

My IBD Care Book

**Stanford Children's Self-
Management Handbook
for Patients and Families
with Inflammatory Bowel
Disease (IBD)**

The following are examples/templates of documents you can use to track your health and keep your doctors up-to-date on current symptoms, medications, and recent procedures. Use whatever works to keep yourself organized!



**Stanford
Children's Health**

**Lucile Packard
Children's Hospital
Stanford**

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Stanford's IBD Team - Who We Are

Stanford's IBD center uses a team approach in the assessment and treatment of children and adolescents with IBD. This team provides comprehensive health care in a family-centered environment that recognizes the physical, emotional, behavioral, financial and social needs of patients and families. Our goal is to engage patients and families to participate in tailoring and maintaining a personalized therapy plan as guided by the best available scientific evidence.

Our Mission Statement:

We at Stanford Children's IBD Center first and foremost seek to deliver the highest-quality care for children, adolescents, and young adults and families affected by pediatric Crohn's disease and ulcerative colitis. Highest-quality care is evidence-based, supported by and participating in collaborative and innovative research, family-centered, individualized, and interdisciplinary in approach aimed to optimize treatment success, whole-person wellness and quality-of-life.

Members of our IBD Center team who will partner with you:

- Physicians
- Psychologist
- Nurse Practitioners
- Nurses
- Dietitians
- Social Worker
- IBD Center Coordinator
- Parents and Patients*

*Interested in being a parent or patient partner?

Want to get the most up-to-date information from our center? *Join our listserv!*

Email Megan:
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Our Quality Improvement Team:



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GI Social Worker



Megan Christofferson
IBD Center Coordinator



Mary McGowan
Parent Working Group Lead

Inbal Kavalier
Family Advisory Council Lead

Clinic locations:

Palo Alto: 730 Welch Road, 2nd floor, Palo Alto, CA 94304; (650) 721-2250
Capitola: 824 Bay Ave Suite #70, Capitola, CA 95010; (831) 457-2361
CPMC: 3801 Sacramento Street, San Francisco, CA 94118; (415) 600-0770
Emeryville: 6121 Hollis Street, Suite 2, Emeryville, CA 94608; (925) 932-2402
South Bay: 14601 South Bascom Ave, Ste 200, Los Gatos, CA 95032; (650) 721-2250
Walnut Creek: 106 La Casa Via, Suite 100, Walnut Creek, CA 94598; (925) 239-2900

Outreach:

Eureka: 525 2nd St Suite 300, Eureka, CA 95501; (650) 721-2250
Stockton: 1414 N. California St, Stockton, CA 95206; (650) 721-2250

Contact information for the Palo Alto Clinic:

To schedule **appointments** for 730 Welch or South Bay, call: 650-721-2250

My IBD Team

Your IBD Doctor: _____ Phone # _____

Your Nurse: _____

Your Nurse Practitioner: _____

Dietitian: _____

Social Worker: _____

Psychologist: _____

Therapist: _____

Pediatrician: _____

Your Surgeon: _____

IBD Center Coordinator: _____

School: _____

School Nurse: _____

To leave a message for your doctor, nurse practitioner, or one of our GI nurses, call the Pediatric GI office 650-723-5070 option 2. Our office is open Monday through Friday from 8:30am to 5pm, and is closed at lunchtime between 12pm and 1pm. Please be prepared to tell our staff your (or your child's) name, date of birth, medical record number and provider's name as well as the reason for your call. Non-urgent messages will be returned within 1-2 business days. Please request medication refills with at least 2-3 business days' notice and provide us with the current medication, dosage, and pharmacy information.

For online access to appointment information and messaging to your medical team, ask the front desk staff about signing up for **MyChart** at the time of your visit.

We have pediatric GI doctors on call for urgent issues at all times, including evenings, weekends, and holidays. If there is an issue that requires urgent attention during daytime hours, please call the Pediatric GI office. For urgent issues on weekends, evenings and holidays, please page the GI doctor on call through the Stanford Operator at 650-497-8000. For emergencies, please call 911 or proceed to your nearest emergency department.

When to Contact my IBD Doctor

Please contact your IBD doctor promptly regarding increased symptoms so we can work with you to provide the best treatment.

Call us if your child is experiencing:

- Increase in abdominal pain
- Increase in number or volume of stools
- Blood in stools—either bright red or black and tarry
- Constipation
- Vomiting, especially if bloody
- Significant bloating of stomach
- Severe headache, especially if your child has been on recent corticosteroids
- Sudden or severe changes in vision
- Change in weight by five pounds or more (up or down)
- Sudden change in your child's skin, eye, or urine color
- A significant change in your child's energy level
- Fever that persists without other medical cause
- Mouth sores, sores on the skin or in the genital area
- Joint pain
- Unusual bleeding or bruising.

Call your Primary Care Physician if your child is experiencing:

- New onset of fever
- Cough, cold or congestion symptoms
- Skin rash
- Any other health care concerns.

Why this is important:

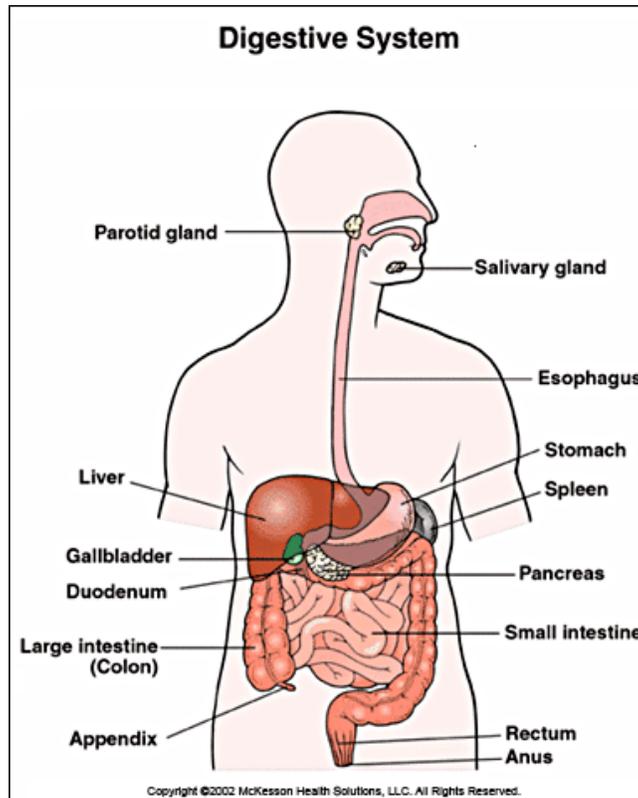
Even with medical treatment, a person with IBD can experience a flare: an episode when symptoms reappear. It is important that you report your symptoms early so that your doctor can provide the best treatment for you. This may help you stay well and prevent some of the complications related to IBD. Avoiding a flare is better than treating a flare. Taking your medications as directed can help control your symptoms and help to avoid a flare.

My IBD Fact Sheet

I have _____

I was diagnosed (date) _____

My presenting symptoms were _____



Inflammatory Bowel disease (IBD) is a chronic inflammation (irritation) of the intestines that is not due to infection. In IBD, the immune system overreacts and leads to injury of the intestines. There are two main types of IBD: Crohn's disease and ulcerative colitis. Crohn's disease can involve any part of the intestine from mouth to bottom. Ulcerative colitis usually involves only the large intestine (colon).

Signs and Symptoms of IBD May Include:

- Diarrhea or bloody bowel movements
- Weight loss or poor growth
- Abdominal pain
- Change in appetite
- Unexplained fevers, joint pains, or mouth sores
- Fatigue/ Decreased energy level
- Anemia (low red blood cell count)
- Nausea/ vomiting

Common Medications

Some of these medicines may require pre-authorization from your insurance

Corticosteroids:

These are drugs that usually bring on a rapid "remission," controlling most symptoms within a short period of time. There are possible side effects which may increase and become more serious the longer the medication is taken. Therefore these medications may only be taken for short periods of time. A sudden stop in steroids can also bring on dangerous side effects, so always follow the schedule your doctor prescribes. Entocort, another corticosteroid, has a local effect and is released slowly in the last section of the small bowel and the first section of the large bowel. These medications include: Prednisone, Orapred, Methylprednisolone, Hydrocortisone, Entocort, Cortifoam.

Side effects can include weight gain, hunger, and changes in mood and sleep patterns. These usually improve as the dose is lowered. Other side effects can include weakening of the bones, increased risk of infections, high blood pressure, high blood sugar, and stomach irritation. If you take prednisone or other corticosteroids, you should be up to date on vaccines, undergo regular eye exams, and may need to have bone density testing.

Antibiotics:

Many medications have been found to be effective in the treatment of IBD and often help bring flares under control. Our immune system helps provide protection from invading bacteria and helps prevent infections. In IBD, there may not be an infection, but the immune system acts as if it were responding to an infection and may attack parts of the bowel. Antibiotics may help to reduce inflammation by changing the type and amount of bacteria in the bowel. These antibiotics include: Ciprofloxacin, Flagyl and Rifaxmin.

5-ASAs:

These drugs are anti-inflammatory medications, chemically related to aspirin. Similar to aspirin, they help start healing, reduce inflammation and decrease discomfort. They may be given orally or rectally. There are 5-ASAs that are released at different parts of the bowel, which allow treatment where the disease is located. Some examples include: Pentasa, Lialda, Apriso, Colazol, Delzicol, Asacol, Sulfasalazine, Canasa, Rowasa.

Immunomodulators:

These medications are immunosuppressants. Suppressing the immune system reduces inflammation in the GI tract. These medications do not work right away, so you may need to be on a combination of medications at first. Blood tests will be done regularly to check for possible side effects, including low white blood count and irritation of the liver or pancreas. Patients taking these medications should be cautious about their amount of sun exposure. They are also at a small increased risk for lymphoma (a tumor of the lymph glands) compared to the average person. These medications include: Methotrexate, 6-Mercaptopurine (6MP), Imuran (Azathioprine) and Tacrolimus (Prograf).

Biologics:

These **Anti-TNF medicines** include Infliximab (Remicade), Adalimumab (Humira), and Certolizumab pegol (Cimzia). They block the action of a protein in the body called TNF-alpha (tumor necrosis factor). TNF-alpha is made by the body's immune system. People with IBD may produce too much TNF-alpha which can cause inflammation. Remicade is given as an IV infusion and takes about 3 hours to infuse. The frequency of the infusions depends on your symptoms, but it is usually given every 8 weeks. Humira is given by injection every 2 weeks, and Cimzia is given by injection every month. Before receiving any of these medications, your doctor will test you for tuberculosis.

You will have regular blood tests to monitor for possible side effects, including low white blood cell count, irritation of the liver, and infections such as tuberculosis.

There are also **Integrin Receptor Antagonists**: These biologics prevent the cells that cause inflammation from moving out of blood vessels and into tissues by blocking a protein on the surface of those cells. Examples of this type of medication include: Natalizumab (Tysabri) approved for adults and Vedolizumab (Entyvio) approved for adults.

Interleukin-12 and 23 Antagonist: This biologic targets specific proteins (interleukin-23 and interleukin-12) that play a key role in the inflammation process. An example of this type of medication is: Ustekinumab (Stelara), not yet approved for pediatrics. The first dose is a one-time intravenous (IV) infusion. The following doses are given as injection every 8 weeks.

Additional Treatment Options

Surgery:

Although treatment with medications is the first option for patients with IBD, some patients may require surgery. Surgery may be needed to address serious IBD complications, or for disease that has not responded to medications.

Complications of IBD that may require surgery include:

- Intestinal obstruction (blockage in the intestine)
- Uncontrollable bleeding
- Stricture Formation (narrowing of a section of the intestine)
- Perforation of the intestine (tear or hole in the intestine)
- Formation of a fistula (abnormal connection from the intestine to another part of the body) or abscess (collection of pus and inflammation)
- Toxic megacolon (bacteria and gas build up in the intestine causing it to become very dilated or stretched out)

Common Surgical Procedures for Ulcerative Colitis:

- **Proctocolectomy with Ileostomy** In this procedure, the colon and rectum are removed (proctocolectomy). A surgically created hole in the abdomen (ileostomy) is made for the removal of stool. After this procedure, an external bag is worn over the hole to collect stool. The ileostomy can be permanent or temporary. Newer surgical techniques have eliminated the need for a permanent ileostomy in many people.
- **Proctocolectomy with ileal pouch-anal anastomosis (IPAA)** This procedure is performed in two or three stages. The colon and rectum are removed, and a temporary ileostomy (surgically created hole in the abdomen) is made. The ileum (end of the small intestine) is then made into a pouch and connected to the anus. Once this pouch has healed, the ileostomy is closed.

Common Surgical Procedures for Crohn's Disease:

- **Strictureplasty** This procedure widens a narrowed or tight area of the intestine, and prevents the removal of a section of the intestine. It is most effective in the lower parts of the small intestine (jejunum and ileum).
- **Intestinal Resection** In this procedure, a section of unhealthy intestine is removed (resection) and the two ends of healthy intestine are joined together (anastomosis). Unfortunately, IBD can reappear at or near the area that was joined together.
- **Proctocolectomy with Ileostomy** This is an option for patients who have severe Crohn's disease that affects their colon. This is described above

Diet and Nutrition

Nutritional / Enteral Therapy:

In addition to medications and surgery, there are other treatment options focused on nutrition as therapy that may be discussed with you.

Enteral Therapy (a liquid formula diet): This involves providing all your nutrition as formula - either by mouth or by a naso-gastric tube (a tube that delivers the formula directly into the stomach). This type of therapy has been shown to be a safe and successful option for inducing remission in place of medication, but requires close monitoring by your IBD team.

The Specific Carbohydrate Diet (SCD): The SCD is a nutritionally balanced wholesome diet focused on removing grains, processed foods, sugar and limited dairy. The SCD focuses on nutrient rich foods including vegetables, fruits, meats, eggs, legumes/beans, nuts and nut flours. Some patients have used this diet successfully to control symptoms of IBD. In conjunction with ImproveCareNow (ICN - a national collaborative for pediatric IBD), Stanford is currently conducting studies regarding the effectiveness of SCD in controlling IBD. *Resource:* <https://www.nimbal.org/>.

FODMAP Diet: This diet is used to control the symptoms of IBS (Irritable Bowel Syndrome); many children who have IBD experience IBS symptoms and modify their diets accordingly, but this diet is NOT a treatment for IBD.

Vitamins and Minerals:

Vitamins and minerals are important for bodies to work properly and perform daily tasks. There are some vitamins and minerals that may be affected by IBD and some that may need to be increased during times of inflammation.

Calcium: Research has shown that individuals with IBD are at risk for osteoporosis (a condition that leads to thin, weak bones). This may happen for several reasons: (1) Decreased amounts of calcium and vitamin D due to not eating or drinking enough dairy products, (2) improper intestinal absorption and/or (3) long term steroid therapy.

Steroids may interfere with the body's ability to absorb calcium. Eating the recommended amounts of dairy products and/or taking vitamin and mineral supplements can help prevent weak bones.

<u>Recommendations for intake of Calcium:</u>	<u>Sources of Calcium per serving:</u>
0-6 months 210 mg	Milk (1 cup) 300mg
7-12 months 270 mg	Yogurt (8 oz.) 400mg
1-3 years 500 mg	Soy Milk (1 cup) 300mg
4-8 years 800 mg	Fortified cereal (1 cup) 1000mg
9-18 years 1300 mg	Cheese (1.5 oz.) 300mg

Vitamin D: Vitamin D deficiency is common in patients with IBD, even when your disease is in remission. It is unclear exactly why this is so common, but it is probably a combination of low vitamin D intake, poor absorption of vitamin D, and decreased time spent outdoors. Just like calcium deficiency, vitamin D deficiency can be associated with increased risk of osteoporosis. Your doctor may check your vitamin levels and may recommend supplements.

Folic Acid: Folic acid deficiency can occur because of decreased appetite or decreased intake of foods containing folic acid, or because certain medications can interfere with its absorption. Meats, breads and cereals, and dark green leafy vegetables are high in folic acid. Your doctor may recommend additional folic acid supplements.

Iron: Iron deficiency can occur if you have ongoing blood loss from the intestines. This may lead to anemia which can cause fatigue or weakness. Increasing foods in your diet which contain iron is important. These foods include meats, fortified breads and cereals, and some fruits and vegetables like raisins, spinach, and bananas. Your doctor will be checking for anemia and may recommend an additional iron supplement. Iron supplements work best when taken with Vitamin C, such as a glass of orange juice.

Multivitamins: Since eating less and intestinal inflammation may reduce your intake and absorption of other vitamins and minerals, a "complete" multivitamin and mineral supplement is usually recommended. Each multivitamin and mineral supplement is different. It is important to check the label to make sure that the key vitamins/ minerals are in the supplement (vitamin D, Calcium, Folic Acid, Zinc, and Iron) and that most of each of the nutrients in the supplement supply 100 percent of recommended amounts.

Omega-3 Fatty Acids and Probiotics: see *"Integrative Medicine," Page 13.*

Consult with your/your child's physicians when considering dietary changes.

The overall goal of your diet should be to eat a variety of foods with adequate calories and nutrients to support healthy growth and development. Growth is a concern for young people with IBD. When the wall of the gastrointestinal tract is inflamed, it can leak proteins and other substances needed by the body. You may also eat less because of abdominal pain or lack of appetite. During times of increased disease activity, you may need additional nutrients or other alterations to your usual diet to maintain your nutritional status. Stanford has a dietician available to assist you with any concerns you have about your child's growth and nutrition.

Diet can also improve overall gut bacteria diversity and abundance. A high fiber diet is actually recommended for most patients with IBD (except for those with structuring, fistulizing Crohn's). Check with your GI doctor and dieticians to see what diet changes may be right for you.

Resource: Read [The Good Gut](#), by Justin and Erica Sonnenburg.

While dietary choices can certainly have an impact on symptoms, IBD is not caused by any specific diet. Some patients notice that certain trigger foods may cause an increase in symptoms. For example, you may notice that large amounts of colas, coffee, and other caffeine-containing products can increase diarrhea. It is important to contact your IBD team for any significant change your diet and together we can develop a safe and appropriate plan for you.

Resource: [Food Journal Log](#) in the Additional Documents Section.

Integrative Medicine

Surveys have reported that anywhere from 21 to 68 percent of patients with gastrointestinal diseases have used some method of integrative medicine (also known as complementary and alternative medicine), including herbs, fish oil, probiotics, and mind-body interventions. There is limited scientific evidence on their safety and efficacy for pediatric patients with IBD. It is important to speak with your doctor and dietitian about any herbal supplements you currently use or are thinking about using. Some herbs may interact with your medications or may worsen IBD symptoms so it is important to discuss all additional medicine practices with the medical team. Below we have listed some common integrative medicine treatments and interventions. If you are interested in learning more, ask your GI doctor or pediatrician for recommendations.

Omega 3 Fatty Acids: Fish oil has anti-inflammatory actions and has been proven to be effective in the treatment of many inflammatory diseases. There have been several studies using fish oil in adults with IBD with varying results. Fish oil can increase risk of bleeding - make sure your doctors know you are taking it and stop taking 1 week before any procedures.

Probiotics: Probiotics are supplements that have been well-researched. Probiotics are microorganisms present in the gastrointestinal tract that may benefit certain health conditions. There is promise in the use of probiotics with ulcerative colitis and pouchitis; less so for Crohn's disease.

Acupuncture: Traditional Chinese medicine explains acupuncture as a technique for balancing the flow of energy or life force – known as qi or chi (CHEE) – believed to flow through pathways (meridians) in your body. By inserting extremely thin needles through your skin at strategic point on your body, acupuncture practitioners believe that your energy flow will re-balance. In contrast, many Western practitioners view the acupuncture points as places to stimulate nerves, muscles and connective tissue. Some believe that this stimulation boosts your body's natural painkillers and increases blood flow.

Massage: Massage can help to relieve symptoms of IBD.

Yoga: Yoga can help relieve some symptoms of IBD. It's an increasingly common type of exercise in the United States that was originally developed in India to promote health and wellbeing. Yoga combines physical postures, breathing techniques, meditation, and relaxation strategies.

Mindfulness-based therapies: Mindfulness-based therapies can help relieve symptoms of IBD by helping one become more aware of his or her thoughts, emotions and body sensations—in an accepting and non-judgmental manner.

Mindfulness is usually practiced via a series of breathing, movement, or meditation exercises to support emotional and physical wellbeing. Our IBD psychologist provides training in mindfulness-based therapies at Stanford.

Medical/Self-Hypnosis: Medical/self-hypnosis can relieve symptoms and improve physical and emotional comfort via creative thinking and visual imagery. Our IBD psychologist provides training in medical/self-hypnosis training. Community referrals can also be provided by your GI provider or the IBD psychologist.

Biofeedback: Biofeedback can also support IBD patients and relieve symptoms. It involves the use of electronics (e.g., phones, iPads) to receive immediate feedback about physical signs of relaxation (e.g., reduced tension, increased body temperature). Our IBD psychologist provides training in biofeedback. Local providers can also be found at: <http://BCIA.org/>.

Labs: Blood and Stool Tests

Labs are tests that are done to look at specific body functions. Some test results will be available within a few hours while others may take weeks. Once labs are available, you will be able to view them in your Stanford Children's MyChart account.

Some common labs are:

Hemoglobin (HGB) is the part of the red blood cell that carries oxygen. Red blood cells can be lost due to bleeding and patients with any type of chronic illness may not produce as many red blood cells. Indications that Hgb is low (anemia) include paleness and tiredness.

White Blood Cells (WBC) fight infections. Some of the medications used to treat IBD can slow the bone marrow's production of WBCs, making your child more prone to infection.

Platelets (PLT) are blood cells that help form clots to prevent bleeding. Platelets can be low due to slower production by the bone marrow, or high due to response to inflammation.

Albumin (ALB) is a protein in the blood that helps keep fluid from leaking out of blood vessels. Inflamed tissue can lead proteins to leak into the intestine. Low albumin can lead to puffiness of the face, feet, or stomach.

Liver Function Tests (LFTs) or Hepatic Function Panel AST, ALT, GGT, Alk Phos are abbreviations for enzymes produced by the liver. Inflammation, blockage in the liver or certain medications can increase these enzyme levels.

Blood Urea Nitrogen/Creatinine (Bun/CR) are enzymes that reflect kidney function. These can be affected by hydration status (how dry the body is) and certain medications.

Glucose (GLU) is the blood sugar level. This can be high when a person is on Prednisone or Solumedrol.

Thiopurine Metabolites look at the level of the active form of 6MP or Imuran to help your doctor determine the effectiveness or toxicity of each patient's dose.

C-Reactive Protein (CRP) is a protein that is made by the liver and released in the blood when there is inflammation in the body. Your doctor may order this test to see if there is inflammation inside your body and check your response to treatments.

Erythrocyte Sedimentation Rates (ESR) is also called sed rate. This test is done to see if you have new or ongoing inflammation in your body. Your doctor may order this test along with CRP to check for inflammation and see how you are responding to treatment.

Stool Tests are often performed when your child has an increase in symptoms to decide if the cause is an infection or a flare of their IBD. You may be asked to collect these samples at home and bring them to your local lab. Some Common Stool Tests:

Clostridium Difficile (C. Diff) is a bacterium commonly found in your gut. Sometimes antibiotics used to treat an infection kill good bacteria, allowing *C. difficile* to grow out of control. Symptoms include diarrhea.

Ova and Parasites helps your provider rule out a parasitic infection. People are exposed to these types of infections from community settings such as a daycare, community pool or other untreated water sources such as camping grounds or lakes.

Fecal Calprotectin is a biochemical measurement of the protein calprotectin in the stool. Elevated fecal calprotectin shows the migration of neutrophils to the intestinal mucosa, which occurs during intestinal inflammation.

Stool occult blood (also called guaiac or hemocult) looks for hidden blood in the stool.

Stool Culture/GI PCR is a test to rule out an intestinal infection from common bacteria. GI PCR is a more specialized comprehensive stool test which includes screening for additional bacterial and viral pathogens. It is not available at all laboratories.

Imaging Studies

There are several types of radiologic imaging studies that can be helpful in the care of patients with IBD.

Abdominal X-Rays (KUB, FLAT PLATE) are standard x-rays that look at the amount of air, fluid, and stool in the intestines. No special preparation is needed.

Barium Enema (BE) is done after the child is given an enema with a small amount of barium contrast. We then take a series of x-rays to look at the outline of the intestine as the barium passes through. The only preparation needed is eating or drinking nothing by mouth for 6-8 hours prior to the x-ray.

Computerized Tomography (CT) is a more refined series of x-rays. To help determine what normal bowel content is and what is abnormal. Special contrast may be given either by mouth or through an IV prior to the scan. Because the child needs to lie still for a longer time than for standard x-rays, he or she may need to be given sedation (medication to help him or her feel relaxed and sleepy). Instructions for preparation will be given when the exam is scheduled.

Ultrasound (US) uses sound waves instead of x-rays to look inside the body. Gel is applied to the abdomen and a painless wand is passed over the area. Preparation needed is eating or drinking nothing by mouth for a specific period (the amount of time varies). You will be instructed when the exam is scheduled.

Bone Scan or Bone Density Study is done using standard x-rays. This looks for thinning of the bones related to disease, malnutrition, or medications. The entire body will be x-rayed. Your child will need to lie still for approximately 15 minutes to complete the study. This study requires that no CT or barium studies are done three days prior to the scan.

Magnetic Resonance Enterography (MRE) uses a powerful magnet which provides images that help assess and evaluate the intestines in IBD. MRE does not use radiation. Special contrast is taken by mouth prior to the study and an IV needs to be placed. The study cannot be done with sedation. Full instructions for preparation will be given when the exam is scheduled. The patient can't have a history of metal in their body or a history of renal disease.

Endoscopy / Colonoscopy

To confirm the diagnosis of IBD, as well as to help in the evaluation of therapy, upper endoscopy (esophagogastroduodenoscopy or EGD) and/or colonoscopy will be performed.

Esophagogastroduodenoscopy (EGD) An EGD is a test done to examine the lining of the esophagus, stomach, and duodenum (first part of the small intestine). The exam is done with a flexible tube called a scope, which has a light and a camera on the end. The doctor will look for redness, swelling, bleeding, ulcers or infections and may collect small tissue samples called biopsies to be looked at under a microscope.

Colonoscopy A colonoscopy is done to examine the entire colon (large intestine). A flexible tube (scope) with a light and camera on the end will be used for the test. The doctor will look for redness, swelling, bleeding ulcers, or infections of the bowel wall and may collect biopsies.

Capsule Endoscopy A way to record images of the digestive tract for use in medicine. The capsule is the size and shape of a pill and contains a tiny camera. After a patient swallows the capsule, it takes pictures of the inside of the gastrointestinal tract. This procedure is particularly helpful to evaluate the small intestine where traditional endoscopy and colonoscopy would not reach.

Here are some helpful hints about what to expect before and after an EGD and/ or colonoscopy.

- You will be asked to not eat or drink for several hours before the procedures. You may also be asked to stay away from red and purple liquids and certain medications such as aspirin and ibuprofen (ex. Advil, Motrin, etc.).
- One to two days before a colonoscopy, you will be asked to undergo a "cleanout". The medications used for this may vary. You must clean out the colon by sticking to a strict diet for at least the day prior to the procedure. This will all be explained to you and it is *very important* to complete the cleanout to ensure a successful procedure.
- Most procedures are same-day, meaning that after you wake up from the sedation/ anesthesia, you can go home.
- Although most patients have no problems after these procedures, you may have some bloating, abdominal cramping or pain, nausea, sore throat, or some blood in your bowel movements. If you have continued blood in your bowel movements, worsening abdominal pain, high fevers, or vomiting, you should contact your doctor, the on-call GI team, or the emergency department.

Living with IBD

IBD like any chronic condition impacts the whole-person, including the physical, emotional, behavioral, and social realms of one's life. IBD affects the patient and his or her entire family.

IBD can be challenging at times, and we want to support you and your family with all aspects of your life that can be affected by IBD. It can be stressful to receive a new diagnosis and cope with a chronic illness. We know that it can be difficult to come to frequent medical appointments and remember to take all your medications, all while trying to live a "normal" life. You may also experience pain, fatigue, anxiety, fear, sadness, depression, frustration, anger, and body image changes. These experiences are normal for anyone dealing with a chronic illness. That being said, it can be helpful to seek support from your IBD team if you have continuous emotional or physical concerns or challenges. Our goal is to support each child and family and help you cope with all aspects of IBD.

It is important to observe and discuss how IBD affects siblings. Siblings often exhibit feelings of jealousy, fear, guilt, or anger when their brother or sister experiences a chronic illness. Open, honest communication between family members will provide support and reassurance for siblings.

Stanford Children's IBD Center has many resources available to help patients and families with psychosocial challenges. Our psychologist, Dr. Anava Wren, is dedicated to supporting our IBD patients and their families. She is available to meet with patients and/or families to discuss any psychosocial concerns related to IBD (e.g., stress, anxiety, low mood, pain, treatment adherence, family conflicts) and provide treatment recommendations as needed. Individual, family, and group therapy services are provided in Palo Alto (730 Welch Rd). Our GI social worker, Annie Diep, LCSW, can meet with patients and families during their medical appointments in Palo Alto. Additionally, Stanford offers Child Life and Community Services to support patients and families during hospitalizations.

Coping with Stress: Some things to keep in mind to help you cope with stress:

- Identify current stressors in your life and ways that you cope with stress (e.g., healthy vs unhealthy coping strategies)
- Exercise and follow a healthy diet (consult with GI nutritionists)
- Get enough sleep (at least 8 hours per night)
- Talk to someone, such as a therapist, parent, sibling, teacher, friend, or support group.
- Create time to engage in activities you love and/or pick up a new hobby
- Use relaxation techniques such as: deep breathing, guided imagery and/or meditation

School

Because IBD is a life-long condition, it is important for you and your family to learn to incorporate care for your disease into your daily life. Patients should be encouraged to maintain as normal a life and routine as possible, including going to school regularly.

Managing school work can be difficult when dealing with a chronic illness such as IBD. Doctor's appointments and flares may lead to missed school days. It is important to communicate with teachers, school nurse, coaches, and other caregivers so they are aware of your diagnosis and can help with needs as they arise. Teachers and school administrators may not fully understand your disease. There are several resources that may be helpful to address these concerns. For example, an individualized educational plan (IEP) or a 504 plan can be developed with the help of your school to address any IBD-related school challenges and support school accommodations to help you succeed academically. Your Stanford GI doctor, psychologist, or social worker can help you with this.

Some examples of requests that you may want to include in an IEP or 504 plan include:

- Hall passes for the bathroom
- Pass for the nurses' office for medications
- Access to and location of bathrooms for outdoor activities
- Any diet modifications necessary
- Exercise and activity with the ability to rest as needed during times of increased symptoms
- Extended deadlines for school work missed due to doctor appointments, procedures, hospitalization, or sickness and fatigue.

For prolonged hospital stays, Stanford Children's Hospital provides a teacher through our Child Life Department. Homebound or "Home and Hospital" instruction may be needed with special circumstances for illness, but should be considered as a last resort (integration back into mainstream school is recommended by our team). If you feel you need this service, contact your care Team.

Please see the sample 504 plan in the additional documents section or one our website (<http://tinyurl.com/StanfordChildrensIBD>)

Your Stanford Children's IBD Team recognizes that the transition to college can be a stressful time for patients with IBD and their families. Ask your GI provider about our resources for college planning and what options may be available at your new school.

Online Resources for Parents and Patients

- **Stanford Children's Inflammatory Bowel Disease Center**

<http://tinyurl.com/StanfordChildrensIBD>

The internet is a big place, so we have pulled together the best online resources into one website! Please visit **our website** to find the best educational resources covering a wide range of topics including nuts and bolts of IBD, IBD treatment options, and resources for living with IBD.

- **Crohn's and Colitis Foundation**

<http://www.crohnscolitisfoundation.org/>

The Crohn's and Colitis Foundation is on a mission to find the cure for IBD and improve the quality of life for patients of all ages. With 40 local chapters, they provide education and support to patients all across the United States.

- **Join a community!**

Our IBD Center Page: <http://www.facebook.com/StanfordChildrensIBD>

A local group: <https://www.facebook.com/groups/BayAreaKidsWithIBD/>

Sign up for the ImproveCareNow Loop blog: <http://www.improvecarenow.org/loop>

- **Join our listserv!**

For details on upcoming events, ongoing research projects, and more, join our email listserv by emailing our IBD Center coordinator: mchristofferson@stanfordchildrens.org

ImproveCareNow



IMPROVECARENOW™

ImproveCareNow (ICN) is an international collaborative that brings patients, parents, and their medical teams together to improve the care given to children with Crohn's and ulcerative colitis. Over 100 care centers are a part of this network, and Stanford Children's IBD Center is proud to be counted as one.

Building Community and Sharing Experiences

ICN Centers meet twice a year at Community Conferences to learn from each other, plan improvements, and conduct research in IBD. This is in addition to Virtual Community Conferences you can join from your own home.

Interested in hearing from patients and families who have lived with this disease? Join the CIRCLE community (https://www.improvecarenow.org/get_involved_signup) and sign up for the LOOP blog (<http://www.improvecarenow.org/loop>).

Volunteer

You can take an active role in this community by joining the ICN Patient Advisory Council or Parent Working Group.

Find out more about these groups and how to join at: <https://www.improvecarenow.org/patients-parents>

Quality Improvement and Research

Part of our joint mission is to use data to inform improvements. ICN has a registry in which patient data from all participating centers is entered. The information is de-identified; each patient is assigned a random number, and all health information used is only associated with that number. That allows centers to run reports to make sure we are providing the best care we can to our patients, and shows us that our efforts to improve the care we deliver are positively impacting our patients' lives. This data could also be used for research with your consent. An IBD provider could ask ICN for a dataset to answer particular research questions. ICN would only release pertinent data from patients who had consented for their data to be used in research.

If you would like your/your child's data to be available for use in research, please contact Megan at mchristofferson@stanfordchildrens.org.

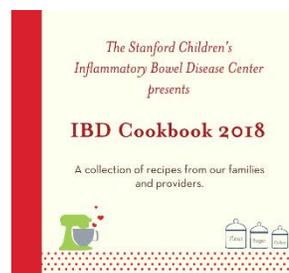
Family Advisory Council

Interested in getting involved at the local level? The IBD Family Advisory Council (FAC) meets once every other month for an hour and a half on Stanford campus. They give their input on ongoing projects and help us set goals for planned improvements to our clinics.

Parents who join the IBD FAC also have the opportunity to be involved in the hospital-wide Family Advisory Council. The hospital FAC advises on initiatives that impact the care that all patients coming to Lucile Packard Children's Hospital Stanford and Stanford Children's Health receive.

Here are some past and current projects that have received parent input:

- *Ambulatory in-clinic depression screening*
- *COMBINE*: An ICN study looking at the outcomes of combination therapy (methotrexate + infliximab or adalimumab) versus monotherapy in pediatric Crohn's disease
- *PRODUCE*: An ICN, N-of-one study that looks at outcomes with the Specific Carbohydrate Diet as treatment for Crohn's disease
- *IBD Parent and Patient Cooking Night*: our FAC submitted a proposal to the very first ICN Parent and Patient Innovation Fund and received the award to put on a cooking night where patients and their parents could spend time together while learning a few healthy recipes.
- *IBD Center Cookbook*
- *Summer Scamper Picnic*
- *Annual review of the IBD Care Book*
- *Review of patient educational materials*



If you would be interested in joining the council, please contact us for more information. Email Megan at mchristofferson@stanfordchildrens.org

Did You Know?

More people have IBD than you may think. According to the Crohn's and Colitis Foundation, 1.6 million Americans have IBD, and there may be as many as 70,000 new cases diagnosed each year. Here are a few people you may have heard of who also happen to have IBD:



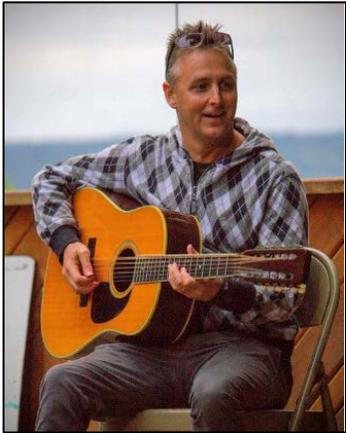
President Dwight D. Eisenhower was diagnosed with Crohn's disease while in office in 1956.



Kathleen Baker, diagnosed with IBD at age 13, won the silver medal in the 100m backstroke at 2016 Olympics.



David Garrard was diagnosed with Crohn's 3 years before being named starting quarterback for the Jacksonville Jaguars. He has since started his own foundation to help children affected by breast cancer and Crohn's disease.



Mike McCready, a founding member of the band Pearl Jam, was diagnosed with IBD when he was 21 years old.

UCLA gymnast Katelyn Ohashi, whose floor routine went viral after scoring a perfect 10, was diagnosed with ulcerative colitis in 2016. She talks about her diagnosis on her blog: <https://behindthetmadnesssite.wordpress.com>



Cynthia McFadden, senior legal reporter for NBC News, has Crohn's.



Comedian and Saturday Night Live cast mate Pete Davidson has Crohn's disease.



Actress Amy Brenneman has had a couple of surgeries to treat her ulcerative colitis.



My Documents

**Stanford Children's Self-
Management Handbook
for Patients and Families
with Inflammatory Bowel
Disease (IBD)**

The following are examples/templates of documents you can use to track your health and keep your doctors up-to-date on current symptoms, medications, and recent procedures. Use whatever works to keep yourself organized!



Stanford
Children's Health

Lucile Packard
Children's Hospital
Stanford

Diet Log

Week # :

Breakfast	Midmorning Snack	Lunch	Afternoon Snack	Dinner	Misc.	Symptoms

Office Visits

Date: _____

- Changes since your last visit? (Ex. Symptoms? Concerns? Studies or procedures performed? Medication changes?)

- Questions for your health care provider today?

- Lab/ Radiology/ Procedure Results

- Changes made at today's visit (including treatment changes and tests/ labs ordered)

- Need any Medication Refills?

504 Plan

Below you will find a sample 504 plan that contains some common accommodations for children with IBD. Your child's plan should be revised annually, typically in a meeting with the school administrators, teachers, parents, and social worker if necessary.

Identified 504 Conditions	504 Accommodations	Starting Date	Person Responsible	Effectiveness of Accommodations
Autoimmune Disease	Preferential seating near the door of classrooms		Teacher, Student	
	Unlimited use of the restroom		Teacher, Student	
	Excused breaks to restroom (as needed)		Teacher, Student	
	Extended deadlines for make-up work as needed due to illness and absence		Teacher, Student, Parent	
	Physical Education: Student will inform school health services assistant and instructor when he is unable to complete assigned tasks during PE		Teacher, Student, Parent	
	Priority registration of classes to reduce workload on any given day		Guidance, Parents	
	Excuse or provide alternate assignments that cannot be completed due to illness		Teacher, Student, Parent	
	Create alternate assignments (take home assignments) in lieu of in-class assignments that cannot be completed.		Teacher, Student, Parent	

My Notes

My Notes