelet Count	<ul style="list-style-type: none">• platelets are small cells that help stop bleeding• elevated values reflect infection, inflammation or severe stress on the body or may be the result of medications such as corticosteroids
C-Reactive Protein (CRP)	<ul style="list-style-type: none">• CRP is a non-specific marker for infection and inflammation
Erythrocyte Sedimentation Rate (ESR or SED Rate)	<ul style="list-style-type: none">• measures how quickly red blood cells settle in a test tube• this is a non-specific marker for infection and inflammation

Signs of a disease flare

Inflammatory bowel disease is a chronic condition. Many patients experience periods of remission, or feeling well, and have few or no symptoms, or periods where the disease symptoms are very active. These active periods are called flares.

Flare symptoms may range from mild to severe and are often similar to the symptoms that children experience when first diagnosed with IBD. While some symptoms strongly suggest a flare, others may be signs of a virus or other illness instead.

Some common symptoms are listed to the right.

Although flares may occur for no obvious reason, certain factors can trigger flares in some people. Triggers may include stress, certain foods, smoking or medications such as ibuprofen. Your child's gastroenterologist can help you understand more about IBD flares.



What to do when you have a flare?

POSSIBLE SYMPTOMS

- Diarrhea that persists
- Urgent bowel movements
- Blood in the stool or black, tar-like stools
- Painful stomach cramps for multiple days
- Fatigue, involuntary weight loss, lack of appetite
- Ongoing fever that's not tied to a viral illness like the flu
- Nausea and vomiting that persists for multiple days
- Unexplained mouth ulcers
- Joint pain and swelling
- Eye inflammation
- Painful bumps on the arms and/or legs that are coin-sized and either purple or red

WHAT TO DO

Contact your child's gastroenterologist for an evaluation. They may need to do some testing to see what is causing the symptoms to return and locate the area of inflammation. Oftentimes a flare-up is a sign that a new treatment may be needed, such as a change in medication.



How is IBD treated?

Once your child has been diagnosed with Crohn's disease or ulcerative colitis, a medical team will choose the right treatment plan for them. Typically, IBD is treated with a combination of medication and dietary changes. In more serious cases, surgery may be needed to remove or repair a segment of diseased intestine. The majority of IBD patients require long-term treatment with medication.

Many different medications are used to treat Crohn's disease and ulcerative colitis. The main classes of medications include aminosalicylates, immunomodulators and biologics. Your provider will recommend specific medications based on your child's disease type and severity. These medications are given to limit or avoid flare-ups of symptoms. Providers may also prescribe antibiotics, enteral nutrition or steroids.

Your IBD specialist will provide additional information about dietary changes and medications used to treat IBD.



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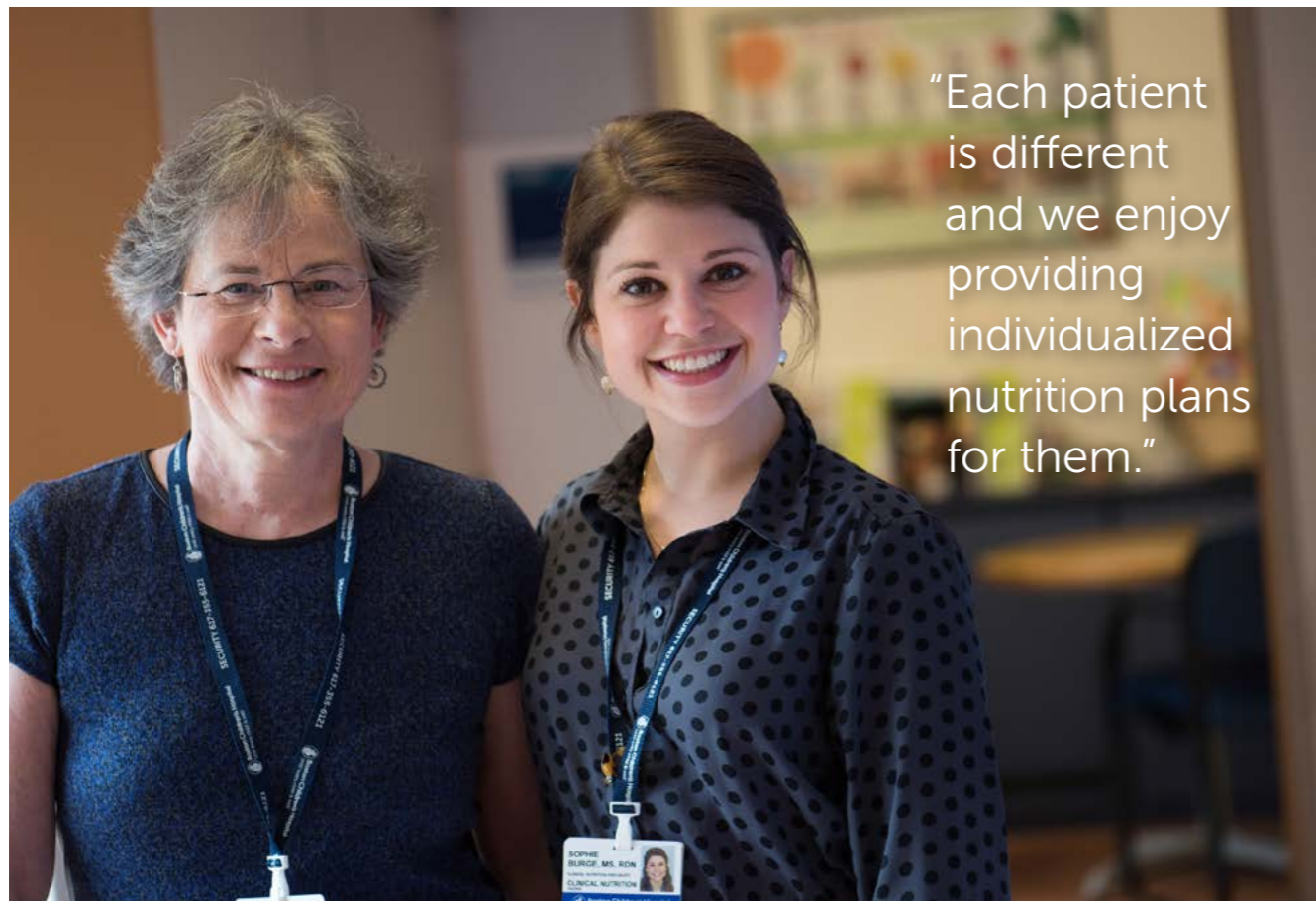
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Boston Children's approach to care

The Inflammatory Bowel Disease Center at Boston Children's is made up of many IBD and child care specialists — each with a unique role in providing care for our patients and their families. Our entire team is specially trained to make treatment as easy as possible for young patients and their families.

With so many experts working together — each with a deep understanding of the causes, clinical progression and treatment of IBD — the team at Boston Children's is able to care for all young patients from infants with early-onset IBD to patients entering early adulthood. We also provide consultations for those who have already been diagnosed with the condition but need a second opinion related to diagnosis or treatment.



“Each patient is different and we enjoy providing individualized nutrition plans for them.”

YOUR CARE TEAM

When you make an appointment at Boston Children's Inflammatory Bowel Disease Center, you and your child have access to a comprehensive care team including:

Gastroenterologists, who are doctors with special training focused on the digestive system and its disorders.

Nurses and nurse practitioners, who help care for your child and teach you about your child's illness.

Dietitians, who understand how food choices can affect IBD and who will assess your child's vitamin, protein and caloric intake.

Psychologists, who offer emotional and psychological support.

Clinical social workers, who can facilitate school advocacy, identify available community resources and help you and your child deal with stress caused by living with IBD.

Surgeons, who in some cases may need to operate on patients with severe cases of Crohn's disease and ulcerative colitis.

Endocrinologists, dermatologists, rheumatologists and ophthalmologists are some other specialists who may be part of your care team.

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Living with IBD

While IBD is a serious chronic illness, most people with the condition have an excellent quality of life. It's important for your child to:

- take medications as prescribed
- follow dietary recommendations
- get plenty of sleep and exercise
- have regular follow-up visits with their health care provider

Stress management

As with any chronic illness, having IBD can be stressful, and stress management may help reduce symptoms. For patients with ongoing intestinal symptoms, knowing where nearby restrooms are can reduce stress associated with the condition.

Support

Having the support of a close-knit group of family, friends and your care team is also important because it helps make dealing with IBD symptoms easier and less isolating.

Care team

To help manage stresses associated with the disease, the Inflammatory Bowel Disease Center at Boston Children's includes a team of social workers and psychologists that specialize in children, teens and young adults with chronic gastroenterological illnesses. The team can also offer guidance and support for children with IBD learning to adjust to the stresses of this condition.



Going to school

Students with IBD:

- may be absent from class for days at a time
- may need to make sudden trips to the bathroom
- may have very specific dietary concerns

For these reasons, it's important for parents or caregivers of children with IBD to set up a meeting with the school staff and a social worker to discuss how the condition impacts day-to-day life at school. A 504 educational plan should also be considered to ensure that your child is fully accommodated at school.

Going to school and participating in extracurricular activities is very manageable with the support of family, teachers, school nurses and an experienced medical team.



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Going away from home

The idea of being away from home can be stressful for children and young adults with IBD. But sleeping over at a friend's house, attending camp or going on vacation doesn't have to be uncomfortable. Here are some tips to manage IBD when traveling:

Overnight stays

- Take enough medication with you to last the entire time you will be away.
- If you are on a special diet, bring some snacks or other food with you from home.
- If possible, let a supervising adult know about your IBD and what it means.

Travel

- Talk to a member of your care team about where you are going and for how long, so they can help you plan accordingly.
- Always store medication in carry-on bags in case your luggage is lost.
- Keep medicines in their containers with the original labels and bring copies of your prescriptions. A medical letter explaining your medication, nutrition and other needs related to IBD may also be helpful.
- Bring your health care provider's name, phone number and email address. Try to get the name and phone number of a doctor in the area you'll be visiting.

Keep in mind that dietary changes, as well as smoking and other habits, can trigger IBD flares in some people.



Heading off to college

The first year of college can be stressful for many young adults with IBD, especially if it's the first time they are managing their health independent of their parents or caregivers. One way to deal with stress is cut out uncertainties. Ask your child to make a list of potential problems or concerns they have about living at school and then work with a caregiver, friend or medical professional to talk about how to handle the concerns. That way, if problems do arise, they won't seem so overwhelming. Some things to consider:

- Who will you call in a medical emergency?
- Can you eat the food in the cafeteria?
- Is there a gastroenterologist near your college and do you know how to reach them?
- Will you have a roommate? If so, will you bring up your IBD with him or her?
- Will going off to college affect your insurance plan? If so, how?

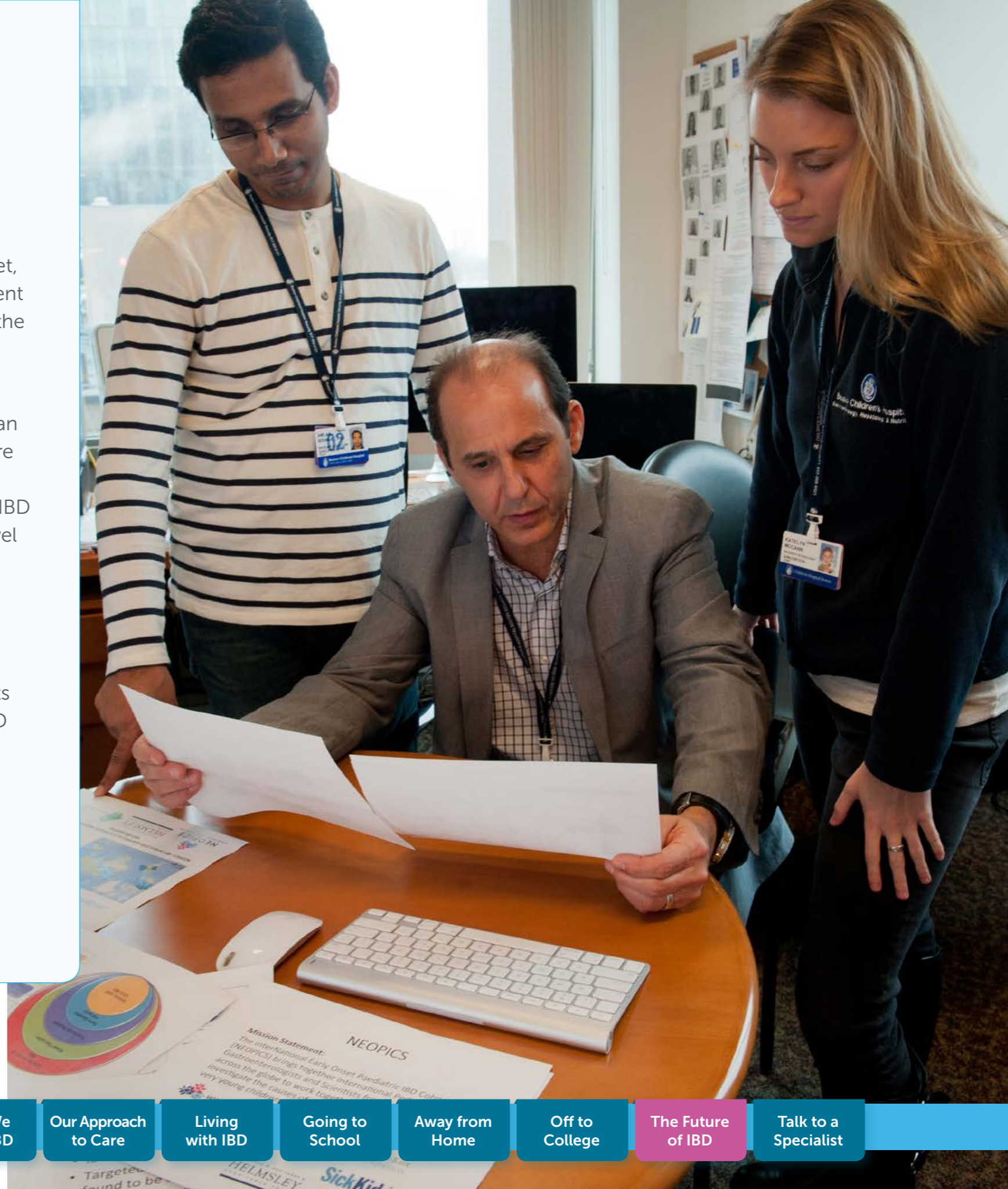
What's in the future for IBD?

The doctors and scientists at Boston Children's are leading research to improve the lives of children with IBD. They are currently studying the role of genes, diet, intestinal bacteria and other factors in the development of IBD, which will likely lead to better treatments for the condition.

Because children under age five with IBD often have different symptoms and require different treatment than older children or adults with IBD, we also have an entire team of investigators devoted to studying very early-onset IBD (VEO-IBD). To better understand how VEO-IBD affects the body, researchers at the Inflammatory Bowel Disease Center are actively researching many aspects of the disease, which has led to customized, targeted treatments for patients.

As the field continues to evolve, our researchers are confident they will be able to improve diagnostic tests and treatments for the condition, making life with IBD much easier for young children and their families.

Learn more about our research program at BostonChildrens.org/IBDresearch.



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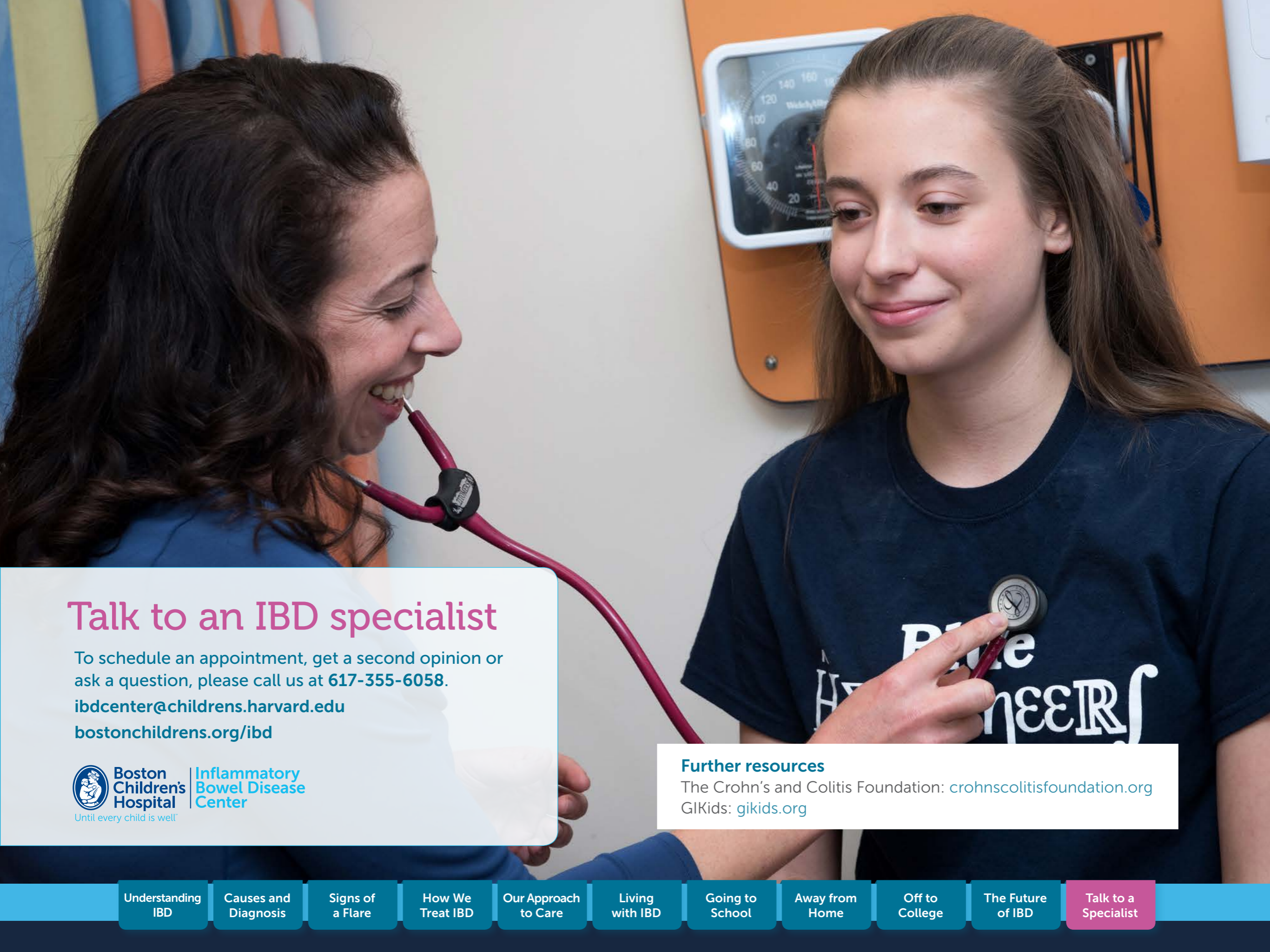
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Talk to an IBD specialist

To schedule an appointment, get a second opinion or ask a question, please call us at **617-355-6058**.

ibdcenter@childrens.harvard.edu

bostonchildrens.org/ibd



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Further resources

The Crohn's and Colitis Foundation: crohnscolitisfoundation.org

GIKids: gikids.org

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