



I'm
Better than this
Disease

UNDERSTANDING
INFLAMMATORY
BOWEL DISEASES

What **TYPES OF PEOPLE** have learned how to manage their IBD?

Athletes
Musicians
Firefighters
Doctors
HEROES
Artists
Presidents
Actors
Dancers

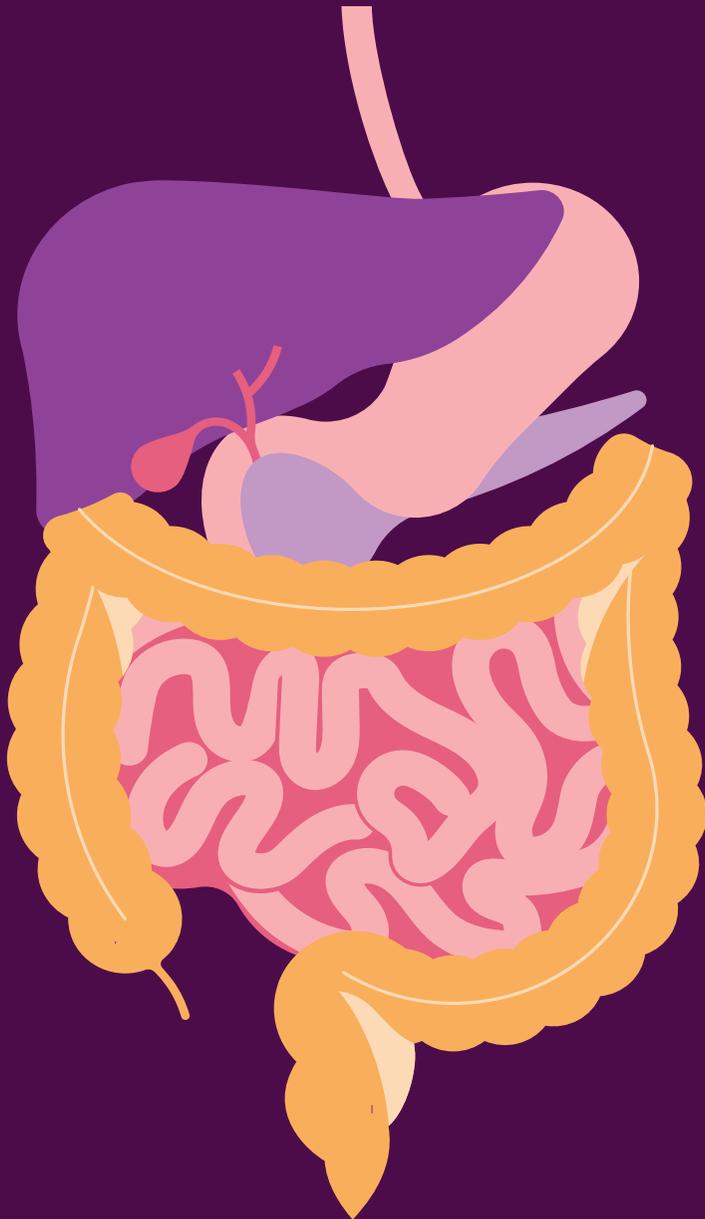
Welcome to the **INFLAMMATORY BOWEL DISEASE CENTER**

The Inflammatory Bowel Disease (IBD) Center at UPMC Children's Hospital of Pittsburgh offers advanced medical care and compassionate support for patients and their families. Our team of health care professionals uses a comprehensive approach and the latest advances in research and technology to control symptoms and improve the quality of life for children with IBD. The IBD Center is part of the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at UPMC Children's, giving patients access to world-class experts in general pediatric gastroenterology and a broad range of specialty areas.



For information or to schedule an appointment at the Inflammatory Bowel Disease Center, please call **412-692-5180**.

Understanding its causes, effects,
and treatments will **EMPOWER YOU**
to better manage your inflammatory
bowel disease (IBD).



What Is IBD?

IBD is lifelong inflammation of the gastrointestinal (GI) tract that may have symptoms that range from mild to severe. IBD and irritable bowel syndrome (IBS) are not the same condition, but sometimes occur together. Types of IBD include:

- **Crohn's disease** — Commonly affects the end of the small intestine or colon, but any area of the GI tract can be affected from mouth to anus. The involvement can affect the full thickness of the intestine and can have a patchy distribution. The disease can be further classified as stricturing (narrowing), penetrating (abscesses/fistulas), or inflammatory.
- **Ulcerative colitis** — Inflammation that affects the lining of the colon in a continuous fashion.
- **Indeterminate colitis** — The disease is not distinctly classified as either Crohn's or ulcerative colitis.

In addition, other parts of your body (**extraintestinal manifestations**) can be affected, such as eyes, joints, bones, skin, kidneys, and liver.

What Causes IBD?

IBD is not contagious, but researchers believe it can be triggered by a range of genetic or environmental risk factors, including family history, Jewish heritage, if the patient was born by Cesarean delivery, minimal breast milk exposure, early use of antibiotics, if the patient takes oral contraceptives, tobacco exposure, Western diet (processed, high fat,

refined sugar), physical inactivity, or use of anti-inflammatory medicines (NSAIDs). In the body of a genetically susceptible individual, white blood cells have an abnormal immune response and attack the GI tract by sending out proteins (cytokines like TNF-alpha and interleukins) that cause inflammation and tissue injury.

Symptoms

People with IBD may experience weight loss, stunted growth, fever, abdominal pain, bloody diarrhea, decreased appetite, mouth ulcers, and involvement around the anus (fistulas, skin tags, fissures, and abscesses).

How Is IBD Diagnosed?

Diagnosis begins with a **physical exam**, checking for weight loss, abdominal tenderness, mouth ulcers, delayed puberty, skin lesions, joint tenderness and swelling, and involvement around the anus (tags, fissures, fistulas, and abscesses). Your care team may also order the following:

- **Stool samples** to detect infection, blood, and inflammation
- **Blood tests** to check for anemia, inflammation, nutritional deficits, liver and kidney function, and electrolytes
- **Colonoscopy and upper scope** to visualize and biopsy diseased areas of the GI tract by inserting a flexible tube called an endoscope
- **CT scan or MRI** of the abdomen to examine parts of the small intestine that the scope cannot reach

MANAGING Your Disease

There is no cure for IBD. However, a team of care providers including a gastroenterologist, nurse practitioner, nurse, dietitian, and medical coping specialist will work with you to develop a comprehensive treatment plan to eliminate symptoms, improve growth, heal the intestines, and maintain quality of life with medications and diet. Certain medications are used short-term to stop IBD symptoms (**induction therapies**), and others are added to manage the disease over the long term (**maintenance therapies**). Treatment recommendations will be discussed between you and your pediatric gastroenterologist to find the best combination of therapies for disease activity. Medications often used to treat IBD suppress the immune response. Lab tests are usually done every three to six months to monitor for side effects and response to therapy.

5-ASA (oral or rectal)

Induction

Maintenance

- Balsalazide (Colazal®)
- Mesalamine (Apriso™, Asacol® HD, Canasa®, Delzicol™, Lialda™ Pentasa®, Rowasa®)
- Sulfasalazine (Azulfidine®)

Biologics (infusions and injections)

Induction

Maintenance

- Adalimumab (Humira®)
- Infliximab (Remicade®)
- Ustekinumamb (Stelara®)
- Vedolizumab (Entyvio®)

Small molecule (oral)

Induction

Maintenance

- Tofacitinib (Xeljans®).
- Upadacitinib (Rinvoq®).

Corticosteroids (intravenous and oral)

Induction

- GI tract specific: budesonide (Entocort®EC, Uceris™)
- Systemic: prednisolone, prednisone, methylprednisolone

Immunomodulators (oral and injections)

Maintenance

- 6-mercaptopurine (Purinethol®)
- Azathioprine (Imuran®)
- Methotrexate

Exclusive enteral nutrition (EEN) (By mouth or nasogastric tube)

Induction

- A diet where 80 to 100% of daily calories come from medically complete formula for 8 to 12 weeks.
- Can work as well as corticosteroids to induce remission in children with mild-to-moderate Crohn's disease.



Diet and Nutrition

Generally, a well-balanced and unprocessed diet is recommended, similar to a Mediterranean diet.

Special diets can be effective as sole therapy for a few children, but they generally are used to complement medications. These include:

- **Crohn's disease elimination diet (CDED)** — a combination of formula and specific foods
- **Specific carbohydrate diet (SCD)** — a diet of whole, unprocessed foods that is low in sugar and lactose and eliminates grains

Treatment Helps

Left untreated, patients with IBD may experience worsening symptoms, poor growth and delayed puberty, and increased risk of colon cancer and serious complications with potential for hospitalization. Even with treatment, surgery may be necessary to alleviate severe symptoms or remove a damaged area of the intestine that medications cannot improve.

Important Reminders

Self-care is important, so be sure to do the following:

- Yearly influenza vaccine
- Yearly dilated eye exam
- Yearly skin exam (especially for those taking medications that have a risk of skin cancer)
- Always use sun protection with SPF 30 or greater
- It's important to stay up-to-date on vaccinations (no live virus vaccines if immunosuppressed)
- DEXA scan to monitor bone health if you have a history of fractures and/or prolonged steroid use
- Avoid tobacco use and tobacco exposure

Your care team will provide you with a letter to set up a 504 plan with your school that allows for special accommodations such as stop-the-clock testing, an unlimited bathroom pass, and the ability to make up missed assignments.

Inflammatory Bowel Disease Center

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