



AN EDUCATIONAL GUIDE FOR
**Inflammatory
Bowel Disease**



Children's Mercy
KANSAS CITY

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INFLAMMATORY BOWEL DISEASE

Inflammatory bowel disease (IBD) is an inflammatory condition of the intestine or gut affecting approximately 80,000 children in the U.S. and Canada alone. Two main forms of IBD are Crohn’s disease and ulcerative colitis. These are lifelong conditions with symptoms that may get better or worse from time to time, depending on response to medications, other illnesses and overall health. Even though the cause of IBD is still unknown, we do have many treatments available to help your child lead an active and healthy life.

The IBD program at Children’s Mercy is dedicated to helping you and your child find therapies that control symptoms and promote a healthy quality of life.

Much of the information contained in this booklet is based on information from the Crohn’s and Colitis Foundation (CCF). We recommend you look at the CCF’s website as well as our website for additional information. If you do not have internet access, please let us know and we can obtain pamphlets for you. You can contact us with any questions.

RESOURCES

Crohn’s and Colitis Foundation of America (CCFA)
crohnscolitisfoundation.org

Inflammatory Bowel Disease Clinic
childrensmercy.org/inflammatory_bowel_disease

GI Kids
gikids.org

WHEN TO CALL US

Contact us quickly 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 that can be either bright red or black/tarry in color
- Vomiting, especially if bloody
- Significant bloating of stomach
- Severe headache, especially if your child has been on corticosteroids recently
- Sudden or severe changes in vision
- Change in weight by 5 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

HOW TO CONTACT OUR OFFICE

THE PATIENT PORTAL

The patient portal gives you the option to send messages through your email with non-emergent issues or questions regarding your child to their provider. The patient portal also gives you access to your child's discharge instructions, labs and appointments. You can sign up for the patient portal at our GI clinic locations. If you use the patient portal to provide an update, please include your child's current medication list and symptoms.

CONTACT OUR IBD NURSE LINE (816) 760-8834

Leave a brief message for one of our highly trained staff nurses. The phone system is staffed from 8 a.m. to 5 p.m. Monday through Friday. We make every attempt to return messages left before 3 p.m. the same business day. Calls after 3 p.m. will be returned the next business day.

Please only leave the following information when prompted:

- Your name
- Your child's name
- Your child's date of birth
- Doctor and/or nurse practitioner who sees your child
- Your child's diagnosis (example: Crohn's disease)
- Number where you can be reached
- Reason for calling (example: flare-up, test results, questions)

WHAT WILL HAPPEN WHEN I LEAVE A MESSAGE?

- One of our staff members will call you to discuss your questions and concerns. We can often answer questions when we call you back.
- For medical questions, we may contact your child's provider to address concerns and will call you back with a plan.
- Additionally, our nutritionists, social worker, pharmacist and psychologist can also be contacted through this clinic number.

EMERGENCIES

For emergencies, after-hours calls or on holidays, please call the Children's Mercy 24/7 Nurse Advice Line at (816) 234-3188 and request to speak with the GI physician on call. Tell this doctor that your child has IBD.

WHO WE ARE

Our clinic uses a team approach in the assessment and treatment of children and adolescents with IBD. This team provides comprehensive health care for children and adolescents with IBD in a family-centered environment that recognizes the physical, emotional, behavioral, financial and social needs of patients and families.

YOUR CHILD'S IBD TEAM:

Attending Gastroenterologist: _____

Pharmacist: _____

Nurse Practitioner: _____

Psychologist: _____

Registered Dietitian: _____

Social Worker: _____

IBD Nurse Coordinator: _____

IBD Research Nurse Coordinator: _____

HELPFUL PHONE NUMBERS

TO MAKE A CLINIC APPOINTMENT:

Children's Mercy Adele Hall Campus or other clinic locations: (816) 234-3066

Children's Mercy Hospital Kansas location: (913) 696-8220

Children's Mercy Northland location: (816) 413-2500

Toll-Free: 1 (888) 246-1088

GI Procedure Room: (816) 234-3704

REFILLS

For refills, we ask that you call your pharmacy directly. Prescription information can then be electronically transferred for accuracy.

For faster service please use the patient portal.



CROHN'S AND ULCERATIVE COLITIS

IBD is a result of an abnormal response by the body's immune system. Normally the cells and proteins that make up the immune system protect your child from infection. In people with IBD, however, the immune system mistakes food, bacteria and other materials in the intestine for foreign or invading substances. When this happens, the body sends white blood cells into the lining of the intestines where they produce chronic (long-term) inflammation and ulcerations. The development of IBD is a combination of genetic predisposition, immune system dysfunction and trigger factors including environmental pollutants, the food we eat and substances that can alter our gut microbiome. **Please understand there is nothing you or your child did or could have done differently that would have prevented IBD. We will explain the basics about IBD, and show you how to safely care for your child at home.**

CROHN'S DISEASE (CD) is a chronic disease that causes inflammation of the lining of the digestive tract and sometimes a variety of symptoms outside of the GI tract. The areas of inflammation can develop anywhere from the mouth to the anus with patches of healthy tissue in between. Crohn's disease can also affect layers of the intestinal tissue deeper than the top lining. Sometimes it causes symptoms outside of the GI tract, such as in the skin or eyes.

ULCERATIVE COLITIS (UC) is a chronic disease of the large intestine, also known as the colon, in which the lining of the colon becomes inflamed. The combination of inflammation and ulceration can cause abdominal discomfort, bloody stools and possibly a variety of symptoms outside the GI tract, such as in the skin or liver.

INDETERMINATE COLITIS (IC) is a form of IBD with features of both ulcerative colitis and Crohn's disease. This usually occurs when the person has IBD that involves the large intestine (like UC) but has some features that may suggest CD.

TREATMENT AT CHILDREN'S MERCY

THE GOALS are to work with you and your child to:

- Control symptoms
- Promote nutrition and growth
- Maximize quality of life
- Provide support
- Treat extra-intestinal manifestations (symptoms outside of the gut)
- Prevent complications

THE STEPS you should follow to help us with these goals:

- Bring your child to clinic for regular follow-up visits every three to four months unless your child's GI provider says otherwise.
- Bring the names and doses of each medication.
- Be honest about symptoms and feelings. Your child's physician needs this information to help make the best treatment decisions.
- Ask questions about anything you or your child do not understand.
- Keep a simple journal regarding symptoms, medications and questions for clinic visits and other issues. Please bring the journal with you to clinic visits. (There is a section for notes at the back of this booklet to get you started).
- Have your child's blood drawn and stool samples submitted when the doctor recommends it. This will help monitor disease activity and tolerance of medications. Blood tests will either be done at the time of your child's clinic visit or may be arranged through your child's local physician.

QUALITY IMPROVEMENT AND COLLABORATION

ImproveCareNow

Children's Mercy is a member of ImproveCareNow (ICN), a national and international network of over 100 pediatric gastroenterology centers, whose primary focus is to continuously improve the care for all children and adolescents with IBD. ICN is a sustainable collaborative chronic care network that enables patients, families, clinicians and researchers to work together to further research, accelerate learning and share knowledge across care centers seamlessly.

What to know more? Visit improvecarenow.org

YOUR IBD TEAM QUALITY IMPROVEMENT (QI) FOCUS

Children's Mercy is dedicated to the continuous improvement of the care we provide children and adolescents with IBD. Our IBD QI team meets on a weekly basis to review newly diagnosed, nutritionally or medically complex patients, and hospitalized patients with a focus on QI initiatives in collaboration with our Parent/Family Advisory Council (PFAC).

PARENT/FAMILY ADVISORY COUNCIL (PFAC)

Our PFAC was started in 2012 and has grown into an actively engaged team of parents whose children are followed and treated by Children's Mercy Gastroenterology. Our PFAC is actively involved with our IBD QI team to ensure the changes we make are an outcome of the collaboration between parents, families and the QI team. If you'd like to know more about our IBD PFAC, please reach out to one of the IBD Coordinators for more information.

MEDICATIONS

1. Remember, your child's medicine will not work unless they take it. Please reach out to your medical team if you have any concerns with adherence.
2. Be sure to alert us to any allergies.
3. Do not change the dose of medication or stop using the medication unless told to do so by a member of the IBD team.
4. Keep a list of ALL medications and bring them with you for clinic visits.
5. If your child misses a dose of medication, it is important to have them take it as soon as they remember it. If it is almost time for the next dose, they should skip it and take the next regularly scheduled dose. DO NOT take a double dose.
6. If your child has a hard time taking medication or if other factors get in the way of giving your child their medication (such as the cost of medication or if your child is having difficulty swallowing pills), let us know immediately.
7. Please communicate with your IBD team if any antibiotic use is recommended by a different provider.



COMMON MEDICATIONS USED TO TREAT IBD

AMINOSALICYLATES (5-ASAS)

- APRISO® (MESALAMINE) – EXTENDED RELEASE CAPSULE
- ASACOL HD® (MESALAMINE) – DELAYED RELEASE TABLET
- AZULFIDINE® (SULFASALAZINE) – TABLET, DELAYED RELEASE TABLET, SUSPENSION
- CANASA® (MESALAMINE) – RECTAL SUPPOSITORY
- COLAZAL® (BALSALAZIDE) – CAPSULE
- DELZICOL® (MESALAMINE) – DELAYED RELEASE CAPSULE
- LIALDA® (MESALAMINE) – DELAYED RELEASE TABLET
- PENTASA® (MESALAMINE) – EXTENDED RELEASE CAPSULE
- ROWASA® (MESALAMINE) – RECTAL ENEMA

These are anti-inflammatory medications, chemically related to aspirin. They are typically used to help start healing, reduce inflammation and decrease discomfort and can be given orally or rectally, depending on the product. The type of aminosalicylate prescribed depends on several factors, including where in the digestive tract the inflammation occurs. Most commonly seen side effects include nausea, diarrhea, abdominal cramps and headaches.

COMMON MEDICATIONS USED TO TREAT IBD

STEROIDS

- CORTIFOAM® (HYDROCORTISONE)
- ENTOCORT® (BUDESONIDE)
- ORAPRED® (PREDNISOLONE)
- PREDNISONE
- SOLU-CORTEF® (HYDROCORTISONE)
- SOLU-MEDROL® (METHYLPREDNISOLONE)
- UCERIS® (BUDESONIDE)

These medications are typically used to bring on a “rapid remission” by controlling symptoms quickly, however, they are not preferred to use long-term due to potential side effects. Steroids may cause an increased appetite, insomnia, mood swings, stomach upset or swelling. It is very important to follow the taper schedule provided by your provider to slowly decrease the steroid dose over time and decrease the risk of steroid withdrawal.

IMMUNOMODULATORS

- GENGRAF®/NEORAL®/SANDIMMUNE® (CYCLOSPORINE)
- IMURAN® (AZATHIOPRINE)
- MERCAPTOPYRINE (6-MP)
- METHOTREXATE
- PROGRAF® (TACROLIMUS)

These medications work by regulating the immune system. They typically take about 6-8 weeks before becoming effective. Methotrexate is unique in that it can be taken orally or as an injection weekly. We monitor labs closely while patients are on these medications in order to determine if a child is tolerating the medication and to watch for potential side effects. Many of these medications can also be monitored by measuring the level of drug in your child’s bloodstream. Azathioprine has a “boxed warning” for an increased risk of malignancy, specifically hepatosplenic T-cell lymphoma (HSTCL). This would be extremely rare, and our team will carefully weigh risks and benefits with your family prior to starting this medication.

COMMON MEDICATIONS USED TO TREAT IBD

BIOLOGICS

- CIMZIA® (CERTOLIZUMAB)
- ENTYVIO® (VEDOLIZUMAB)
- HUMIRA® (ADALIMUMAB)
- REMICADE® (INFLIXIMAB)
- SIMPONI® (GOLIMUMAB)
- STELARA® (USTEKINUMAB)

These are monoclonal antibodies that target certain inflammatory proteins in the body and help to reduce inflammation. They are typically given by either an injection or IV infusion every 2 to 8 weeks. Injectable versions of these medications will usually be mailed to your home from a specialty pharmacy. These medications are typically well-tolerated but can increase your child's risk of infections. Your child will likely be tested for tuberculosis and hepatitis B immunity prior to their first dose. Some biologics may include a "boxed warning" for malignancies such as lymphoma, leukemia and melanoma. This would be extremely rare, and our team will carefully weigh risks and benefits with your family prior to starting these medications.

BIOSIMILARS

- AVSOLA® (INFLIXIMAB-AXXQ)
- INFLECTRA® (INFLIXIMAB-DYYB)
- RENFLEXIS® (INFLIXIMAB-ABDA)
- AMJEVITA® (ADALIMUMAB-ATTO)
- CYLTEZO® (ADALIMUMAB-ADBM)
- HYRIMOZ® (ADALIMUMAB-ADAZ)
- HADLIMA® (ADALIMUMAB-BWWD)
- ABRILADA® (ADALIMUMAB-AFZB)
- HULIO® (ADALIMUMAB-FKJP)
- YUSIMRY® (ADALIMUMAB-AQVH)

Biosimilars are designed to be very similar to the approved biologic therapies. They are not exact copies of the biologic, but still contain the same active ingredient, work in the same way, and have the same dosing. They also are taken in the same form (injection or intravenous). They are just as safe and effective as the original biologic therapy. They are still carefully monitored, reviewed, and approved by the Food and Drug Administration (FDA), just like approved biologic therapies are. However, since they are not exactly identical, they cannot be considered a "generic" medicine.

COMMON MEDICATIONS USED TO TREAT IBD

JANUS KINASE INHIBITORS (JAK INHIBITORS)

- XELJANZ® (TOFACITINIB)

This is an immunosuppressive medication that works by blocking JAK enzymes from activating specific types of immune system cells that cause inflammation. This medication comes with an increased risk of blood clots and serious bacterial, viral or fungal infections which may result in hospitalization. JAK inhibitors are currently FDA approved to treat moderate to severe ulcerative colitis in adults. This medication is taken by mouth.

ANTIBIOTICS

- CIPRO® (CIPROFLOXACIN)
- FLAGYL® (METRONIDAZOLE)
- VANCOCIN® (VANCOMYCIN)

These antibiotics have been found to be effective in the treatment of IBD and often help control flares. 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.

PROBIOTICS

The body has good bacteria in the intestines that assist with digesting food and keeping the GI tract healthy. When your child has IBD, there may be times when the intestines need a boost of these good bacteria. Ask the GI team if this would be a beneficial therapy for your child.

MEDICINES TO AVOID

There are many medicines available to help relieve pain. Your child should avoid over-the-counter (OTC) and prescription medicines in this category that contain aspirin or nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or naproxen. These medicines have been shown to cause irritation sores or ulcerations in the intestines, which can increase the chance of a flare. Your child should not take these products unless ordered by your doctor. Examples of NSAIDs medications or aspirin-containing products to avoid are listed below:

- ADVIL® (IBUPROFEN)
- ALEVE® (NAPROXEN)
- ALL DAY RELIEF® (NAPROXEN)
- ASPIRTAB®/ BUFFERIN® /BUFFINOL®/ECOTRIN® (ASPIRIN)
- DAYPRO® (OXAPROZIN)
- EXCEDRIN MIGRAINE® (ACETAMINOPHEN, ASPIRIN, & CAFFEINE)
- MEDIPROXEN® (NAPROXEN)
- MOTRIN® (IBUPROFEN)
- NAPRELAN® (NAPROXEN)
- NAPROSYN® (NAPROXEN)

GENERAL IBD NUTRITION INFORMATION

Good nutrition is important for everyone, especially for people with IBD. People with IBD are at increased risk of malnutrition due to poor appetite, not being able to eat all the foods they usually eat or inability to absorb the nutrients they are eating. Sometimes, people with IBD notice some foods can make GI symptoms feel worse. It can be helpful to keep track of these foods and limit intake if they are bothering you. Individuals with IBD are at an increased risk for certain vitamin and mineral deficiencies, especially during a time of flare. Your GI provider may recommend specific vitamin or mineral supplements to help your body get the appropriate nutrients it needs for best long-term outcomes. Some common supplements your GI provider may recommend include:

- Vitamin D3 (cholecalciferol)
- Calcium
- Iron (ferrous sulfate)
- Vitamin B12
- Zinc
- Folate

Other changes you can make to improve overall well-being include:

- Eat more fruits, vegetables and whole grains
- Choose lean proteins like chicken, fish and beans
- Limit red meat
- Eat foods that are less processed
- Cut back on sugary food, drinks and soda

Diet is unique to each individual with IBD, and it is important to work with your GI provider or with a registered dietitian who specializes in IBD to help develop a plan that works for you.

NUTRITION AS THERAPY

EXCLUSIVE ENTERAL NUTRITION (EEN)

Enteral nutrition has been used as a primary therapy to induce remission. Studies have shown that enteral therapy can be as effective as steroids without side effects. These formulas contain all the necessary nutrients, vitamins and minerals to help with healing and growth. Formulas can be taken orally, but usually are given through a nasogastric tube that is passed through the nose and into the stomach. Enteral therapy typically lasts 8-12 weeks, after which your doctor and dietitian will discuss incorporating oral foods again and long-term medication management.

PARENTERAL NUTRITION

Parenteral nutrition delivers essential nutrients, vitamins and minerals directly into the bloodstream via a central line (catheter that is inserted into a large vein in the arm or neck). This is only used in severe cases when the gut may not be working appropriately and does not absorb nutrients of the food that is consumed.



NUTRITION AS ADJUNCT THERAPY

Diet can play special role in managing inflammatory bowel disease during flares or in periods of remission. Depending on your disease type or location, your doctor may recommend a trial of a special type of diet. These diets are typically used as adjunct (in addition to) medication therapies.

Specialized IBD diets are still debated within the medical community because they do not work for every person, and can be restrictive in nature. This can cause weight loss and impact lifestyle/social interactions. It's important to discuss specialized diets with your doctor and dietitian so individual nutritional needs are met.

Common specialized IBD diets include:

- Specific Carbohydrate Diet (SCD) – exclusion of grains and certain sugars
- Partial Enteral Nutrition and Crohn's Disease Exclusion Diet (PEN+CEDD) – nutrition comes from oral nutrition supplements and following a specialized diet free of processed foods
- Mediterranean Diet – rich in fiber and plant-based foods – limited red meat – poultry, eggs, yogurt and cheeses in moderation

OUTPATIENT INFUSION SERVICES

Children's Mercy Outpatient Infusion offers infusion services and lab draws for our patients. Your child will be cared for by a team of highly trained registered nurses and a care assistant. They will frequently check in on your child, assessing vital signs and observing your child's IV pump and IV site. The center has individual rooms, each with a recliner, TV, DVD player, video game system and a single chair for a parent/guardian.

BEFORE YOU COME TO THE INFUSION APPOINTMENT

Have your child drink a lot of liquids/water the day before and the day of the appointment. This will increase the ease of IV placement.

DURING YOUR CHILD'S INFUSION

- The nurse will start an IV. Comfort measures are available! Ask our infusion team what options are available to make the IV start less painful. J-tips, EMLA cream and buzzy bees are all wonderful options to help ease the pain. You can also discuss having a child life specialist available.
- Your care provider may order labs. Labs will be drawn before your child's infusion begins. The nurse draws labs with the IV start so there are no additional pokes.
- The length of infusion depends on many factors. Ask your nurse for more information.

WHEN TO CALL

There may be times when your child should NOT receive the infusion. Please call or message your care team if:

- Fever of 100.4 degrees or higher
- New onset illness that may require a primary care provider visit (strep throat, upper respiratory infection, flu, etc.)
- Newly started antibiotics
- Recent procedure or surgery
- Non-healing, open wounds

OUTPATIENT INFUSION SERVICES

WHY IT'S IMPORTANT TO KEEP YOUR CHILD'S APPOINTMENT

The timing (frequency) of your child's infusions is very important. Many infusion medications have an induction period, meaning they require more frequent infusions when first starting the medication. Please make every effort to stay on schedule. Missing doses or spacing doses out longer than recommended by your provider could cause flare, loss of response or cause a reaction toward the medication. Talk with your IBD team if you have any issues getting to infusion appointments.

INFUSION LOCATIONS

- **Adele Hall Campus Outpatient Infusion Clinic:** This is the main infusion location. Located on the 2nd floor of the outpatient clinics.
- **Children's Mercy Hospital Kansas:** Outpatient infusions can occur at our Children's Mercy Hospital Kansas location. Your child may be required to start their infusions at the Adele Hall Campus location first before transitioning to Children's Mercy Hospital Kansas Infusion Clinic.

CONTACT INFORMATION

Outpatient Infusion Therapy
2401 Gillham Road
Kansas City, MO 64108
Phone: (816) 983-6611
Fax: (816) 234-9419

RADIOLOGIC IMAGING STUDIES

Several types of radiologic imaging studies can be useful 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.

COMPUTERIZED TOMOGRAPHY (CT) AND COMPUTERIZED TOMOGRAPHY ENTEROGRAPHY (CTE) are 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. The patient needs to lie still for a longer time than for standard X-rays. 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. To prepare for the test, do not let your child eat or drink anything by mouth (NPO) for a specified period of time (the amount of time varies). You will be given information when the exam is scheduled.

RADIOLOGIC IMAGING STUDIES

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 3 days prior to the scan.

MAGNETIC RESONANCE ENTEROGRAPHY (MRE) uses a powerful magnet which provides images that help assess and evaluate the GI tract. Arrival time is 1-1/2 hours prior to the scan, in order to complete the oral preparation for the study. The patient should not have any metal in their body or a history of renal disease. Nothing is to be taken by mouth for 6 hours before the scan. Since MRE does not use radiation, it is beneficial in patients who may need to undergo numerous future studies and need to avoid repeat exposure to radiation. All patients get an IV for contrast when they get an MRE.



BLOOD TESTS

Blood tests are completed to look at specific body functions. The timing of results varies from hours to weeks depending on the test.

COMMON TYPES OF BLOOD TESTS:

CBC – COMPLETE BLOOD COUNT measures several features of your blood to help us identify blood loss, anemia or infection. Common markers we monitor in a CBC are:

- White blood cells, hemoglobin, hematocrit, red blood cell counts

BMP – BASIC METABOLIC PANEL measures your sugar (glucose) level, electrolytes, fluid balance and basic kidney function. Common markers we monitor in a BMP are:

- Potassium, calcium, sodium, chloride, carbon dioxide, glucose, blood urea nitrogen (BUN), creatinine

LFT – LIVER FUNCTION TEST measures certain enzymes and proteins in the bloodstream. They help monitor or diagnose potential liver disease or damage.

Common markers we monitor in LFTs are:

- Protein, albumin, bilirubin, AST/ALT (liver enzymes)

ESR – ERYTHROCYTE SEDIMENTATION RATE is a blood test that measures how quickly red blood cells sink to the bottom of a test tube. Typically, red blood cells settle slowly.

A quicker rate can indicate inflammation.

BLOOD TESTS

CRP – C-REACTIVE PROTEIN is a protein made by the liver. When increased, it indicates inflammation somewhere in the body. It is a non-specific marker, meaning it can be elevated due to infection or any other inflammation in the body. This test is helpful in monitoring inflammatory disorders.

6MP METABOLITES look at the level of activity of the medications 6 MP or Imuran to help the provider determine the effectiveness or toxicity of each patient's dose.

BIOLOGIC TROUGH/ANTIBODY LEVELS look at the levels of biologic medications (Remicade, Humira, Entyvio, Stelara, etc.) circulating in the bloodstream and help monitor for antibodies that could cause a reaction or loss of response toward that medication. Your provider may increase the dose and/or shorten the frequency based on the result and/or clinical symptoms.



STOOL TESTS

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 then bring them to the Children's Mercy lab or your local lab.

COMMON TYPES OF STOOL TESTS:

CLOSTRIDIUM DIFFICILE (C-DIFF) is a bacteria commonly found in the gut. Sometimes antibiotics used to treat an infection kill good bacteria, allowing *C. difficile* to grow out of control. Symptoms include diarrhea and bloody stools.

OVA AND PARASITES evaluate for a parasitic infection. People are exposed to these types of infections from community settings such as a daycare, community pool, camping grounds or lakes.

STOOL CULTURES help doctors look for other types of bacterial infections in the gut.

HEMOCCULT STOOLS look for microscopic blood in the stool.

CALPROTECTIN/LACTOFERRIN is a stool test that evaluates and monitors for inflammation specific to the GI tract.

*Note: The stool studies obtained at home need to be refrigerated. Stool samples need to be submitted within 24 hours of collection.

ENDOSCOPY

To confirm the diagnosis of IBD, as well as to assist in the evaluation of therapy, upper endoscopy (esophagogastroduodenoscopy or EGD) and colonoscopy will be performed. The physician can look at the intestine directly, as well as obtain biopsies (small tissue samples) for microscopic examination. This greatly helps the physician in making the best treatment decisions. It is likely that your child will have to undergo these procedures often throughout his or her life. Even though this may be a source of stress for your child, it is important that he or she understands the importance of the information obtained.

Capsule endoscopy (small bowel capsule – SBC) is a procedure that uses a small wireless camera that sits inside of a capsule shaped like a pill. It travels through the small intestine taking pictures that are transmitted to a recorder that is worn like a belt. SBC helps the provider see inside the small intestine, which is not easily reached with normal scopes. Your provider may order this test if they are concerned there is inflammation in the small intestine that is not captured with imaging studies.

People with Crohn's disease of the colon or ulcerative colitis have a higher risk for colorectal cancer than the general population. Colorectal cancer rarely occurs in the first 8 to 10 years after initial diagnosis of IBD. The risk increases the longer a person lives with the disease. An analysis of all published studies found that as many as 18% of people with IBD may develop colorectal cancer by the time they have had IBD for 30 years. The degree of increased risk is also related to the length of colon involved and the severity of disease. Because of this increased risk, people with IBD are advised to undergo more frequent colonoscopies than the general population (every 1 to 2 years after 8 years of disease). As a result of this increased risk to patients, we feel it is essential that you take your medications as prescribed by your provider and go to all routine clinical follow-up appointments.

The GI Procedure Room schedules the endoscopies and will provide you with all the instructions (laxatives, clear liquid diet, NPO [nothing to eat/drink by mouth], medications) to follow for preparation. Please follow these carefully and call the GI Procedure Room with any questions or concerns about the preparation and instructions.

GI Procedure Room: (816) 234-3704

HOSPITAL STAYS

It is possible that your child will need to be hospitalized when symptoms are severe.

- Parents or guardians can visit 24 hours per day on our inpatient units. Parents may sleep in your child's room at night. Visitor restrictions may apply during cold and flu season. Please check with your child's nurse. All visitors must be free of all signs and symptoms of illness.
- Brothers, sisters and friends may visit during regular visiting hours, after the hospital nurse has made sure they are not sick.
- Your child may wear his or her own clothing and bring games/toys, pillow/blanket, etc., from home.
- Our Child Life department works to provide age-appropriate activities, teaching and support for children throughout the hospital. These activities provide help in pain management and promote coping skills.
- It is important to note that you may see a different IBD doctor during your child's stay, but know they are in communication with your child's primary IBD provider.

SCHOOL/ACTIVITY

Because IBD is a lifelong condition, it is important for you and your child to learn to incorporate care for your child's disease into his or her life. Children should be encouraged to maintain as normal a life and routine as possible, including going to school.

Communicate with teachers, the school nurse, coaches and other caregivers so they are aware of your child's diagnosis and can help with needs as they arise.

SOME EXAMPLES:

- Hall passes for the bathroom for the entire school year
- Pass for the nurse's 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
- Talk to your child's doctor before allowing your child to participate in full contact sports.

This communication will also be important for times when your child might have to miss school or other activities because of doctor's appointments, procedures, hospitalization or illness. School programs such as a 504 plan provide assistance with studies or tutoring if necessary. Our social worker can help with this, and our psychologist can work with you to develop a system for gradually returning to school after many absences.

For prolonged hospital stays, Children's Mercy provides a teacher through our Child Life department. Homebound instruction may be needed with special circumstances for illness, but should be considered as a last resort.

PSYCHOSOCIAL NEEDS

IBD, like any chronic condition, impacts the entire family.

Having IBD can be hard at times, and we want to help your family with all the aspects of your life that can be affected by IBD. It can be stressful to have a chronic illness, come to frequent office visits, and remember to have your child take all of his or her medications while trying to live a “normal” life. Your child may deal with pain, anxiety, fear, depression, anger, body image changes and other emotions through the course of this condition. These factors are normal for anyone dealing with a chronic illness. Our goal is to support each child and family and teach strategies to cope with these issues as they may arise.

Siblings need to be kept involved as appropriate for their ages. Siblings often exhibit feelings of jealousy, fear, guilt or anger when their brother or sister experiences serious illness. Open, honest communication with the rest of the family will provide needed support and reassurance for siblings and help ease their fears.

Children’s Mercy has many resources available to help you and your child, such as Developmental and Behavioral Sciences, Social Work, Child Life, Community Services, the Kreamer Resource Center for Families and the IBD website, cmh.edu/inflammatory_bowel_disease.

Our IBD psychologist is available to meet with you and/or your child to discuss any of these concerns and provide treatment recommendations as needed.



GENERAL HEALTH CARE

The IBD team will work closely with your child’s primary care physician to care for your child. We will be sure to keep them updated on your child’s progress and expect that they will continue to care for your child for all other general health care needs.

HEALTH MAINTENANCE:

- Certain IBD medications can increase sun sensitivity and skin cancer risks. We highly recommend that your child wear at least SPF 30 sunscreen when outside and see a dermatologist yearly for a skin check.
- Some children with IBD may also develop inflammation of the inner eye or uveitis. We highly recommend yearly eye exams with an ophthalmologist for all patients.
- Please continue to see your child’s primary care physician (PCP) for annual visits, standard vaccinations and non-IBD related concerns.

A NOTE ABOUT IMMUNIZATIONS:

- Please speak with your child’s IBD team before scheduling any routine vaccinations.
- Live vaccines are NOT recommended for patients taking any immunosuppressive medication such as steroids, immunomodulators or biologics.
- Please notify your IBD team immediately if your child is exposed to chicken pox, shingles or tuberculosis (TB).
- We highly recommend that all children with IBD receive their annual flu vaccine.
- Your child’s IBD provider may recommend that your child receive additional pneumococcal vaccinations to broaden the number of pneumonia strains your child is protected against.
- Your child may be a candidate to receive a hepatitis B booster if they are not found to have immunity against hepatitis B from their childhood vaccine series.

A NOTE ABOUT ALCOHOL, DRUG AND TOBACCO USE:

- Alcohol can intensify the effects or side effects of many of the medications used for treating IBD. Please speak with your doctor or pharmacist before giving your child any alcohol-containing products, including mouthwash.
- Nicotine is a stimulant and both smoking and second-hand smoke can make your child’s IBD more active. Please don’t smoke around your child!
- Please remind your child of the possible severe reactions and negative implications caused by drinking alcohol, smoking, vaping or other illicit drug use.

ONGOING CARE

IBD is a lifelong condition. We will help your teenager learn to manage their own health care as they transition into a young adult. The IBD Transition Team's goal is to help promote independence, encourage decision-making and teach important skills for managing health needs. As your child gets older, the transition team and your child's providers will work with you and your child to gradually shift disease management responsibilities from parent to patient. These skills will be necessary as your child prepares to transfer from the pediatric setting to an adult GI doctor.

We will assist with the process of transferring care to an adult gastroenterologist as your child becomes a young adult. Generally, this transfer of care will occur around the time of high school graduation or somewhere between their 18th to 21st birthday. We can provide care to your child until their 22nd birthday.

SOME TOPICS THAT WILL BE ADDRESSED DURING THIS PROCESS:

- Changes of disease management responsibilities from parent to patient
- Adult health concerns such as work/school, sexuality, cancer surveillance and bone health
- Worries or fears about transferring to an adult doctor
- Choosing an adult gastroenterologist
- Medical and life insurance
- Obtaining medications
- Exercise and fitness
- Use of alcohol and tobacco products

The IBD team at Children's Mercy strives to follow the hospital's vision of providing the highest quality care available for your child. We look forward to working with you to help your child lead a healthy and active life.

HOW TO TALK TO YOUR FRIENDS AND FAMILY ABOUT IBD

SOME COMMON QUESTIONS YOU MIGHT HEAR AFTER DIAGNOSIS:

WHAT CAUSES IBD?

- The exact cause of IBD remains unknown. We do know, however, that there are a combination of factors. The environment, genetics, immune system and bacteria in the gut all play a role in the development of IBD. Parents sometimes feel guilty that they somehow caused the development of IBD in their children. This is certainly not the case as there is nothing known to prevent IBD.

HOW IS IBD DIFFERENT FROM IBS?

- IBD stands for Inflammatory Bowel Disease. Crohn's and ulcerative colitis are forms of IBD. IBS stands for Irritable Bowel Syndrome. People with IBD and IBS can have abdominal pain, diarrhea or constipation. However, the difference is people with IBS do not have inflammation in their GI tract like people with IBD do. Treatment for IBS and IBD is very different.

DOES YOUR CHILD NEED TO AVOID CERTAIN FOODS?

- Some people think that IBD is caused by eating certain foods. This is not true. People with IBD do sometimes notice that certain foods make their symptoms worse. Dairy products and foods high in fiber will sometimes cause abdominal pain or loose stools. Keeping a food journal can be helpful to determine what potential trigger foods, if any, might exist.

WHAT IS THE TREATMENT FOR IBD?

- The goal of treatment is to decrease inflammation in the GI tract and reduce symptoms. IBD is normally treated with medications that attempt to help calm the immune system. When the immune system overreacts, it attacks the digestive system. IBD medications are aimed at trying to suppress that reaction. It may take time to find the right treatment plan for your child. Our hope is that with treatment, most kids with IBD can lead active lives, including sports, after-school clubs and much more.

HOW DOES IBD AFFECT DAILY LIFE?

- The main change for most kids with IBD is the need to take medication daily. When symptoms are present, kids can have abdominal discomfort, frequent bathroom breaks, changes in appetite and fatigue. With treatment, most people with IBD live active lives. Your child with IBD should be able to play sports, attend school and socialize like other kids. We would like our patients with IBD to do all the things they did before they knew they had IBD.

COMMON ABBREVIATIONS

BE: Barium Enema
BMP: Basic Metabolic Panel
CBC/CBCD: Complete Blood Count/Complete Blood Count with Differential
CD: Crohn's Disease
CRP: C-Reactive Protein
CT: Computed Tomography
DEXA: Dual-Energy X-ray Absorptiometry; a bone density scan
ED/ER: Emergency Department/Emergency Room
EGD: Esophagogastroduodenoscopy
ESR: Erythrocyte Sedimentation Rate
GI: Gastrointestinal
IBD: Inflammatory Bowel Disease
IBS: Irritable Bowel Syndrome
IC: Indeterminate Colitis
ID: Infectious Disease
KUB: Abdominal X-ray (Stands for Kidneys, Ureters, Bladder)
LFT: Liver Function Test
MRE: Magnetic Resonance Enterography
NPO: Nothing by Mouth (No Eating or Drinking)
PA: Prior Authorization
PCP: Primary Care Provider (Pediatrician, Family Practice Physician)
PRN: In regard to medications, take only as needed
UA: Urine Analysis
UC: Ulcerative Colitis
UGI: Upper GI
UGISBFT: Upper GI with Small Bowel Follow-Through
US: Ultrasound

NOTES

QUESTIONS?

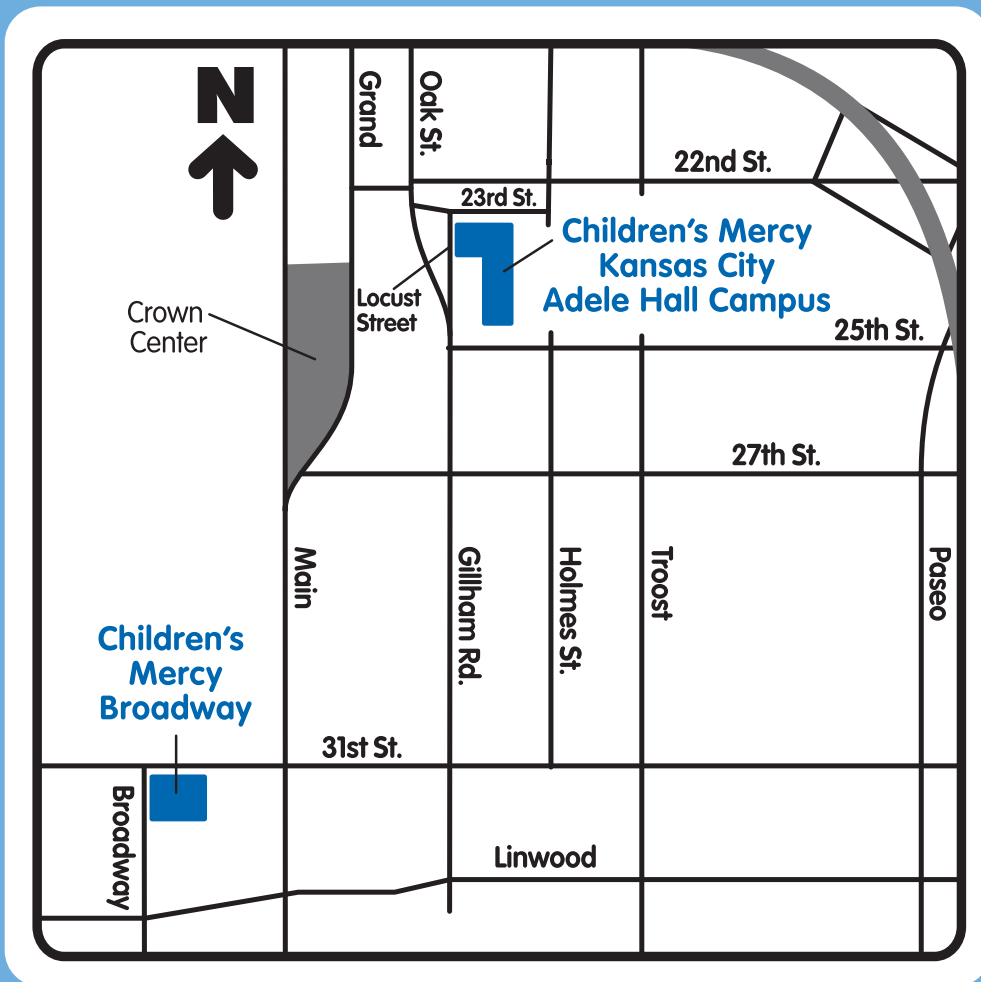
If you have any questions about the information, or if you would like to talk with someone in the Inflammatory Bowel Disease Program about your child's health, behaviors or lifestyle, please contact:

Children's Mercy IBD Program

GI Clinic Nurse Line: (816) 760-8834

Toll Free: (888) 246-1088

Children's Mercy 24/7 Nurse Advice Line: (816) 234-3188



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