

# My Inflammatory Bowel Disease (IBD) Book



# Dear Parents and Guardians

Thank you for choosing MemorialCare Miller Children's & Women's Hospital Long Beach for your child's health care needs. Inflammatory bowel disease (IBD) is a very complex disease that requires the expertise of many caregivers.

You are receiving "My Inflammatory Bowel Disease Book" because your child has recently seen one of our pediatric gastroenterologists and is suspected of having or been diagnosed with IBD.

This book was created by our dedicated IBD Nurse Practitioner to help guide families as they learn more about this new diagnosis. Our team has compiled the latest, evidence-based information and resources on IBD for you and your family.

The "My Inflammatory Bowel Disease Book" is intended to help you and your family understand your child's IBD diagnosis. This book is a first step to a path toward IBD control and a healthy and active life for your child. The more you learn about IBD, the more confident you will be about helping your child avoid serious flares or medical emergencies.

Although there is currently no cure for IBD, we are constantly staying up to date on the latest treatments including medications and nutritional therapies to best manage this lifelong condition. This booklet is designed to teach you the basics. Beyond this, we will work to keep you informed on the latest updates regarding IBD treatment. Understanding IBD, staying informed and close communication will increase the likelihood that your child will stay in remission. As always, we are here for you and your child through this journey.

**Important:** The information contained in this booklet is not meant to replace or substitute medical treatment given by a doctor. Do not change or add any medications or make changes in your IBD plan without first contacting your doctor and IBD Team.



# Our Inflammatory Bowel Disease Program

## Our comprehensive IBD Center team consists of:

- Board-certified pediatric gastroenterologists
- Multi-disciplinary team including a certified nurse practitioner, registered dietician, social worker, psychologist, radiologists and surgeons
- Dedicated IBD Clinic at the Children's Village where your child can see the entire multidisciplinary team
- Outpatient care offered in Long Beach, Torrance and Fountain Valley
- Infusion services that are open six days a week at our Infusion Center
- Ongoing research into new evidence-based practices and treatments
- Care coordination and open communication, including access to MyChart® (an online patient-physician communication platform)
- Improved Care Now (ICN): A nonprofit organization that networks with patients, families, and health care professionals to enhance care for children with IBD. Benefits include many useful tools and handbooks for patients and families, community conferences and an exchange that allows participants to share information.



# Inflammatory Bowel Disease Facts

Inflammatory Bowel Disease (IBD) is an umbrella term and most commonly includes Crohn's Disease (CD) and Ulcerative Colitis (UC).

- IBD results in chronic inflammation of the gastrointestinal (GI) tract.
- The GI tract extends from the mouth to the anus.
- IBD cannot be cured but can be controlled with many various treatment options.
- The exact cause of IBD is unknown but involves a family history (genetics), an overactive immune system and many environmental factors.
- IBD can occur at any age but is most commonly diagnosed between the ages of 15 and 35 years.
- Crohn's disease is more likely to occur in children by almost twice as much compared to ulcerative colitis.
- Developed countries have a higher number of IBD reported cases – although this is changing.
- IBD can affect any race or ethnic group.

## IBD by the numbers



**1.6 million**  
Americans  
have IBD



**80,000**  
patients are  
children under 18



**20 percent**  
of patients have a  
family member  
with IBD



**70,000**  
new cases  
are diagnosed  
each year

Source: Crohn's & Colitis Foundation of America

# Your Child's Gastrointestinal Tract

The gastrointestinal (GI) tract is an organ system that takes the food that we eat and digests it to provide our bodies with energy and nutrients and expels the waste as a bowel movement.

## Upper GI tract includes:

- Mouth
- Pharynx
- Esophagus
- Stomach
- Duodenum

## Lower GI tract includes:

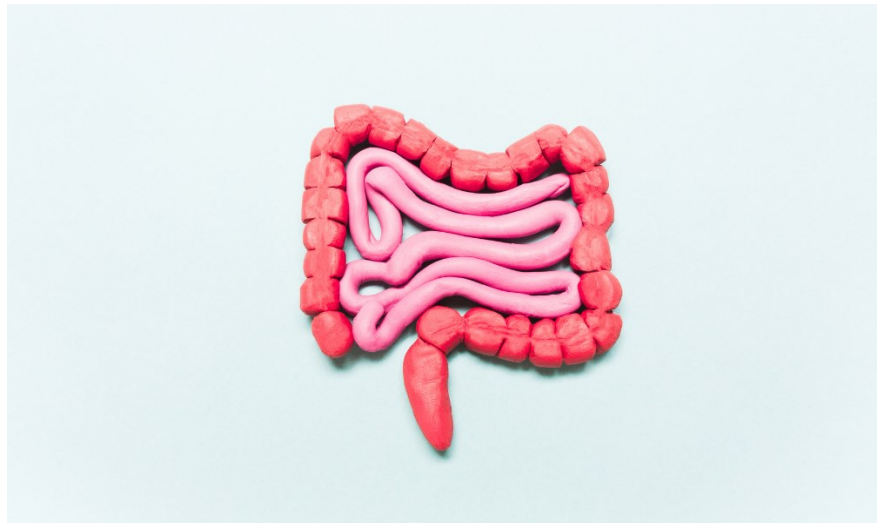
- Small intestine
- Large intestine

## Small intestine includes:

- Duodenum
- Jejunum
- Ileum
  - The main function of the small intestines is to absorb carbohydrates, proteins, fats and vitamins from digestion into the bloodstream.

## Large intestine (aka colon) includes:

- Cecum
- Ascending Colon
- Transverse Colon
- Descending colon
- Sigmoid colon
- Rectum
- Anus
  - The main function of the large intestines is to reabsorb water and create stool.



# Overview of Ulcerative Colitis

## What is Ulcerative Colitis?

Ulcerative Colitis (UC) is a chronic disease that causes the lining of the colon (large intestine) to become inflamed and develop sores and ulcers. Only the innermost lining of the colon which is called the mucosa becomes inflamed.

## Age of Onset

- UC may occur at any age but most commonly at 15-35 years

## Signs & Symptoms

- Abdominal cramping or pain
- Increased bowel movements (diarrhea)
- Rectal bleeding
- Mucous in the bowel movements
- Stool urgency or sensation of incomplete stooling
- Nocturnal bowel movements
- Fatigue
- Unexplained fevers



## Complications

- Loss of appetite
- Weight loss
- Anemia
- Delayed growth and development in children

# Overview of Crohn's Disease

## What is Crohn's Disease?

Crohn's disease is a chronic inflammatory process of the gastrointestinal tract that can occur anywhere from mouth to anus. Crohn's can skip large segments of intestines and reappear in other parts. The inflammation from Crohn's can burrow through the entire thickness of the intestinal wall.

## Age of Onset

- May occur at any age, but most commonly at 15-35 years

## Signs & Symptoms

- Abdominal cramping or pain
- Increased bowel movements (diarrhea)
- Rectal bleeding
- Fatigue
- Unexplained fevers
- Malnutrition
- Oral ulcers
- Anal skin tags



## Complications

- Loss of appetite
- Weight loss
- Delayed growth and development in children

## Serious Complications

- Fissures
- Fistulas
- Strictures

# Test to Confirm Diagnosis

## Upper Endoscopy

Also known as an EGD, this procedure involves a lighted tool with a small camera which is inserted into the mouth and used to visualize the upper digestive tract starting at the esophagus and ending in the duodenum.

## Colonoscopy

This is a procedure with lighted flexible tube that is inserted into the anus and allows the doctor to visualize the inside of the colon and last part of the small intestine (ileum).

## Biopsy

These are small pieces of intestinal lining removed from the intestine to send for further analysis under the microscope by a pathologist.



## Capsule Endoscopy

This is a pill sized wireless camera that travels through your digestive tract and takes pictures or video of your GI tract. It is often used to assess areas of intestine that cannot be reached by an upper endoscopy or colonoscopy. It cannot take biopsies, however.

## Radiological tests

- Magnetic Resonance Imaging (MRI) – which is the highest definition imaging available and has no radiation.
- Computed Tomography (CT Scan) – this is a collection of x-rays put together to make a three-dimensional image.
- X-Rays – simple one view of the intestine/body.

## Stool infectious studies

Stool test to make sure there is no bacterial, viruses or parasites.

## Fecal calprotectin

This is a test used to measure inflammation along the GI tract. A normal fecal calprotectin means there is no detectable inflammation which is good.



# What is an IBD Flare?

An IBD flare is reappearance of disease symptoms which may include frequent bowel movements, diarrhea, bloody stools, abdominal pain, nausea and vomiting or weight loss.

## Factors that Affect IBD Flares

- Natural progression of disease
- Missing medication or taking the incorrect dose
- Overuse of non-steroidal anti-inflammatory drugs (NSAIDs) including ibuprofen, naproxen sodium or others
- Antibiotics
- Smoking
- Stress
- Certain types of food



## Admission Criteria Curing an IBD Flare

- Abdominal pain that does not respond to over-the-counter medications (Tylenol®, Motrin®, etc.)
- Abnormal labs, including profound anemia
- Increased frequency of diarrhea
- New or increased frequency of nocturnal bowel movements
- Increased blood in bowel movements
- Fever of unknown origin

# What to Expect if Your Child is Admitted to the Hospital

Your child may be admitted to the hospital if his/her IBD is not in control, home treatments have failed or if IBD symptoms become life-threatening.

Coming to the hospital can be a stressful and scary time for patients and their family members. Having good communication with your health care team and keeping track of your symptoms will help your team treat your child more effectively. Some steps that will be taken upon admission include:

- Your child will be taken care of by a multidisciplinary team including a Pediatric Hospitalist, Gastroenterologist, NP, RNs, Registered Dietitians and many more
- Some tests may include endoscopy/colonoscopy as well as radiographic studies such as CT or MRIs
- Your child's vital signs will be taken. These are a measurement of your child's heartbeat, how fast he/she is breathing, blood pressure, and temperature. Vital signs may be taken every one to four hours during the day and night.
- A pulse oximeter will be placed on your child's finger or toe. This is a non-painful, red light taped to your child's finger that measures the amount of oxygen his/her blood.
- An intravenous catheter (IV) may be on your child's hand, arm or foot to give fluids, medicines, or provide gut rest for your child.
- Your child will receive medicines by pill, syrup, or IV.
- A child life specialist may visit you to answer questions and make your stay more comfortable for you and your child.



*A child life specialist helps a patient adjust to hospitalization through a process called “medical play.”*

# Treatment Options

There are many different treatment options and depending on how mild, severe or frequent your symptoms are will help to determine your options. We will work with each patient and family member to develop a plan of care that will work for everyone and provide the best care for your child. There are several different categories of treatments that are used in IBD for children. Some children may require combination therapy but your doctor will let you know if this is an option. It is extremely important to adhere to the treatment plan because even the best medications in the world won't work if you don't take them.

## Aminosalicylates (5-ASA)

- For mild-to-moderate disease or help maintain remission
- Decreases inflammation in the last part of small intestine and colon
- No suppression of the immune system
- Can be given by mouth or in the rectum
- Side effects: diarrhea, headaches, and nausea
  - Examples: Mesalamines: Asacol HD, Lialda, Apriso, Pentasa, Azulfidine

## Corticosteroids

- For moderate-to-severe IBD
- Effective for short term flare-ups, not to be used to maintain remission
- Suppresses the immune system and decreases inflammation
- Can be given by mouth, rectum or intravenously (IV)
- Side effects: weight gain, insomnia, mood swings, osteoporosis, scalp hair loss, facial hair growth, acne, increased susceptibility of infection and bruising, long term effects can even include stunted growth
  - Examples: Prednisone, Deltasone, Medrol, Entocort, Uceris

## Immunomodulators

- Chosen when 5-ASA and corticosteroids aren't effective or partially effective
- Decreases inflammation in the intestines by suppressing the immune system
- Frequently used to maintain remission
- Can be given by mouth
- Side effects: nausea, decrease in white and red blood cells, inflammation of the pancreas (pancreatitis) or liver (hepatitis), increased risk for infection, very small increase in risk for melanoma skin cancers and lymphoma
- Risks should be weighed against long term remission of IBD
  - Examples: 6-mercaptopurine, Azathioprine (Imuran), Tacrolimus

# Treatment Options

## Biologics

- For moderate-to-severe IBD and to maintain remission
- Medication that directly targets key components of the inflammatory process and essentially short-circuits inflammation in the intestine
- Can be given by injection or IV with a schedule that varies from weekly to every few months
- Side effects: redness, itching, bruising or pain around injection site, headache, fever/chills, difficulty breathing, increased risk of infection, low blood pressure, hives or rash, stomach pain, joint pain, and increased incidence of lymphoma with Anti-TNF medications
- Anti-Tumor Necrosis Factor Agents (Anti-TNF) - binds and blocks small protein that promotes inflammation in the intestine and other organs and tissues
  - Examples: Adalimumab (Humira®), Certolizumab (Cimzia®), Infliximab (Remicade®)
- Integrin Receptor Antagonists- prevent inflammatory cells from moving out of the blood vessels and into tissues by blocking protein on the surface of the cells
  - Examples: Vedolizumab (Entyvio)
- Interleukin-12 and -23 Antagonist—targets specific proteins in the inflammation process
  - Examples: Ustekinumab (Stelara)



# Goals of IBD Treatment

- Reduce inflammation that triggers signs and symptoms
- Reduce complications associated with IBD
- No hospital stays or emergency room visits because of your IBD
- No missed school days because of your IBD
- Achieving remission
- Maintaining/long term remission
- Improved quality of life

## What if we do not meet our goals?

In the event that we are not able to meet our goals and you continue to have symptoms and complications associated with your IBD, a surgery may be suggested. All options will be exhausted before surgery is discussed.



# IBD and Nutrition

It is important to know that food does not *cause* or *cure* IBD. However, the food you consume is very important to help reduce symptoms, replace lost nutrients and promote healing. Every person with IBD is unique and will have different foods or beverages that aggravate symptoms. It will be helpful for you to keep a log of your food, beverages, and symptoms to avoid them in the future and prevent further flares. We have a registered dietician that also can help you to review your specific dietary needs.

It is not uncommon for our patient's with IBD to experience some form of malnutrition. Causes of malnutrition include:

- Small intestine inflammation - can result in problems digesting foods and absorbing nutrients
- Large intestine inflammation - can result in problems absorbing water and electrolytes

## Vitamin and Mineral Supplementation

Supplementation with vitamins and minerals may be necessary if blood tests show that there is a nutritional deficiency. You should always check with your doctor prior to starting any supplements even if they are over the counter. Common supplements include:

- Calcium
  - Maintains bones and teeth
  - Recommended for patients on corticosteroids, have low bone density or osteoporosis
  - Food examples: low fat milk products- cheese, yogurt milk, dark leafy greens, tofu, broccoli, shrimp
- Folic Acid
  - Helps body produce and maintain new cells
  - Helps process fats and carbohydrates
  - Certain medications such as sulfasalazine and methotrexate interfere with folic acid absorption
  - Food examples: strawberries, black-eyed peas, enriched rice, Brussel sprouts, lettuce, asparagus, spinach, dark leafy greens, orange juice, avocado
- Iron
  - Component of hemoglobin, carries oxygen throughout the body
  - Iron deficiency can lead to anemia
  - Inflammation and blood loss can cause a deficiency
  - Iron should be paired with vitamin C rich foods (bell peppers, broccoli, berries, citrus) to enhance absorption
  - Food examples: iron-fortified cereals, oysters, beans, beef, poultry, spinach, sardines

# IBD and Nutrition

## Vitamin B12

- Helps to keep the nerve and blood cells healthy
- Absorbed in the last section of the ileum
  - Food examples: clams, trout, tuna, liver, beef, milk

## Vitamin D

- Helps to absorb calcium
- Recommended for ALL IBD patients
- Can help control intestinal inflammation
  - Food examples: salmon, tuna, cod liver oil, sardines, vitamin D fortified orange juice, milk, fortified cereals



When you have IBD and have experienced weight loss, obstruction, surgery or severe inflammation, it may be difficult to consume enough calories and nutrients from food and supplements and nutritional support may be required.

## Enteral Nutrition (EN)

- Liquid supplemental nutrition that can be given orally or by a feeding tube
- Nutrient-rich formula contains proteins, carbohydrates, fats, minerals, and vitamins necessary to sustain and promote healing

## Exclusive Enteral Nutrition (EEN)

- Formula based diet with no solid foods
- Designed to induce remission
- Short term program lasting 6-12 weeks

## Parental Nutrition (PN)

- Delivers nutrients and calories directly into your bloodstream through an intravenous catheter (IV)
- “Parenteral” means outside of the digestive system

# Beyond The Intestines

IBD affects your intestines, but it is important to know that people can experience symptoms in other areas of the body that is associated with your disease process. Some individuals may be experiencing symptoms outside of the intestines first or may be present right before a flare.

Some signs and symptoms of the disease may be evident in:

- Eyes (redness, pain, and itchiness)
- Mouth (sores)
- Joints (swelling and pain)
- Skin (bumps, ulcerations, and other sores or rashes)
- Bones (osteoporosis)
- Kidney (stones)
- Liver (hepatitis and cirrhosis, although rare)

Your IBD can affect your health in so many different ways. To ensure that we stay on top of all of your care we advise you to follow the health maintenance tool.





# Health Maintenance Tool

Your IBD can affect your health in so many different ways. To ensure that we stay on top of all of your care we advise you to follow the health maintenance tool.

## Health Maintenance Checklist for Pediatric IBD Patients



Vaccines Outside of Routine Age Schedule <sup>1</sup>	Which Patients	How Often
Pneumococcal disease	All with altered immunocompetence <sup>2</sup> The plan for immunization should be discussed with the patient's pediatric gastroenterologist.	<ul style="list-style-type: none"> <li>If aged &gt; 6 yrs and not previously received PCV13, give this first (wait 8 weeks before giving PPSV23)</li> <li>If aged &gt; 2 yrs, give 1st dose PPSV23, then second dose 5 years later</li> </ul>

Cancer Prevention	Which Patients	How Often
Full Skin Screen	All on chronic immunosuppression <sup>2</sup>	Annual
Colonoscopy	All with colonic disease for > 8 years	Every 1–3 years

Other Screenings	Which Patients	How Often
Nutritional evaluation	All	Height, weight, labs and BMI at each visit
Smoking status	All	Annual
Depression check	All	Annual
DEXA Scan	All	At time of diagnosis and periodically (every 5 years) after diagnosis based on DEXA findings
PPD or IGRA	Prior to anti-TNF or anti-IL-12/23	Once (repeat if potential TB exposure or in a high-risk region)
Serologies: HepBsAg, HepBsAb, HepA IgM	Prior to anti-TNF or anti-IL-12/23	Once (repeat if potential exposure or in a high-risk region)

DEXA: dual energy X-ray absorptiometry; PPD: purified protein derivative; IGRA: Interferon Gamma Release Assay

1. Source: <https://www.cdc.gov/vaccines/hcp/acip-recs/general-recs/immunocompetence.html>

2. Altered immunocompetence is assumed to occur with high-dose prednisone ( $\geq 2$  mg/kg for  $\geq 14$  consecutive days), azathioprine, mercaptopurine, methotrexate, anti-TNFs, anti-IL-12/23 and JAK inhibitors

Resource for your patients: <http://www.justikemeibd.org/parents/healthcare-maintenance-guide.pdf>

Developed by Crohn's & Colitis Foundation Professional Education Committee subgroup; Alan Moss MD, Jill Gaidos MD, MariaStella Serrano MD • V2\_July\_2019

# Glossary

- **Flares:** Periods of time that the disease is active
- **Remission:** When the patient is not experiencing any symptoms
- **Fissure:** Tears or sores in the lining of the skin around the anus
- **Fistula:** Abnormal channel that connects one internal organ to another
- **Stricture:** Narrowing of the intestine due to the chronic inflammation
- **Anemia:** Low red blood cell count
- **Nocturnal:** Occurring at night
- **Feeding Tube:** A small thin tube called a nasogastric tube that is place into your nose, down your esophagus into your stomach and maybe even placed into your small bowel (duodenum)

# IBD Resources

## Crohn's and Colitis Foundation of America

- [ccfa.org](http://ccfa.org)

## Camp Oasis:

- Co-ed residential camp program for children with IBD
- [ccfa.org/camps](http://ccfa.org/camps)

## Crohn's & Colitis Community:

- Online support program
- [ccfacommunity.org](http://ccfacommunity.org)

## GI Buddy:

- CCFA's interactive disease management tool for patients designed to track and manage their disease
- [ccfa.org/gibuddy](http://ccfa.org/gibuddy)

## Quiz My IBD Skills Online Assessment Tool:

- Short quiz on management of UC or CD with feedback at the end
- <http://ibdskillsquiz.org/>

## 504 Plan for Children with IBD:

- Plan developed to help a child who has a disability receive accommodations to ensure academic success and access to their learning environment while meeting the needs of the health
- [crohnscolitisfoundation.org/science-and-professionals/patient-resources/template-section-504-plan](http://crohnscolitisfoundation.org/science-and-professionals/patient-resources/template-section-504-plan)

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