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## **Welcome to the Vanderbilt University Medical Center Inflammatory Bowel Disease Clinic**

**We are glad you have chosen us to help you manage your inflammatory bowel disease.**

This binder is a resource that will help you take an active role in your medical care. It will also help you understand inflammatory bowel disease and how it will impact your life. You will also find information about treatment options and other helpful resources.

**How our clinic works: The quality of your care is our number one goal.**

We are a team of physicians, physician extenders (including nurse practitioners and physician assistants), registered nurses, research coordinators, dietitians, psychologists, and administrative assistants. On your first visit or first few visits, we will ask you to meet with our dietician to help find the best diet for you. We also understand the importance of mental health and the affect it can have on your disease so we ask you to meet with our psychologist. If you find this useful, you may continue to see the psychologist.

We have other resources available at times in our clinic setting, such as integrative health practitioners, social workers, and pharmacists which can help with things like coping, pain management, and smoking cessation.

Some patients will see us for a one- time consultation and we will make recommendations. We are also available for further follow up or questions by your primary gastroenterologists.

Some patients will be cared for solely within the inflammatory bowel disease clinic. On follow-up visits, you may see the nurse practitioner or physician assistant between times seeing your physician. We are a team experienced in caring

for inflammatory bowel disease patients and work closely together.

**We need to see you at least once every 3 to 12 months and maybe more often, if necessary.**

We care a great deal about our patients. Your well-being is our number one concern. We have expectations for our patients so we can take the best possible care of you. We expect you to see us regularly. If you are not able to attend your scheduled clinic visits or have lab tests done as needed, we will not be able to care for you safely. If you miss 3 appointments in a row (this includes clinic visits, radiology scans, and/or endoscopy), you may be asked to seek care elsewhere.

- Late policy: We know there are unexpected life events that can cause you to be late. To meet the needs of all our patients, we request the following: If you are more than 15 minutes late for your appointment, you may be offered the option to wait for the next available work-in visit. (The wait time will vary depending on the day's schedule.) If you do not wish to wait for the next available work-in visit, we will be happy to reschedule your appointment.

- Cell phone use: In order to give you the best medical care, please do not use cellphones while a clinic provider is in the room with you.

## **Contact Information**

If you need to contact the office, you may:

- **Call us at (615) 322-0128 between 8:30 am and 4:30 pm for questions and scheduling. Our fax number is (615) 936-6977.**

- **If you have an urgent question after 4:30 pm on a weekday or on the weekend, call the gastroenterology on call service at (615) 322-0128. You will speak with a physician covering the answering service, not your personal physician.**

• **You may use the My Health at Vanderbilt messaging service**, a great way to communicate with our team. Here is how to sign up:

- 1) Access Vanderbilt University Medical Center website.
- 2) Top right- Click My Health log in
- 3) Scroll down to new accounts and select register. Complete required information and save.
- 4) You can now email your physician's office.
- 5) Finally- show your ID to the staff at the front desk and gain full access. This allows you to view your records.

• **Other phone numbers that you may need:**

- Guest Services (615) 322-7700
- Guest Accommodations (615) 936-7666
- Endoscopy (615) 322-1881
- Radiology Scheduling (615) 343-2617
- Travel Clinic (615) 936-1174
- Central Registration (615) 322-2971
  - **(must call this number for insurance changes)**
- Patient Affairs (615) 322-6154
- Financial Counseling (615) 936-3938

• **If you are experiencing a flare/start having symptoms, please send a My Health at Vanderbilt message or contact the office.** It is best if you can let us know what symptoms you are having--number of bowel movements in 24 hours, pain and location of pain, intensity of pain (0-10 with 10 being the worst), any fever and if you are taking any new medicines. Please have your **date of birth** and a **list of your current medicines**.

• **If you are admitted to the hospital due to a flare of IBD, your outpatient IBD gastroenterologist may not be able to see you**

**during the hospitalization.** Our physicians covering the service work closely with your IBD doctor.

• **Always tell us about any new health problems you have or any ER visits or hospital stays.** Please try to bring records about your hospital stays to your visits with us. The most important records to bring are the discharge summary and reports of any tests, such as endoscopies, operations, biopsies, CT scans, MRIs, and blood tests or have them faxed to (615) 936-6977.

• **Forms such as FMLA/Short Term Disability**

- Please allow at least 5 business days for forms to be completed
- Patients must have a clinic visit **within the past 3 months** for forms to be completed
- Please complete the patient portion of the forms and sign them before presenting them to the clinic. We do not give completed forms to patients, we fax directly to your employer.
- We **do not** complete long term or social security disability forms. Your physician is happy to provide you a letter to accompany your application and medical records. We recommend your Primary Care Doctor complete these forms.

## **Medication Policy:**

- For medicine refills, call the office at (615) 322-0128 or message us through My Health at Vanderbilt (details on the previous page). **Please call at least 2 working days before you will run out of your medicine.** If you use a mail order service, please call at least 3 weeks before you need the refill so there is enough time for your medicine to be mailed.
- If it requires insurance authorization, this will cause a further delay for you to receive the medicine. If you need it sent to a different pharmacy than the previous refill,

please provide the pharmacy name and phone number. If you use a mail order service, please contact us at least 3 weeks before you need the refill so there is enough time for your medicine to be mailed.

- If you are told that your medicine will no longer be covered or your cost changes and you cannot afford it, please do the following:
  - Contact your insurance company/ pharmacy carrier and ask them what the alternative medicines are.
  - Write the name (s) of these medicine (s) down.
    - Example: If you are taking Asacol HD and you are told it will no longer be covered ask your insurance company what medicines will be covered in its place.
    - Example: If you are told Humira, Cimzia, Remicade, Stelara, Simponi, etc. will no longer be covered ask if you can get them a letter of medical necessity or a pre-authorization so the medicine can be covered.
  - Send a My Health at Vanderbilt message or call our office. Tell us the options to replace the medicines your insurance will no longer cover.
  - The nurses will then check with your physician who will pick the best medicine for you.

- When you start a new medicine, we will let you know how often to get your labs completed. We will also give you a lab letter with this information. See the details of the labs needed in Medication Protocol on the next page.

**It is your responsibility to get your labs done on time.** For us to continue prescribing your medicines, we must see you in the office as your physician requests. If you are overdue for labs, office visits, or other testing then we will only refill a 30-day supply of your medicines. We will not give you any more refills until you

are up-to-date on your labs, office visits, or other testing.

## **Basic Information about Inflammatory Bowel Disease (IBD)**

### **What is inflammatory bowel disease?**

Inflammatory bowel disease is a chronic inflammatory condition of the intestines. The cause of IBD is not well understood, but may be related to the response of the body's immune system against bacteria in the intestines. Inflammation causes the lining of the intestinal tract to become inflamed (red and swollen). IBD is thought of as an autoimmune disease. An autoimmune disease is a disease in which the immune system attacks itself rather than bacteria.

There are three different types of inflammatory bowel disease.

1. Ulcerative colitis affects only the colon.
2. Crohn's disease often affects the small intestine, but it can also affect the stomach, esophagus, and colon.
3. Indeterminate colitis affects the colon only, but cannot be distinguished from ulcerative colitis or Crohn's disease.

### **What is ulcerative colitis?**

Ulcerative colitis starts in the rectum and can affect the entire colon or only part of it. It may be called proctitis if only the rectum is affected and left-sided colitis if only the lower half of the colon is affected. If most of the colon is affected, it may be called extensive colitis or pancolitis.

The inflammation is continuous, which means that it does not stop and then start again in a different part of the colon. The disease is chronic, which means that it is always present,

although the inflammation may come and go. Symptoms "flare" when the colon is inflamed. Ulcerative colitis is different from irritable bowel syndrome, infectious colitis, and ischemic colitis.

### **What is Crohn's disease?**

Crohn's disease can affect any part of the digestive tract: mouth, esophagus, stomach, duodenum, jejunum, ileum, colon, and anus. The most common area affected is the part of the small bowel called the ileum.

The inflammation usually occurs in segments, with healthy segments of bowel in between inflamed segments. It is called Crohn's ileitis when only the ileum is affected, Crohn's colitis when only the colon is affected, and Crohn's ileocolitis when both the ileum and the colon are affected.

It can cause inflammation all the way through the intestine and cause tiny tracts called fistulas that can go to other parts of the body including other intestines or skin. It can also cause scarring or narrowing of the intestine called strictures.

### **What is indeterminate colitis?**

Indeterminate colitis also only affects the colon, but it is not the same as ulcerative colitis or Crohn's colitis. IBD may be called indeterminate colitis when the biopsy cells under the microscope look more like cells from a person with ulcerative colitis, but with the naked eye the inflammation in the colon looks more like that of Crohn's disease.

Inflammation in Crohn's disease is more likely to affect segments of the colon, rather than continuous stretches of the colon, as happens in

ulcerative colitis. Also, in Crohn's disease the ulcerations can look deep and long.

### **Who is most at risk of getting IBD?**

IBD affects men and women equally. It can occur at any age, but often starts between the ages of 15 to 25. Crohn's disease is more common among people who have a family history of the disease. IBD affects about 1.4 million people in the United States.

Diet can affect the symptoms of IBD, but diet does not cause IBD. IBD results from the way the body's immune system reacts to the bacteria in the digestive tract. An overactive immune system may be genetic in families that have multiple members with IBD.

### **What are the symptoms of IBD?**

The symptoms of IBD partly depend on where the inflammation occurs.

Inflammation in the colon often causes diarrhea and bloody stools.

Inflammation in the rectum often causes urgency (the need to have a bowel movement quickly) and tenesmus (frequent urges to have a bowel movement, but passing very little stool). If the colitis is severe, the inflammation may extend deep into the wall of the intestine and cause abdominal pain and cramping.

Inflammation in the small bowel often causes diarrhea. It can also result in abdominal pain, tenderness, and cramping. These symptoms occur as the muscles in the intestine push food through narrowed areas. Stomach cramps and bowel blockage may lead to nausea and vomiting.

In addition to bowel symptoms, you may have other symptoms such as severe fatigue, weight

loss, loss of appetite, fever, sore or red eyes, skin rashes, and pain in the joints. People with IBD tend to have flares with active symptoms and periods of remission with no symptoms.

### **What are the complications of IBD?**

Scar tissue may result as the inflamed tissue heals. This scarring can narrow or even block the intestine. The narrowed area is called a stricture. If food can't move through your intestine, this is called an obstruction. As a result, you may have nausea and vomiting.

Long-term obstruction raises the pressure in the part of the intestine before the narrowed or blocked area. This pressure can cause the inflamed intestinal wall to burst. This is called a perforation. An untreated perforation lets intestinal contents out into the abdominal cavity. This is quite painful and requires immediate surgery.

More commonly, the perforation forms a small hole with a tunnel to another organ. This is called a fistula and is a way to release the pressure that builds up from the blockage. A fistula most commonly connects to another part of the intestine, to the skin, to the bladder, or to the vagina.

If a fistula does not connect to an exit site, it can form a cavity filled with infected intestinal contents and pus. This is called an abscess. Fistulas and abscesses can also develop in the tissues around the anus. These complications are called perianal fistula and perianal abscess. Long-term inflammation of the colon can lead to colon dysplasia (abnormal or pre-cancerous cells) and colon cancer.

Long-term inflammation of the small intestine rarely leads to cancer. However, inflammation of the small intestine can decrease the body's

ability to absorb iron, vitamin D, and vitamin B12.

A lack of iron or B12 can cause anemia. Blood loss into the stool over time can also cause anemia. Decreased vitamin D absorption can lead to bone loss. Steroid use can make bone loss worse.

In addition to intestinal inflammation, you may have inflamed joints (arthritis), skin problems (sore red bumps or ulcers on the skin) and inflammation of the eyes or mouth. If your eyes suddenly become very red and sensitive to light, you need to have an eye exam right away.

Crohn's disease in the small intestine increases the risk for kidney stones and gallstones. The risk is higher if part of the small intestine has been removed.

### **How is IBD diagnosed?**

You will have a complete history and physical exam. You may need some tests, such as blood tests, stool tests, CT or MRI scans, and colonoscopy with biopsy. The colonoscopy will look for ulcers or inflammation in the intestine.

Because most of the treatments for IBD have risks, you need to be completely sure that you have IBD before it is treated. Your intestinal tissue will be looked at very closely under a microscope to be sure you have IBD and not an infection or another illness. You also may need an other tests.

### **How are Crohn's disease and ulcerative colitis treated?**

There is no cure for IBD at this time. Treatment helps to eliminate or reduce symptoms, prevent flares, and decrease complications of the disease.

What you can do:

- If you stop smoking, the inflammation in your intestines will decrease and your symptoms may go away.
- Avoid using Nonsteroidal Anti-Inflammatory Drugs such as Motrin, Ibuprofen, Naproxen, Aleve, Goody's or BC powders. Patients who use NSAIDs, even infrequently, are more likely to have a flare of the IBD than those who do not use them. Also, their flare is more likely to be resistant to IBD medicines. Be sure to discuss the use of NSAIDs with your IBD physician.
- Medicines for inflammation. Most drugs used to treat IBD reduce inflammation.
- Medicines for symptoms. Until the medicines start working by reducing the inflammation, you may take medicines that will help ease your symptoms such as cramping, urgency, or diarrhea. These medicines are only used when you need them. (More detailed discussion of medicines can be found in the Medications for IBD section.)
- Surgery to remove the part of the intestine that is inflamed is an important part of IBD therapy. It should always be considered as a reasonable alternative to medical therapy.
- Changing your diet, especially during flares, may ease your symptoms. It will not reduce inflammation, nor will it lower your risk for complications.

Herbal, alternative, or complementary therapies have not been shown to work on inflammation in clinical studies, nor have they been fully tested. Although some help ease symptoms, they usually work only in very mild cases or as a supplement to existing therapy.

Ask your health care team about the safety and effects of these products. Always let your healthcare team know if you are using them.

**What should I know about my IBD to be an informed partner in my care?**

- Do you know if you have Crohn's disease, ulcerative colitis, or indeterminate colitis?
- Do you know what part of your intestines is involved?
- Do you know what year you first starting having symptoms (how long you have had IBD)?
- Do you know if you have had any strictures, fistulas, or abscesses in the past?
- Do you know what medicines you have taken in the past? Why did you stop taking each one? Did the medicine improve your symptoms?
- Do you know if you have had surgery for your Crohn's disease, ulcerative colitis, or indeterminate colitis? When did surgery occur? What parts of the intestines were removed?



## **Testing in IBD**

### **Colonoscopy and Flexible Sigmoidoscopy**

#### **Why does a person with Crohn's disease or ulcerative colitis need a colonoscopy?**

A colonoscopy is used to make the diagnosis of Crohn's disease or ulcerative colitis. A colonoscopy can also assess the inflammation during IBD flares and the response to treatment. A third important use of a colonoscopy is to screen for early colon cancer or to look for abnormal cells that may turn into cancer cells.

#### **What happens before a colonoscopy?**

You will get detailed instructions when your appointment is made for the colonoscopy. Starting the day before the procedure you will have to take a colon cleansing preparation or "prep". This is a special laxative that helps clear away the stool so the lining of the colon can be inspected. Many people say the "prep" is the hardest part.

#### **What happens during a colonoscopy?**

A colonoscopy is usually an outpatient procedure. In the preparation area a caregiver will explain the steps of the procedure to you and also the risks involved. You will be asked to sign a consent form. You will have an intravenous (IV) line started to give you a sedative. In the exam room, you will lie on your left side connected to oxygen and blood pressure monitors. The sedative will make you comfortable and sleepy while the lining of the colon and the last part of the small intestine are inspected. Biopsies (tissue samples) obtained during the procedure do not cause pain.

#### **How often do patients with ulcerative colitis or Crohn's disease need a colonoscopy?**

A colonoscopy is done at the time you are diagnosed with Crohn's disease or ulcerative colitis. After that time, a colonoscopy may be done if there is a significant change in your symptoms.

A routine colonoscopy is not needed unless you have had ulcerative colitis or Crohn's disease affecting the colon for more than 8 to 10 years. If you have had inflammation of the colon for that length of time and it involves a significant area of your colon, there is an increased risk for colon cancer. For that reason, and from that time on, you will need a colonoscopy every 1 to 3 years, depending on other risk factors.

This is called a surveillance colonoscopy. The purpose of a surveillance colonoscopy is to screen for colon cancer or abnormal cells that may turn into colon cancer. During a surveillance colonoscopy, the lining of the colon is closely examined. Suspicious areas are biopsied so we know if there are abnormal cells or colon cancer.

#### **What happens after a colonoscopy?**

You will be taken to the recovery room where your driver can join you. You will be given your colonoscopy results at this time. The biopsy results will not be ready for about a week. You may have some bloating due to the air introduced during the procedure, but this should pass quickly. You cannot drive yourself home, as you may be drowsy from the sedative.

#### **What are the possible complications of a colonoscopy?**

A colonoscopy is generally very safe. Complications are rare, but may include

bleeding, problems with the sedative, or a perforation (tear) in the intestinal wall.

If you notice any signs of bleeding or if you have significant abdominal pain after a colonoscopy, contact your provider or the gastroenterologist on call.

### **What is a flexible sigmoidoscopy?**

A flexible sigmoidoscopy is a procedure similar to a colonoscopy but the scope is smaller and only inserted a short way into the colon. The bowel preparation usually requires taking two enemas the morning of the exam.

A flexible sigmoidoscopy typically causes less discomfort than a colonoscopy. Most people do not need a sedative. A flexible sigmoidoscopy has the same complications as a colonoscopy.

### **Why do some patients with ulcerative colitis need a flexible sigmoidoscopy?**

Ulcerative colitis usually starts at the end of the rectum and moves upward along the colon in a continuous fashion. For this reason, some patients with ulcerative colitis are only affected in the rectum, or the rectum plus the lower part of the colon. If this is the case, a flexible sigmoidoscopy instead of a colonoscopy may be used to monitor your disease.

To check for colon cancer you need a colonoscopy, so the entire colon can be seen and biopsies can be taken.

People who have had colectomy with ileoanal pouch anastomosis (an operation that removes almost the entire colon and connects the small bowel to the rectum) may have a flexible sigmoidoscopy every 1-3 years. This is done to check for rectal symptoms and to screen for

colon cancer or abnormal cells that may turn into colon cancer.

## **Upper Endoscopy**

### **Why do some patients with Crohn's disease or ulcerative colitis need an upper endoscopy?**

An upper endoscopy (sometimes abbreviated EGD) is an exam of the upper gastrointestinal (GI) tract – esophagus, stomach, and duodenum (first part of the small intestine). Unlike a colonoscopy, which is usually required for everyone with IBD, an upper endoscopy is used only if you have upper abdominal pain, problems swallowing, or nausea. Crohn's disease may affect the upper GI tract. Biopsies taken during an upper endoscopy can confirm this. If you have Crohn's disease in the upper GI tract you may benefit from taking a medicine called a proton pump inhibitor or PPI.

### **What happens before an upper endoscopy?**

You will get detailed instructions when your appointment is made for the upper endoscopy.

### **What happens during upper endoscopy?**

An upper endoscopy is usually an outpatient procedure. In the preparation area, a caregiver will explain the steps of the procedure to you and also the risks involved. You will be asked to sign a consent form.

In the exam room, you will lie on your left side connected to oxygen and blood pressure monitors. You will have an intravenous (IV) line started to give you a sedative. The sedative will make you comfortable and sleepy while the lining of the upper GI tract is inspected. Biopsies (tissue samples) taken during the procedure do not cause pain. The actual procedure lasts only a short time, but you will be in the recovery

area for up to several hours after the procedure.

### **What happens after upper endoscopy?**

You will be taken to the recovery room where your driver can join you. You will be given your upper endoscopy results. The biopsy results will not be available for about a week.

### **How often do patients with Crohn's or ulcerative colitis need an upper endoscopy?**

An upper endoscopy is done only if you have symptoms of upper GI tract problems. Many patients with IBD will never need one.

### **What are the possible complications of upper endoscopy?**

An upper endoscopy is generally very safe. An uncommon side effect is a sore throat. Very rare complications include bleeding, problems with the sedative, or a perforation (tear) in the intestinal wall.

If you notice any signs of bleeding or if you have significant abdominal pain after an upper endoscopy, contact your doctor or contact the gastroenterologist on call.

## **Capsule Endoscopy and Deep Enteroscopy**

Crohn's disease often involves the small intestine. Making the diagnosis of Crohn's disease can be hard when the affected portions of the small intestine are beyond the reach of the standard scopes used in upper endoscopy or colonoscopy.

The small intestine is about 20 feet long and recent advances including capsule endoscopy and deep enteroscopy have made it possible to see this area of the intestine.

### **What is capsule endoscopy?**

Capsule endoscopy, often referred to as the "pill camera," is one way to look at the entire small intestine. The capsule, which is the size of a large pill, is swallowed. The pill travels through the intestine taking two pictures per second. A recorder worn on a belt holds the pictures.

A doctor will review the pictures on a computer and send a report. You will pass the capsule in the stool. The pictures from this test may show signs of Crohn's disease.

The capsule is not able to take biopsies of the tissue. Because a narrowing (stricture) of the intestine may keep the capsule from moving, you may be asked to swallow a "test capsule" or patency capsule first.

### **What is deep enteroscopy?**

Deep enteroscopy is a test to look at the small intestine that is beyond the reach of an endoscope or a colonoscope. Double-balloon enteroscopy, single-balloon enteroscopy, and spiral enteroscopy are all examples of deep enteroscopy.

The deep enteroscopy technique uses a long scope with an overtube to move the scope deep into the small bowel. Deep enteroscopy can be used to find signs of Crohn's disease that were seen during capsule endoscopy or on the results of other tests, like a CT scan.

It can be useful in the diagnosis and care of Crohn's disease because it makes it possible to do biopsies deep within the small intestine. Also, narrowed areas of the small intestine can be dilated (made wider) to open them up and improve symptoms.

## **Rectal Endoscopic Ultrasound**

Crohn's disease occasionally involves the area around the anus, resulting in perianal fistulas (tunnel between skin and anus) and abscesses (infections). Making sure that fistulas and infections are found is very important to control symptoms and prevent more infections.

This test is often done before a surgeon performs an exam under anesthesia to place setons (silk string or rubber band) around the anus so that an infection does not form as the fistula heals.

### **What is Rectal endoscopic ultrasound?**

Rectal endoscopic ultrasound is one way to look at the rectum and surrounding tissues. A special endoscope is inserted into the rectum. The rectum is then filled with water and an ultrasound probe is inflated into the rectum.

A doctor will review both the endoscopy and ultrasound pictures during the procedure. If needed, biopsies can be taken from the rectal lining or from deeper tissues.

### **What happens before a rectal endoscopic ultrasound?**

You will get detailed instructions when your appointment is made for the rectal endoscopic ultrasound.

### **What happens during a rectal endoscopic ultrasound?**

A rectal endoscopic ultrasound is usually an outpatient procedure. In the preparation area, a caregiver will explain the steps of the procedure to you and also the risks involved. You will be asked to sign a consent form.

In the exam room, you will lie on your left side connected to oxygen and blood pressure monitors. You will have an intravenous (IV) line started to give you a sedative. The sedative will make you comfortable and sleepy while the lining of the upper GI tract is inspected.

Biopsies (tissue samples) taken during the procedure do not cause pain. The actual procedure lasts only a short time, although you may be in the recovery area for up to several hours after the procedure.

### **What happens after rectal endoscopic ultrasound?**

You will be taken to the recovery room where your driver can join you. You will be given your rectal endoscopic ultrasound results.

### **How often do patients with Crohn's need a rectal endoscopic ultrasound?**

A rectal endoscopic ultrasound is done only if you have symptoms of perianal Crohn's. Many patients with Crohn's will never need one. A repeat rectal endoscopic ultrasound may be recommended if you do not respond well to therapy, if there are concerns for infection, and to check your response to medical therapy.

**What are the possible complications of rectal endoscopic ultrasound?** A rectal endoscopic ultrasound is generally very safe. Complications are rare, but may include bleeding, problems with the sedative, or a perforation (tear) in the intestinal wall.

If you notice any signs of bleeding or if you have significant abdominal pain after a rectal endoscopic ultrasound, contact your doctor as instructed on your discharge instructions.

## Laboratory Tests

Lab tests are blood tests used to check how severe your disease is, your response to treatment, and the effects of your medicines.

### Common blood tests

- Hemoglobin/Hematocrit - A low count means you may have bleeding and anemia. Testing the levels of iron, vitamin B12, and folic acid in the blood can help to figure out the cause of anemia.
- White blood cell count - A high count is a sign of inflammation or infection. A low count may be a side effect of a medicine, which means your dose may need to be decreased or stopped.
- Platelet count - A low platelet count may be a side effect of a medicine, which means your dose may need to be decreased or stopped. A low count increases your risk for bleeding. A high platelet count can be a sign of inflammation.
- Comprehensive profile - This group of lab tests measures the effects of medicines on electrolytes (sodium, potassium, etc.), liver function (bilirubin, albumin, AST, ALT, alkaline phosphatase), and kidney function (BUN, creatinine).
- ESR (erythrocyte sedimentation rate)/CRP (C reactive protein) – markers of inflammation

### Azathioprine and mercaptopurine testing

- TPMT enzyme - Usually done only once, before you start taking azathioprine or mercaptopurine.

- 6 TG - May be ordered periodically. A high level of 6 TG may be linked to a low white blood cell count, which means your dose of medicine may need to be lowered. A low level usually means that a higher dose of medicine is needed to get a better response.
- 6-MMP - A high level of 6-MMP may be linked to liver toxicity (which can damage the liver).

### Other Tests

- PPD - Skin test done before starting an anti-TNF medicine to make sure you do not have tuberculosis (TB).
- QFTB or Tspot - Blood test done before starting an anti-TNF medicine to make sure you do not have tuberculosis (TB).
- Hepatitis B virus antigen - Lab test that shows if you have a hepatitis B virus infection now.
- Hepatitis B virus antibody - Blood test that shows if you are immune to the hepatitis B virus.

### Testing for infections: Clostridium difficile (C. diff) and cytomegalovirus (CMV)

Colon infections are common in people with IBD. Your stool, blood, or colonic biopsies may be “cultured” to determine if you have an infection. Antibiotics or antivirals are used to treat colon infections.

- C. diff toxin/PCR - Stool test that is done if you have diarrhea. Taking antibiotics can increase the risk of getting C. diff infection.
- CMV stain - Blood test or stain of colonic biopsies that is done if you

continue to have diarrhea despite appropriate treatment for you colitis.

## Osteoporosis Monitoring

Vitamin D is needed for calcium to be absorbed in your intestine. In IBD (especially Crohn's disease), vitamin D is not absorbed as well, so there is an increased risk for osteoporosis and bone fractures.

- Vitamin D level - Low levels mean you may need to take vitamin D pills. For more information about the diagnosis and treatment of osteoporosis see Preventing Bone Loss in the section, Maintaining My Health.

## Imaging Tests

**Abdominal x-ray** – An abdominal x-ray is a picture of structures and organs in the belly. The cause of pain in the abdomen or the cause of ongoing nausea and vomiting may show up on the x-ray. In IBD, an x-ray is helpful to look for a dilated (wide) or perforated (punctured) intestine, which can be a complication of the disease. An abdominal x-ray can show if there is air in the abdomen, which is a sign of a perforation.

**Upper GI Series (UGI)** – This test is used to find narrowing (strictures) in the upper GI tract as well as ulcers and inflamed areas of the intestine in people with Crohn's disease. This exam looks at your esophagus, stomach, and the first part of your small intestine. You will be given a barium solution to drink.

A doctor watches the movement of the barium through your esophagus, stomach, and the first part of the small intestine. Several x-ray pictures are taken at different times and from different views during the exam.

A small bowel follow-through may be done right after a UGI to look at the rest of the small intestine. An exam of just the throat and esophagus is called an esophagram (or barium swallow).

**Computed tomography enterography (CTE)** – This test is similar to a routine CT scan except you drink the contrast material (dye) before the CT scan is started. The contrast material allows for the small intestine to be seen more clearly. Contrast material may also be given through an intravenous (IV) line, which shows inflammation of the small intestine more clearly.

We will check creatinine (a kidney function test) prior to CTE to see if you have any kidney problems. During the test, you will lie on a table that is attached to the CT scanner, which is a large doughnut-shaped machine. The CT scanner sends x-rays through the area of the body being studied. Each rotation of the scanner takes less than a second and provides a picture of a thin slice of the abdomen.

All of the pictures are saved on a computer. They also can be printed. This has become useful to study diseases, such as Crohn's disease. While a routine CT can detect the complications of Crohn's disease, such as a stricture, fistula, and/or abscess, CTE provides greater details of the inflammation that occurs in the small bowel in patients with Crohn's disease.

**Dual-energy x-ray absorption (DEXA)** – Many IBD patients have taken steroids, which can lower bone density. A DEXA measures bone density to find out if you have osteopenia (abnormally low bone density) or osteoporosis (severely low bone density). This test can help predict your chances of having a broken bone. There are no known risks from having a DEXA.

For more information about the diagnosis and treatment of osteoporosis see Preventing Bone Loss in the section Maintaining My Health.

**Fistulogram** – This test is done for people with Crohn’s disease to learn about a fistula (abnormal tunnel). It is done under anesthesia by a radiologist. Contrast dye is injected into the fistula and x-rays are taken. This test more clearly shows which loop(s) of bowel connect to the fistula.

**Magnetic resonance enterography (MRE)** – This is often used instead of a CTE so that you are not exposed to radiation. An MRE involves a powerful but harmless magnetic field and radio waves like the kind that transmit your favorite FM music. The radio waves combine with the magnetic field to produce very clear pictures of parts of the body such as the small intestine.

Contrast material (dye) is given through an intravenous (IV) line so that your small intestine can be seen more clearly. Because the MRE scan involves the use of a powerful magnet, you will be asked questions about whether you have any implanted devices such as a cardiac pacemaker, a cerebral aneurysm clip, a neurostimulator, or a hearing aid. You will also be asked if you have any metal shrapnel in your body or any metal fragments in your eyes.

**Magnetic resonance imaging (MRI)** – Sometimes people with Crohn’s disease develop fistulas (abnormal tunnels) or abscesses (infections) around the anus. In this situation, a MRI can be performed to identify all of the fistulas and abscesses that are not obvious on physical examination.

This test is often done before a surgeon performs an exam under anesthesia to place setons (silk string or rubber band) around the

anus so that an infection does not form as the fistula heals.

Sometimes people with IBD have symptoms in other parts of the body, besides the GI tract. These are called extra-intestinal symptoms. A common extra-intestinal symptom is joint pain or arthritis. When this affects the very low back, where the pelvis attaches to the spine, it is called sacroiliitis. An MRI is a very sensitive way to diagnose this condition. Like an MRE, it uses a harmless magnetic field and radio waves to create pictures. A special MRI called MRCP may be done to look for problems in the bile duct system.

Small bowel follow-through (SBFT) – This test is done for people with Crohn’s disease to find narrow areas (strictures), ulcers, and inflamed areas in the lower part of the small intestine.

The time needed for this test may be as little as 1 hour, but it may last 4 to 5 hours. It may take longer if you have a blockage. You will drink several glasses of barium. Abdominal x-ray pictures are taken at different times, from 15 minutes to 1 hour or more, depending on the activity of your intestine.

## Treatment Options in IBD

### Medicines for IBD

#### Aminosalicylates (5-ASAs)

##### What are 5-ASAs?

5-ASAs are a type of medicine used to treat ulcerative colitis. 5-ASAs work on the lining of the gut to reduce inflammation. 5-ASAs work better for ulcerative colitis than for Crohn's disease because ulcerative colitis affects only the inner lining of the colon. Crohn's disease can affect the deeper layers of the colon and/or small intestine.

##### What are the benefits of taking 5-ASA?

5-ASAs are the first choice to treat mild to moderate ulcerative colitis. It is used to bring you into remission and also keep you in remission. 5-ASAs can decrease your symptoms and prevent flares. When you take a 5-ASA regularly, it may help to protect you from developing colon cancer.

People with Crohn's disease in the colon are more likely to feel relief of symptoms with 5-ASAs than those who have Crohn's disease only in the small intestine. But 5-ASAs do not prevent flares in the long run in Crohn's disease.

5-ASAs do not work as well in treating severe forms of both Crohn's disease and ulcerative colitis.

##### What are the medicine names of 5-ASAs and how do I take a 5-ASA?

- Sulfasalazine (Azulfadine, Sulfazine)
- Mesalamine (Asacol HD, Delzicol, Pentasa, Apriso, Lialda ,Rowasa, and Canasa)

- Balsalazide (Colazal, Giazol)
- Olsalazine (Dipentum)

These medicines are all pills that should be taken with plenty of water. While these medicines work similarly, they can differ in how many pills you need to take and how often you need to take them.

There are two forms of mesalamine made to be given in the rectum: Canasa (suppository) and Rowasa (enema). These medicines treat distal inflammation (when the left side of the colon and/or the rectum is the only area affected). The enema works best if it can be held in the rectum as long as possible, ideally for up to 8 hours.

##### How quickly do 5-ASAs start to work and how long should I take a 5-ASA?

If you take the medicine regularly, your symptoms should start to improve in 2 to 4 weeks. If your inflammation is more severe, you may also need to take a 5-ASA as an enema or a suppository in addition to pills. Taking these along with the 5-ASA pills will help you get better more quickly.

5-ASAs work best if they are taken all of the time, not just when you have a flare. Always talk to your doctor before taking a smaller dose of your medicine or if you plan to stop taking it.

##### Is there anything I should avoid while taking a 5-ASA?

You should not take cardiac glycosides like digoxin when you are taking 5-ASAs. Be sure to tell all of your health care providers about all the medicines you are taking, including over-the-counter vitamins and herbal products. Talk to your doctor if you are also taking aspirin, as their side effects can increase when used at the same time.



### **What are the side effects and risks of 5-ASAs?**

5-ASAs generally cause very few side effects. The most common and less serious side effects of 5-ASAs include headache, abdominal pain, belching, nausea, diarrhea, and pharyngitis (sore throat). The enema and suppository form of mesalamine cause even fewer side effects.

Signs that your body is not able to tolerate these medicines include cramping, severe abdominal pain, and bloody diarrhea, and sometimes fever, headache, or rash. If you have any of these symptoms after starting the medicine call your provider right away. You may need to stop taking the medicine. These medicines only very rarely cause kidney problems.

5-ASAs may also make the varicella (chickenpox) vaccine more toxic. This is called Reye's syndrome and occurs in children. Children should never be given aspirin and 5-ASAs while they are ill with chickenpox or have just received the chickenpox vaccine.

Sulfasalazine (Azulfadine) contains sulfa. A common side effect of this medicine is an allergy to the sulfa. Allergic reactions include hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, and wheezing. Anaphylaxis (shutdown of blood vessels) can occur but is rare. If you have an allergic reaction, stop taking this medicine and call your doctor, call the gastroenterologist on call, go to the emergency room, or call 911. If you know you are allergic or cannot take sulfa drugs, do not take sulfasalazine

Another common side effect of sulfasalazine is headache. To help prevent this you will start with a lower dose and then slowly increase to the needed dose. Most people who cannot

tolerate this medicine can still take other forms of 5-ASAs.

Sulfasalazine can cause anemia and low white blood cell counts. It can reduce sperm counts, but they return to normal after stopping the medicine.

### **Will I need to have any specific tests while I am taking a 5-ASA?**

Your kidney function and blood counts will be tested periodically while on this medicine.

### **Will I have to take medicines in addition to a 5-ASA to treat my ulcerative colitis?**

People who suffer from moderate to severe forms of IBD may need to take other medicines in addition to a 5-ASA. If you develop a flare you may need a course of a steroid medicine such as prednisone or budesonide (Entocort, Uceris). Once the flare has settled down and you taper off of the steroid you may be able to take only a 5-ASA.

Immunosuppressive drugs are frequently needed to treat more severe ulcerative colitis and Crohn's disease. The more flares you have, the more likely you will need to take an immunosuppressive medicine.

*This information is not meant to cover all uses, directions, precautions, warnings, drug interactions, allergic reactions, or adverse effects. If you have questions about the medicines you are taking, please talk to your doctor, nurse, or pharmacist. Take all medications as prescribed by your doctor. Tell your doctor about any side effects you experience. Always check with your doctor before changing or stopping your medications.*

## **Azathioprine/Mercaptopurine**

### **What is azathioprine and how does it work?**

Azathioprine (abbreviated AZA, brand names Imuran and Azasan) is used to treat moderate to severe Crohn's disease and ulcerative colitis. AZA prevents your body from making certain kinds of white blood cells that cause inflammation in the gut. It is an immunosuppressive medicine, which means it partially blocks the action of the immune system, but does not completely turn it off.

### **What is mercaptopurine?**

6-Mercaptopurine (or mercaptopurine) is also called Purinethol (brand name) and is abbreviated 6-MP. It works the same way as AZA to help your disease. But you cannot change one pill for the other because the dose of each medicine is different.

### **What are the benefits of taking AZA or 6-MP?**

If you have disease flares fairly often (uncontrolled inflammation in your gut), you may need several courses of prednisone. But prednisone does not work to keep you in remission, and it has many side effects. This is why it is only used for acute flares.

AZA or 6-MP can lessen the damage to the intestine in both ulcerative colitis and Crohn's disease, which can improve your health in the long-term. If you get better while taking AZA or 6-MP, you will avoid the side effects of prednisone, avoid the complications of untreated inflammation, and improve your quality of life.

It can be used alone or in combination with other medications to treat IBD. AZA and 6-MP

may also reduce your risk of developing colon cancer.

### **How quickly does AZA or 6-MP work?**

AZA or 6-MP may take 2 to 4 months to work, so it is important to keep taking the medicine even though you may feel that it isn't helping. AZA or 6-MP can be slow to work and it can also be slow to wear off.

### **How should I take AZA or 6-MP?**

Take AZA or 6-MP with a full glass of water or with food to prevent stomach upset. If you experience fatigue while on this medicine, you can try splitting the dose (½ in the morning and ½ at night) or you can take the medication before going to sleep.

If you improve while taking AZA, you will take it for as long as you can.

### **Is there anything I should avoid while taking AZA or 6-MP?**

Non-prescription products: Do not take any over-the-counter herbal products with Echinacea or cat's claw because these can reduce the effect of all immunosuppressive medicines, including AZA or 6-MP.

Prescription medicines: Allopurinol is a medicine used to treat gout. Some people find that AZA or 6-MP works better for treating IBD if it is taken with allopurinol. But you should not take allopurinol with AZA or 6-MP unless told to do so because this can suppress your immune system.

AZA or 6-MP used along with ACE inhibitors may cause low white blood cell counts. AZA or 6-MP is not used if you are taking an alkylating agent for cancer chemotherapy such as cyclophosphamide (Cytoxan). Do not take AZA

or 6-MP with methotrexate or natalizumab. Other prescription medicines may interact with AZA or 6-MP.

### **Will I need to have any tests while I am taking AZA or 6-MP?**

Before you start taking AZA or 6-MP, you will have a blood test called TPMT. This test will measure how quickly your body breaks down AZA. The result of this test will show if AZA or 6-MP is safe for you and will help find the best starting dose of the drug.

While you are taking AZA or 6-MP, you will need to have your blood tested on a routine basis to check your blood cell counts and your liver function. For the first few months after starting the medicine, these monitoring blood tests will be done very frequently, every 1-4 weeks.

After you are stable on the medicine, these blood tests will be checked every 1-3 months for as long as you take it. Your dose of AZA or 6-MP may change based on the results of your blood tests. If your dose is changed, the time between your blood tests may also change.

Your doctor may also check metabolite tests, which are blood levels of the breakdown products of AZA or 6-MP, to see if you are on the correct dose.

### **What are the possible side effects and risks of AZA or 6-MP?**

Allergic reactions are rare and usually happen right away. Allergic reactions such as hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, wheezing, and anaphylaxis (vascular shutdown) may occur but are very rare.

If you have an allergic reaction, go to the emergency room or call 911. Fever and rash are also a sign of an allergic reaction to AZA or 6-MP. Stop taking AZA or 6-MP permanently if you have an allergic reaction to it.

You may have side effects such as nausea, vomiting, diarrhea, fatigue, and/or muscle pain. Taking the medicine at night, or dividing the dose can improve some of these side effects. A change from AZA to 6-MP may be another option to help decrease side effects.

Call your doctor if you develop severe upper abdominal or back pain, nausea, and vomiting. If this happens, you will have a blood test to rule out pancreatitis (inflammation of the pancreas). If you develop pancreatitis while you are taking AZA or 6-MP, it will be stopped for good. Because AZA or 6-MP is an immunosuppressive medicine there is a small risk for getting lymphoma, a type of cancer. It is not clear whether this risk is due to the medicine or to the IBD. There is only a very small increase in your risk and you will be monitored closely.

The benefit of getting into remission and maintaining remission often outweighs this small increased risk for lymphoma. Tell your doctor right away if you notice any increase in pain, weight loss, or ongoing fevers you cannot explain. If any of these occur, blood tests or a CT scan may be needed. Be sure to tell your doctor if you have cancer now or if you have had it in the past.

AZA or 6-MP may also increase your risk for certain types of skin cancer. To protect yourself from getting skin cancer while taking AZA or 6-MP, avoid being in the sun and make sure to use sun block when you spend time outside. Do not use tanning beds. You may need to have a

yearly skin exam by a dermatologist if you take AZA or 6-MP long-term.

AZA or 6-MP can increase your risk for infections. Call your doctor if you have a fever, cough, shortness of breath, or other symptoms concerning for infection.

## **Methotrexate**

### **What is methotrexate?**

Methotrexate (abbreviated MTX) is used to treat Crohn's disease. It has been studied less as a treatment for ulcerative colitis. Low-dose methotrexate (15–25 mg weekly) used to treat Crohn's disease reduces inflammation. MTX is an immunosuppressive medicine, which means it partially blocks the action of the immune system but does not completely turn it off.

### **What are the benefits of taking MTX?**

MTX may be used if you cannot stop taking prednisone without your symptoms getting worse. You may also take MTX if you cannot take AZA or 6-MP, two other medicines often used to treat Crohn's disease and ulcerative colitis. MTX can lessen the damage to the intestine, which can improve your health in the long-term.

### **How quickly does MTX work?**

Methotrexate may take 1 to 3 months to work. It can be slow to work and it can also be slow to wear off.

### **How do I take MTX?**

MTX is a teratogenic agent (causes birth defects). Therefore, there are safety measures to follow when handling it and when getting rid of it.

You may take MTX either as a subcutaneous injection (a shot given under the skin) or as tablets that you swallow. A common starting dose is 25 mg. If you have impaired kidney or liver function, your dose will be decreased.

If you improve while taking MTX, you will take it for as long as you can.

### **May I take MTX with other medicines used to treat Crohn's disease and ulcerative colitis?**

You will need to take 1 mg of folic acid daily (a folate supplement) while taking MTX.

### **Is there anything I should avoid while taking MTX?**

Non-prescription products: Do not drink more than 2-3 alcoholic beverages per month while taking MTX because the two together can cause permanent liver damage.

Do not take more than 2 grams per day (two 500 milligram tablets twice per day) of acetaminophen (Tylenol) including other acetaminophen containing products while taking MTX.

Do not take any over-the-counter herbal products with Echinacea or cat's claw because these can reduce the effect of all immunosuppressive medicines, including MTX.

Prescription medicines: Do not take nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen. Severe (sometimes fatal) bone marrow suppression (low blood cell counts), aplastic anemia (the bone marrow does not make enough blood cells), and gastrointestinal damage, have been reported when MTX (usually in high doses) is taken along with NSAIDs.

Do not take MTX with acitretin, cyclosporine, eltrombopag, natalizumab, salicylates, sulfonamide derivatives, trimethoprim, and uricosuric agents. Some prescription medicines may interact with methotrexate.

### **Will I need any tests while I am taking MTX?**

While you are taking MTX you will need to have your blood tested on a routine basis to check

your blood cell counts and your liver and kidney function.

You will have a blood test when you start the medicine and then every 2 weeks for the first few months. If the results of these blood tests are normal, your blood will be drawn every 1-3 months from then on.

Your dose of MTX may change based on the results of your blood tests. If your dose is changed, the time between your blood tests may also change. Ask your doctor about the results of your blood tests and what they mean. Be sure to tell your doctor if you are taking any other medicines because they may affect the level of MTX in your body.

### **What are the side effects of methotrexate?**

Allergic reactions are rare and usually happen right away. Allergic reactions such as hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, wheezing, and anaphylaxis (shutdown of blood vessels) may occur but are very rare. If you have an allergic reaction, go to the emergency room or call 911. Stop MTX permanently if you have an allergic reaction.

You may have side effects such as nausea, vomiting, fatigue diarrhea, or loss of appetite, especially on the day of the injection. Lowering the dose, taking the medicine in the evening, or dividing the dose into three smaller doses (one on Monday, one on Wednesday, and one on Friday) may help to reduce the side effects. Higher doses of folic acid (2 mg daily or 2 mg on the day of injection) can reduce nausea, vomiting, and stomach upset. Some people take an anti-nausea medicine just before the injection.

### **What are the risks of taking MTX?**

If you get sores inside your mouth or on your lips, call your doctor right away. This may mean that the dose is too high.

Liver enzymes spill into the blood if liver cells are damaged. These levels increase in a small number of people who take MTX. You should not take this medicine if you have chronic liver disease. Alcoholism, obesity, advanced age, and diabetes may increase your risk for liver problems.

Kidney damage usually only occurs when high doses of MTX are taken. Your kidney function will be checked by routine blood tests

Bone marrow suppression occurs in a small number of people taking methotrexate. The result is a low blood cell count. This increases your risk for infections and bleeding.

There is a rare risk of developing potentially fatal skin conditions, including Steven's-Johnson syndrome and toxic epidermal necrolysis. Tell your doctor right away if you notice any new rash. Your skin may become more sensitive to light when you take MTX so remember to use sunblock outside. Do not use tanning beds.

If you have chest pain, cough, difficulty breathing, or fever, call your doctor right away. A chest X-ray and CT scan may be needed to check your lungs.

MTX can increase your risk for infections. The risk is higher if you also take another immunosuppressive medicine Use a thermometer to check for a fever whenever you are sick. If your fever is higher than 100.4 degrees call your doctor's office **right away**. If you have a fever, cough, malaise (general sick feeling), trouble breathing, or if you notice new or increasing fatigue, you need to be seen by your doctor right away.

### **Can I get pregnant while on MTX?**

**No, you must not get pregnant while on MTX.**

It is a Category X medicine, which means it should **never** be used by women during pregnancy or by women or men the 6 months before trying to become pregnant. There is a very high risk of birth defects for women if you use MTX while you are pregnant.

If you think you are pregnant, stop taking the medicine right away. Call your doctor so that you can have a high-risk pregnancy visit.

Special safety measures are always needed when using methotrexate during childbearing years. Double contraception is required while taking this medicine and for 6 months after stopping. This means that both the man and the woman need to use birth control. For example, condoms are used by the man and birth control pills or an IUD are used by the woman.

Breast-feeding is also not safe while taking MTX.

## **Corticosteroids**

### **Prednisone**

#### **What is prednisone?**

Prednisone is a steroid that reduces inflammation. It is an immunosuppressive medicine, which means it partially blocks the action of the immune system, but does not completely turn it off.

Prednisone is used to treat many different disorders, such as allergies, asthma, rashes, arthritis, lupus, psoriasis, as well as Crohn's disease and ulcerative colitis.

#### **What are the benefits of taking prednisone?**

Every time you have a severe flare your risk for complications increases. In the short term, prednisone will quickly prevent your flare from getting so out of control that you will need to be in the hospital or have surgery. Prednisone reduces symptoms and brings on remission for most people. But prednisone will not keep you in remission.

Taking prednisone for a long time or taking many short courses for a long time increases your risk for serious side effects. Prednisone is only used as a quick treatment for disease flares while you start a maintenance medicine, with the goal of tapering off as soon as possible.

#### **How quickly does prednisone work?**

Prednisone works quickly. Many people notice improvement in their symptoms by the second day. It generally takes about 5 to 7 days to reach full effect. Higher doses may work more quickly. If you are not getting better, your doctor may need to consider further testing for other causes of your symptoms, or

hospitalization for IV steroids and other treatments.

#### **How should I take prednisone?**

Take prednisone after meals or with food or milk. Most people take it in the morning because it tends to keep them awake at night if taken later in the day.

Prednisone is generally taken at the highest dose (40mg for adults) for 1 to 2 weeks. Then you will decrease the dose by 5-10 mg every 1 to 2 weeks for about 4 to 12 weeks. Do not change your dose without talking to your doctor first because it is hard to know how well the medicine is working if the dose changes.

#### **Is there anything I should avoid while taking prednisone?**

Non-prescription products: Limit alcohol and caffeine to less than 1 to 2 drinks of each daily. Do not take any over-the-counter herbal products with Echinacea, cat's claw, or alfalfa because these can reduce the effect of the medicine. You also need to avoid St. John's wort.

Prescription medicine: Many medicines interact with prednisone. Talk with your doctor about your current medicines and whether they are safe to take with prednisone.

#### **Will I need to have any tests while I am taking prednisone?**

Prednisone may cause a decrease in bone density, which may lead to osteoporosis. This can occur even in very young people who take prednisone. If you have taken prednisone before, you should have a bone density scan to be sure your bones are healthy.



It is a good idea to take 1500 mg of calcium plus 1000 IU (25 mcg) of vitamin D while you are taking prednisone. If you get osteoporosis you may need to take medicines called bisphosphonates. Regular exercise such as jogging or lifting weights can also help protect against bone loss. Talk to your doctor about which type of exercise is right for you.

### **What are the possible side effects and risks of prednisone?**

It is unlikely you will have an allergic reaction to prednisone because steroids are the medicines that work best to treat allergies. If you do have allergy-like symptoms while taking prednisone you may be allergic to one of the other things in the medicine. Allergic reactions such as hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, wheezing, and anaphylaxis (shutdown of blood vessels) are rare. If you have an allergic reaction, go to the emergency room or call 911.

Common side effects include feeling hungry a lot of the time, weight gain, trouble falling or staying asleep (insomnia), mood changes (anxiety, bad temper, anger), blurry vision, increased body fat (especially in the abdomen and the face), swelling of legs and face, slow wound healing, acne (can be severe), dry or thinning skin, easy bruising, increased sweating, increased blood sugar (especially in people with diabetes), increased facial hair, menstrual problems, impotence, and loss of interest in sex.

Less common but more serious side effects include dangerously high blood pressure (which may cause severe headache, blurred vision, buzzing in the ears, anxiety, confusion, chest pain, shortness of breath, uneven heartbeats), extreme mood swings, depression, headache,

trouble falling or staying asleep (insomnia), personality changes, dizziness, easy bruising, stretch marks, flushing, very slow wound healing, low level of potassium (symptoms include confusion, uneven heart rate, extreme thirst, increased urination, leg cramps, muscle weakness or limp feeling), very high blood sugar, osteoporosis, cataracts, and glaucoma. Steroids also increase your risk of serious infections. When used in combination with immune suppressants or biologics, the risks of infection are higher.

### **What are the risks of taking prednisone?**

Never stop taking prednisone all of a sudden without tapering. If you stop without tapering, you will have no cortisol in your body, which is called adrenal crisis. This is a very serious condition, which can cause symptoms of abdominal pain, nausea and vomiting, diarrhea, headaches, fever, fatigue, low blood pressure, low blood sugar, confusion, psychosis, slurred speech, and seizures.

You are also at increased risk for an adrenal crisis during physical stress such as infection, injuries, or after surgery even if you are on prednisone. Your doctor may ask that you take higher doses of prednisone during these time periods.

## **Budesonide**

### **What is budesonide (Entocort, Uceris)?**

Budesonide is a medicine in the same class as prednisone. Budesonide just works in the bowel, which is very different from prednisone, which can affect the whole body. Budesonide is mostly used to treat Crohn's disease, but a new formulation is now approved for ulcerative colitis.

### **What are the benefits of taking budesonide?**

Budesonide is used to treat mild to moderate flares of Crohn's disease and ulcerative colitis. Budesonide has fewer side effects than prednisone, because it becomes inactive once it is absorbed by the body. It works for some patients to reduce symptoms and cause a remission. It has not been proven to be effective after 6 months, so your doctor will likely need to start you on a maintenance medicine.

### **How quickly does budesonide work?**

It works pretty quickly and most people notice their symptoms are better within the first week.

### **How should I take budesonide?**

When you take it, take the pills in the morning and swallow the pills whole. Do not crush or chew them. You will usually start at 9 mg per day.

### **Is there anything I should avoid while taking budesonide?**

Non-prescription products: Do not eat grapefruit or drink grapefruit juice because it makes budesonide less effective. Do not drink more than 1 to 2 drinks of alcohol daily. Do not take any over-the-counter herbal products with Echinacea or cat's claw because these reduce the effect of the medicine.

Prescription medicine: There are many prescription medicines that interact with budesonide. Ask your doctor if your current medicines are safe to take with budesonide. More common medicines to avoid include antacids.

### **What are the possible side effects and risks of budesonide?**

It is unlikely you will have an allergic reaction because steroids are the medicines that work best to treat allergies. If you do have allergy-like symptoms while taking budesonide, you may be allergic to one of the other things in the medicine. Allergic reactions such as hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, wheezing, and anaphylaxis (shutdown of blood vessels) are rare. If you have an allergic reaction, go to the emergency room or call 911.

Side effects are not common with budesonide but may include headache, nausea, diarrhea, respiratory tract infection, sinus infection, and joint pain.

Rare side effects include weight gain, fatigue, muscle weakness, facial rounding, fragile or thin skin, dizziness, throat irritation, and cataracts. Budesonide can cause any side effect that prednisone does but the side effects are less likely and less severe.

Adrenal crisis is much higher with prednisone but it is still possible with budesonide.

***This information is not meant to cover all uses, directions, precautions, warnings, drug interactions, allergic reactions, or adverse effects. If you have questions about the medicines you are taking, please talk to your doctor, nurse, or pharmacist. Take all medications as prescribed by your doctor. Tell your doctor about any side effects you experience. Always check with your doctor before changing or stopping your medications.***

## **Anti-Tumor Necrosis Factor Antibodies (Anti-TNFs)**

### **What are anti-TNFs and how do they work?**

Anti-TNF medicines are antibodies, proteins made by our bodies to help get rid of foreign things that can harm us. When antibodies are bound to TNF, the TNF cannot cause inflammation in the intestine.

### **What are the names of anti-TNF medicines and how do I take them?**

Infliximab (Remicade) is used to treat Crohn's disease and ulcerative colitis. It is given through an intravenous (IV) line in the office or hospital. You first receive three treatments at 0, 2, and 6 weeks. Then, maintenance treatment is needed every 6-8 weeks. The dose and time between doses may be changed to get the best response. Each treatment takes 2-4 hours.

Adalimumab (Humira) is used to treat Crohn's disease and ulcerative colitis. It is given as a shot just under the skin. It comes as a single dose in a pre-filled syringe or pen. The makers of Humira provide at-home injection teaching. You will give yourself the first dose of 160 mg (4 shots, 40 mg each), and the second dose of 80 mg (2 shots, 40 mg each) at 2 weeks. You will then give yourself 40 mg (one shot) every 1-2 weeks. Like Remicade, the dose and times between doses may be changed to get the best response.

Certolizumab pegol (Cimzia) is only used to treat Crohn's disease. The first dose is given as a shot just under the skin of 400 mg (2 shots, 200 mg each) and repeated at weeks 2 and 4. Then the dose is 400 mg (2 shots, 200 mg each) every 4 weeks. Cimzia comes in two forms: 1. powder that needs to be mixed with saline

(sterile salt water) and given by a health professional; 2. liquid in pre-filled syringes that you can give to yourself. If necessary, we will teach you how to give yourself the injections.

Golimumab (Simponi) is only used to treat ulcerative colitis. The first dose is given as a shot just under the skin of 200 mg, and 100 mg at week 2. Then the dose is 100 mg every 4 weeks.

### **What are the benefits of taking an anti-TNF?**

If you have moderate to severe disease, your doctor may start this medication, perhaps with azathioprine/6-MP or methotrexate. If you respond to anti-TNFs, you will have the benefit of not needing to take prednisone for a long period of time.

You will also avoid the complications of inflammation that can lead to surgery. Anti-TNFs can improve your quality of life by controlling your symptoms. Over half of patients who take these medicines notice that their symptoms decrease and their test results improve. Almost half of patients will be in remission (back to normal) by 6 months. If you do get better or reach remission there is a good chance that you will remain free of symptoms for 1 year or longer.

### **How quickly do anti-TNFs start to work?**

You may feel the benefit of anti-TNF agents within a week of starting them, but it can take weeks to months to measure the full effect. Anti-TNFs work best if taken for the long-term. If you are able to take the anti-TNF and it is helping to control your disease you will need to continue taking it.

**May I take an anti-TNF with other medicines used to treat Crohn's disease and ulcerative colitis?**

People with early Crohn's disease may do better if they take Remicade and AZA, 6-MP, or methotrexate together. You may take these two medicines together if you have more severe disease.

Other immunosuppressive medicines such as corticosteroids can be taken along with an anti-TNF as well. But whenever you take more than one immunosuppressive medicine for a long time, your risk for infection or cancer increases. You and your doctor will consider the risks and the benefits to choose the best plan for you.

**Is there anything I should avoid while taking an anti-TNF?**

Non-prescription products: Do not take any over-the-counter herbal supplement with Echinacea or cat's claw because these have the ability to diminish the effect of the medicine.

Prescription medicines: Do not take abatacept, anakinra, natalizumab, or rilonacept with anti-TNF medicines. Other prescription medicines may interact with anti-TNFs.

**Will I need to have any tests while I am taking an anti-TNF?**

You will be asked if you have any side effects while you are taking an anti-TNF. You will also have testing for tuberculosis and hepatitis B infection before starting an anti-TNF.

**What are the possible side effects and of anti-TNFs?**

Most people who take anti-TNFs don't have any side effects.

An allergic reaction right away when you start taking an anti-TNF is rare. Allergic reactions such as shortness of breath, tightness of the chest or throat, wheezing, hives, and anaphylaxis (severe shock) are also rare. If you have these symptoms, go to the emergency room or call 911.

You will stop taking that medicine but you may switch to another anti-TNF. Let your doctor know if you are sensitive to latex because the needle cover of the pre-filled syringe contains latex.

You may have an intravenous (IV) infusion-related reaction, which is a side effect that occurs within 2 hours of the start of a Remicade treatment. Symptoms include headaches, shortness of breath, being lightheaded, joint and muscle aches, rash, flushing, and nausea. These reactions can often be managed with decreasing the amount of the drug and taking Benadryl®, Tylenol®, and/or prednisone.

In some patients, the reaction is too severe to continue the medication. Some people who take Humira or Cimzia have an injection site reaction. The skin can become swollen, red and painful where the shot is given. This can be reduced by taking acetaminophen (like Tylenol) as well as cooling the area with an ice pack before the shot is given.

There is a risk that your immune system may make antibodies against the medicine. If this occurs, your doctor may need to increase the dose, change the frequency of dosing, or stop the anti-TNF.

Anti-TNFs can increase your risk for infections, and a small number of patients of patients can develop a serious infection. This risk is higher if

you take another immunosuppressive medicine along with an anti-TNF.

If you have been exposed to tuberculosis or hepatitis B in the past, anti-TNF agents can cause these into very serious infections again. You will be tested for both of these infections with blood tests or a skin test. If you test positive, you may need to be on treatment for these infections before starting anti-TNF therapy.

Because anti-TNFs suppress your immune system there is a small risk for getting lymphoma, which is a type of cancer. It is not clear whether this risk is due to the medicine or to the IBD. You will be closely monitored while you are taking an anti-TNF. You should call your doctor right away if you notice any increase in pain, weight loss, or fevers that you cannot explain. If this occurs, blood testing or CT scanning may be done. Tell your doctor if you have cancer now or in the past.

If you have congestive heart failure (CHF), multiple sclerosis, or lupus you should not take anti-TNFs.

It is rare, but some people get elevated liver enzymes, low blood count, or serious skin conditions from these medicines. Drug-induced lupus-like syndrome is also rare. If you get joint and muscle pain along with fatigue and a skin rash, call your doctor right away. Reactions like rash, welts, joint pain, fever, malaise, enlarged lymph nodes should also be reported right away.

A small amount of patients can develop a rash on their scalp, hands, and feet that resembles psoriasis. If this occurs, most patients need to stop the anti-TNF.

In very rare cases, patients can have severe neurologic symptoms like blindness or weakness in your arms or legs that are similar to symptoms of multiple sclerosis. Call your doctor if you have these symptoms and you may be referred to a neurologist.

**You cannot take live vaccines while on anti-TNF medications.** These include MMR (measles, mumps, rubella), varicella (chickenpox), rotavirus, oral polio and yellow fever. If you are older than 50, you cannot get a live shingles vaccine unless you are off anti-TNF medication for at least one month before and after the vaccine. There is a new inactivated shingles vaccine (called Shingrix) that you may be able to get. Please contact us or your primary care doctor about this.

## **Vedolizumab (Entyvio)**

### **What is vedolizumab and how does it work?**

Vedolizumab is approved for treatment in ulcerative colitis and Crohn's disease. By blocking a certain protein, it prevents inflammation. It is an immunosuppressive medicine, which means it partially blocks but does not completely turn it off completely. While there are some side effects, most people do not get more infections when taking this medication.

### **What are the benefits of taking vedolizumab?**

Vedolizumab has been shown to ease symptoms, control inflammation, and cause remission of ulcerative colitis and Crohn's disease in many patients.

### **How quickly does vedolizumab work?**

Most patients see some improvement in their symptoms within 12 weeks. Vedolizumab is given as an IV (intravenously) over 1 hour during the first treatment and at weeks 2 and 6. Then it is given every 8 weeks after that. Your doctor may change the interval or give you a "booster dose" if you have had no response by 8-10 weeks on the medicine.

### **May I take other medications with vedolizumab?**

Your doctor may recommend you take other medicines while taking vedolizumab. Medicines such as azathioprine, 6-MP, or methotrexate may be recommended to help the vedolizumab work better. You may also take prednisone or entocort but your doctor will likely want you to be on these for only short periods.

### **What medicines should I avoid while taking vedolizumab?**

Non-prescription products: Do not take any over-the-counter herbal supplement with Echinacea or cat's claw because these have the ability to diminish the effect of all immunosuppressive medicines.

Prescription medications: You should avoid other biologic medicines while on vedolizumab.

Be sure to tell your doctor about all the prescription and over-the-counter medicines you are taking. This includes vitamins, minerals, and herbal products, as well as medicines prescribed by other doctors.

### **What are the possible side effects?**

Most patients do not experience any side effects to vedolizumab.

Allergic reactions can happen when getting vedolizumab. Allergic reactions such as shortness of breath, tightness of the chest or throat, wheezing, hives, and anaphylaxis (severe shock) are also rare. If you have these symptoms, go to the emergency room or call 911.

Vedolizumab can increase your risk of getting a serious infection, but this is very rare. Before you start vedolizumab, tell your healthcare provider if you have an infection or symptoms of an infection like fevers, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, or pain during urination.

Sore throat, cough, or infections of the nose and throat can occur after starting vedolizumab. Please let your doctor know if you experience this side effect.

Liver problems very rarely occur in patients who receive vedolizumab. Your doctor will check

liver tests frequently. Patients who have this side effect sometimes need corticosteroids.

Patients with Crohn's disease have an increased risk of rectal abscess (collection of pus from infection). Tell your doctor if you experience fevers, chills, drainage around your anus, severe pain, swelling, or tenderness around your anus or on your bottom.

Tell your doctor right away if you have the following symptoms: confusion, loss of balance, change in the way you walk or talk, decreased strength or weakness on one side of your body, blurred vision or loss of vision. It could be the sign of a serious condition.

There is a risk that your immune system will make antibodies to vedolizumab, which can make it less effective. Your doctor may want to start you on another medicine such as azathioprine, 6-MP or methotrexate to try to prevent this.

**You cannot take live vaccines while on biologic medicines.** These include MMR (measles, mumps, rubella), varicella (chickenpox), rotavirus, oral polio and yellow fever. If you are older than 50, you cannot get a live shingles vaccine unless you are off this medicine for at least one month before and after the vaccine. . There is a new inactivated shingles vaccine (called Shingrix) that you may be able to get. Please contact us or your primary care doctor about this.

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***your doctor about any side effects you experience. Always check with your doctor before changing or stopping your medications.***

## **Ustekinumab (Stelara)**

### **What is Ustekinumab (Stelara) and how does it work?**

Ustekinumab is a biologic medicine approved for treatment of Crohn's disease. By blocking a certain protein, it prevents inflammation. It is an immunosuppressive medicine, which means it partially blocks but does not completely turn it off completely.

### **What are the benefits of taking ustekinumab?**

Ustekinumab has been shown to ease symptoms and control inflammation and cause response and remission of disease activity in many patients with Crohn's disease.

### **How quickly does Ustekinumab work?**

You may feel the benefit of ustekinumab within a few days of starting it, but it can take weeks to months to measure the full-effect. Ustekinumab works best if taken long term.

### **How do I take Ustekinumab?**

Ustekinumab is given first through an intravenous (IV) line in the office or hospital. After this, it is given as a shot just under the skin every eight (8) weeks. It comes as a single dose in a pre-filled syringe or pen. Your doctor may change the interval if you have had no response to the medicine.

### **What medicines should I avoid while taking ustekinumab?**

Non-prescription products: Do not take any over-the-counter herbal supplement with Echinacea or cat's claw because these have the ability to diminish the effect of all immunosuppressive medicines.

Prescription medications: You should avoid other biologic medicines while on ustekinumab.

Be sure to tell your doctor about all the prescription and over-the-counter medicines you are taking. This includes vitamins, minerals, and herbal products, as well as medicines prescribed by other doctors.

### **What are the possible side effects?**

In general, there are few side effects to ustekinumab.

Ustekinumab can increase your risk of getting a serious infection, but this is very rare. Before you start ustekinumab, tell your healthcare provider if you have an infection or symptoms of an infection like fevers, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, or pain during urination.

Because ustekinumab suppresses your immune system there is a small risk for getting certain cancers such as skin cancer.

A very rare syndrome affecting the brain called Reversible Posterior Leukoencephalopathy Syndrome (RPLS) is possible when taking ustekinumab. This condition cause symptoms such as headache, seizures, confusion, and vision problems. Tell your healthcare provider right away if you develop these symptoms.

**You cannot take live vaccines while on biologic medications.** These include MMR (measles, mumps, rubella), varicella (chickenpox), rotavirus, oral polio and yellow fever. If you are older than 50, you cannot get a shingles vaccine unless you are off this medicine for at least one month before and after the vaccine. There is a new inactivated shingles vaccine (called Shingrix) that you may be able to get. Please



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## **Tofacitinib (Xeljanz)**

### **What is Tofacitinib (Xeljanz) and how does it work?**

Tofacitinib is approved for treatment in ulcerative colitis. It is an oral Janus Kinase (JAK) inhibitor and blocks a process within cells that can cause inflammation. It is an immunosuppressive medication, which means it partially blocks the immune system but does not turn it off completely.

### **What are the benefits of taking tofacitinib?**

Tofacitinib has been shown to ease symptoms and control inflammation and cause response and remission of disease activity in many patients with ulcerative colitis.

### **How quickly does tofacitinib work?**

You may feel the benefit of tofacitinib within a few days of starting it, but it can take weeks to months to measure the full-effect.

### **How do I take tofacitinib?**

Tofacitinib is an oral pill that is taken twice every day.

### **What medicines should I avoid while taking tofacitinib?**

Non-prescription products: Do not take any over-the-counter herbal supplement with Echinacea or cat's claw because these have the ability to diminish the effect of all immunosuppressive medicines.

Prescription medications: You should avoid other biologic medicines while on tofacitinib.

Be sure to tell your doctor about all the prescription and over-the-counter medicines you are taking. This includes vitamins, minerals,

and herbal products, as well as medicines prescribed by other doctors.

### **What are the possible side effects?**

Some patients will develop elevations in their cholesterol while on this medicine. You will have tests to check your cholesterol level frequently while you are on tofacitinib.

Tofacitinib can increase your risk of getting a serious infection including viral infections such as Shingles as well as tuberculosis, but this is very rare. Before you start tofacitinib, tell your healthcare provider if you have an infection or symptoms of an infection like fevers, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, or pain during urination. You will also be tested for tuberculosis before starting this medication.

Tofacitinib can lower your white blood cell count, your hemoglobin, and can cause liver test abnormalities. Your blood tests will be checked while you are on tofacitinib.

Because tofacitinib suppresses your immune system there is a small risk of lymphoma and other cancers, including skin cancers. You will be closely monitored while you are taking tofacitinib. You should call your doctor right away if you notice any increase in pain, weight loss, or fevers that you cannot explain. If this occurs, blood testing or CT scanning may be done. Tell your doctor if you have cancer now or in the past.

**You cannot take live vaccines while on biologic medications.** These include MMR (measles, mumps, rubella), varicella (chickenpox), rotavirus, oral polio and yellow fever. If you are older than 50, you cannot get a shingles vaccine unless you are off this medicine for at least one

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## Surgery for IBD

### Ulcerative Colitis

Possible reasons for surgery:

- Symptoms do not get better or you are unable to tolerate medicine
- Cannot maintain your nutrition and weight
- Lifestyle changes
- Dysplasia (pre-cancer)

People with complications of severe ulcerative colitis such as a perforation (hole in lining of intestine) or severe bleeding need surgery right away. People who have ulcerative colitis for a long time have a higher risk for pre-cancer (dysplasia) and colon cancer. Pre-cancerous changes or colon cancer are other reasons for surgery.

Because ulcerative colitis only affects the colon, once the colon is removed, symptoms are much better. The surgery can be done either openly (a large cut) or laparoscopically (a few small cuts). Sometimes, two or three separate operations are needed.

#### Common types of surgeries for ulcerative colitis:

**Proctocolectomy** – This type of surgery removes the colon and the rectum. It is sometimes called a colectomy. A permanent ileostomy may need to be done. Other times an ileal pouch–anal anastomosis (connection) is done. This is discussed below.

**Ileostomy** – This is done after a proctocolectomy. It involves bringing the end of the small intestine (ileum) through a hole (stoma) in the wall of the abdomen. This allows

the intestinal contents (waste) to drain into an ostomy bag worn outside the body (details later).

Ileal pouch–anal anastomosis (IPAA) – This is also called a restorative proctocolectomy. This allows a person to pass stool through the anus.

It is done by removing the colon and most of the rectum, then turning the ileum into a pouch (functions as a “new rectum”) and connecting it to a small amount of rectal tissue (called a “cuff”).

An ostomy bag is worn for a few months so that the internal pouch can heal. If you are a candidate for an IPAA, the surgeon may choose to do a 3-stage procedure (this means 3 separate operations). This may happen if you have severe colitis or are on high doses of prednisone.

You would have a subtotal (partial) colectomy for the first surgery with an ileostomy. For the second surgery, the rest of your rectum would be removed and the pouch created. You would still have an ileostomy. The third surgery may be a few months later and this would be the ileostomy takedown.

A two-stage procedure would be a proctocolectomy and pouch creation with ileostomy for the first surgery and an ileostomy takedown for the second surgery. Your surgeon will help make the decision about the best option for you.

Subtotal (partial) colectomy – This involves removing most, but not the entire colon. The rectum, or the rectum and part of the sigmoid colon, are not removed.

## Crohn's Disease

Possible reasons for surgery:

- Symptoms do not get better **or** unable to tolerate medicine
- Complications, including strictures (narrowed areas of intestine), perforations (tears), or bleeding
- Abscesses (infected pocket of pus) or fistulas (infected tunnel between the skin and anus) that do not heal

Surgery cannot cure Crohn's disease, but it may greatly improve symptoms and quality of life. However, the disease often reappears in another area of the intestines. This is mostly likely to occur where the surgery was done. About two-thirds to three-quarters of people with Crohn's disease will need intestinal surgery at some point.

### Common types of surgeries for Crohn's disease:

**Resection** – This is the most common type of surgery done for Crohn's disease. The affected part of the intestine is removed. The two healthy ends of the intestine are attached. Putting the two ends together is called an anastomosis.

**Fistula** – The most common surgery to repair a perianal fistula is a fistulotomy (removal of the fistula). An internal fistula is usually removed during a resection.

**Abscesses** – An abscess may be treated in one of two ways. It may be drained by inserting a needle or drain into the abscess through the skin, or the abscess may be cut out with surgery.

**Stricturoplasty** – This is done to widen a stricture (narrowing) made of scar tissue in the small intestine. A cut is made along the scarred narrowed area, the two ends of the cut are pushed together, and then the intestine is sewn together.

**Colectomy** – This involves removing the entire colon. Sometimes a permanent ileostomy is done. In extremely rare cases, an ileal pouch–anal anastomosis (connection) is performed if possible.

**Proctocolectomy** – This involves the removal of both the colon and the rectum. Sometimes a permanent ileostomy is done. In extremely rare cases, an ileal pouch–anal anastomosis (connection) is performed if possible.

**Ileostomy** – This is done most commonly after a proctocolectomy. It involves bringing the end of the small intestine (ileum) through a hole (stoma) in the wall of the abdomen. This allows the intestinal contents (waste) to drain into an ostomy bag worn outside the body (details later).

Some information and tips:

- Talk with your doctor or a dietitian about your diet before and after surgery.
- Ask questions and learn as much as you can about your surgery.
- If you understand what is going to happen, it will help you to feel calmer, less afraid, and you are much less likely to have any surprises.

### Fistula Therapy: Setons, Collagen Plugs, Fibrin Glue, and Advancement Flaps.

Setons are the most common type of surgery to promote fistula healing. Setons are a rubber band that is placed through the fistula tract to help a fistula continue to drain so that it does not form an abscess and heals evenly. Setons also help scar tissue to form around the fistula. Once scar tissue forms and inflammation resolves, the fistula tract may close. The setons can then be removed.

Rarely, collagen plugs or fibrin glue is used in a fistula tract. But they often do not work as well as a seton. Collagen plugs are made of collagen protein and may be used to seal a fistula tract. Fibrin glue can also be used to close the fistula tract.

In selected cases, an advancement flap or rectal advancement flap involves moving a piece of the rectum over the internal opening of the fistula to close it. This is like filling a pothole.

If you have any questions about these options, ask your doctor or nurse.

## **Ileostomy versus Ileal Pouch–Anal Anastomosis**

People who have an ileostomy have fewer problems after surgery and it seems to last longer than an ileal pouch–anal anastomosis. Patients find an ileal pouch–anal anastomosis more cosmetically desirable. But a number of complications can occur over time.

**Standard Ileostomy**--This method has been used for a long time. This procedure works very well with most patients achieving excellent quality of life after the procedure. The small intestine is brought out to the skin and the inner lining is pulled over the tube of the bowel. An ostomy bag is worn outside the body. It is usually a single surgery.

Positives of an ileostomy:

1. Single operation – all inflamed tissue is removed.
2. No risk for colon cancer.
3. Less time to return to usual activity

Negatives of an ileostomy:

The major concerns of most patients are how it will look and affect their lives.

1. Can it be seen?
2. Can I have a bath? Can I go swimming?
3. Will the bag fall off?
4. What about gas? Will it smell?
5. What about diet?

Your IBD doctor, your surgeon, and your nurse will talk to you about your concerns and answer any questions you have.

Over time, some people find that the ileostomy needs to be put in a different place (“re-siting”). The longer you live with an ileostomy, the more likely you are to need surgery. Hernias around the stoma and retraction (scarring after surgery pulls the tube back in) require repeat surgery.

We will answer all of your questions before and after surgery. We want to do all that we can to make sure that both your quality of life and health are good after surgery.

## **Ileal Pouch–Anal Anastomosis**

The entire colon is removed and a small cuff of rectum is left. A portion of the small intestine is then used to create a new rectum. This is called a J-pouch and it is attached to the rectal cuff. This surgery usually requires that an ostomy bag

be worn for a short time so that the internal pouch can heal.

A second surgery is needed to “take down” the temporary ileostomy and so that stool can flow into the J-pouch.

Positives of ileal pouch–anal anastomosis:

1. Lifestyle – no bag, go to bathroom as before.
2. Less than 10% need more surgery in the future.

Negatives of ileal pouch–anal anastomosis:

1. Usual bowel pattern is 6 to 10 bowel movements per day and 1 at night, even 1 year after surgery.
2. Fecal incontinence (unexpected leakage of stool or the inability to control bowel movements) can occur at first, but often improves with time.
3. Inflammation of the J-pouch (pouchitis) occurs in around half of patients. Medicine is needed to treat an inflamed pouch.
4. 10% of patients need the same medicines that they were taking before surgery.
5. Risk for cancer is much lower, but the rectal cuff still needs to be checked for cancer.
6. 15% of patients develop a blockage or bowel obstruction because of scar tissue related to the surgeries.
7. Time to return to usual activities may take up to 1 year.

Gender-related issues

- The ability to become pregnant is lower after this surgery. If this is a concern, talk to your doctor before surgery.

- Retrograde ejaculation (semen goes backward, not forward) is rare but can cause infertility in men.

- Erectile dysfunction occurs in less than 5% of men and typically improves over time.

## **Diet and IBD**

### **Did my diet cause IBD?**

IBD seems to be caused by a mix of genes and things that damage the lining of the intestine. Together, these cause the immune system to be exposed to the bacteria in the intestine more than usual. Inflammation in the intestine of a healthy person lasts for a short time, and then goes away. In people with IBD, the inflammation does not go away without medical treatment. IBD is more common in Western countries, such as the United States. No one diet or food has ever been linked to the cause of IBD. There is no proof that anything in a person's past diet caused his IBD.

### **Do certain foods make the inflammation worse?**

No. Although certain foods can make the symptoms worse, there is no proof that inflammation of the intestine is directly affected by food. However, food that has gone bad can lead to food poisoning or infection.

### **Are there foods I should avoid?**

Many people with IBD are not able to tolerate certain foods. A food diary can help you figure out which foods bother you. Be sure to try foods that gave you trouble in the past to make sure it was the food, not just a change in your IBD.

Many people find that caffeine and alcohol increase their symptoms of IBD. Caffeine speeds up the movement of food through the digestive tract and can cause diarrhea even among people with healthy intestines. Most people with IBD can have moderate amounts of caffeine and alcohol in their diet.

A food diary can show if your diet is providing the nutrients your body needs. You can review your food diary with our dietician to be sure that you are getting the recommended daily allowances for a person of your age, sex, and size. Our dietician will meet and work with you to help you figure out the most appropriate diet for your symptoms and disease type.

### **What about vitamins and minerals?**

It is a good idea for all people with IBD to take a multivitamin every day. People with IBD who are doing well may not need any extra vitamins or minerals.

If the disease is in the ileum (the last part of the small intestine) or if the ileum has been removed, it may be hard to absorb vitamin B12. Blood levels of vitamin B12 should be checked regularly to detect B12 deficiency. Certain medicines (sulfasalazine and methotrexate) can hinder the body's ability to make folic acid (a B vitamin). If you take these medicines, you also need to take a 1 mg folate tablet every day.

If the levels of vitamin D in your blood are measured and found to be low, your physician will likely give you a prescription for a high-dose vitamin D supplement to bring the level back into the normal range. After this, you may need to be on a higher tablet dose of vitamin D (1,000 international units (25 mcg) daily).

Low iron levels are fairly common among people with IBD. Low iron levels are treated with iron tablets or liquid. Taking iron by mouth often turns the stool black, which can be confused with intestinal bleeding. Some patients with Crohn's disease cannot tolerate iron supplements; in this case iron in an IV (intravenous) form can be used.



Other possible problems include low levels of potassium, magnesium, and calcium.

Low potassium levels may be caused by diarrhea or vomiting or as a result of prednisone treatment. Potassium supplements are available in tablet and other forms.

Oral magnesium may be needed by people who have low levels of magnesium. A lack of magnesium can be caused by chronic diarrhea, a large amount of inflammation in the small intestine, or when a large amount of the intestine is removed.

Your doctor will help you figure out if you need extra supplements. Do not take them without a doctor's recommendation as you can take too much and have serious and even life-threatening side effects.

People with IBD who include very little calcium in their diets can have low calcium levels. This is most common when people avoid dairy products. Vitamin D needs to be taken along with the calcium so the calcium is absorbed. Pills with both calcium and vitamin D are widely available over the counter.

### **Should I change my diet during a flare?**

You may have a hard time tolerating food during a flare. During a period of active inflammation, eating can cause make pain, bloating, cramping, and diarrhea worse. But you still need to eat during a flare. You also need to drink plenty of fluids so that you absorb and retain fluid. You need to drink enough so that your urine is nearly clear most of the time or you may become dehydrated.

Becoming lightheaded when you stand up quickly is a sign of severe dehydration. If this happens to you, drink more fluids. If it does not

get better, call your doctor or nurse or go to the nearest emergency room. Our dietician will work with you to make recommendations about the best diet for you during disease flares.

### **What is an elemental diet?**

An elemental diet is made up of liquids with all of the nutrients you need, including amino acids, fats, sugars, vitamins, and minerals. This diet can be taken by mouth using products you can buy over the counter (for example, Ensure).

This diet can also be given through a feeding tube. It is given either through a tube inserted into the stomach from the nose or through a gastric feeding tube placed through the skin into the stomach. People with severe Crohn's disease may need this type of treatment to avoid malnutrition during a severe flare. The goal is to allow the gut to rest and heal before it has to deal with whole foods again.

### **Diet suggestions in IBD**

Although there is **no specific diet** to prevent or treat IBD, there are diets to help you control your symptoms. Different diets are used during a disease flare than during remission.

#### **During a flare of ulcerative colitis:**

- Use a low-residue diet to relieve abdominal pain and diarrhea.
- Avoid foods that may increase stool output such as fresh fruits and vegetables, prunes, and drinks with caffeine.
- Decrease the amount of sweetened foods in your diet such as juices, candy, and soda. This helps decrease the amount of water in your intestine, which will prevent watery stools.
- Decrease alcohol intake.

- Smaller meals eaten more often throughout the day may be better tolerated.
- If you don't have much of an appetite and you cannot handle solid foods well, you may want to try nutritional drinks such as Ensure or Boost.
- Our dietician can help make further recommendations for you during a disease flare.

#### **During a flare of Crohn's disease:**

- Use a low-residue diet to relieve abdominal pain and diarrhea.
- If you have strictures, avoid nuts, seeds, beans, and kernels, because they can cause a blockage.
- Avoid foods that may increase stool output such as fresh fruits and vegetables, prunes and drinks with caffeine. Cold foods may help reduce diarrhea.
- If you have lactose intolerance, follow a lactose-free diet.
- If you have oily and foul-smelling stools, the fat in your diet may not be absorbed properly, which is called malabsorption. Try using a low-fat diet.
- Smaller meals eaten more often throughout the day may be better for you.
- If you don't have much of an appetite and you cannot handle solid foods well, you may want to try nutritional drinks such as Ensure or Boost.
- Our dietician can help make further recommendations for you during a disease flare.

#### **When improving from a flare to remission:**

- Slowly add back a variety of foods.

- Begin with well-tolerated liquids and slowly move to soft solids, then solids.

- Add one or two items every few days and avoid any foods that cause symptoms.

- Add fiber to your diet as you can tolerate it. Sources of fiber that most people can handle include tender cooked vegetables, canned or cooked fruits, and starches like cooked cereals and whole-wheat noodles and tortillas.

- Eat as wide a variety of foods as you can between flares. This includes fruits, vegetables, whole grains, lean protein, and low-fat and non-fat dairy products.

- Increase your calorie and protein intake after a flare.

#### **Additional Resources:**

<http://www.crohnscolitisfoundation.org/assets/pdfs/diet-nutrition-2013.pdf>

## **Complementary and Alternative Medicine and IBD**

### **Is there a cure for IBD that I can find on the Internet?**

No. Lots of time and money is spent on IBD research. There is no real cure or treatment that you can only buy for a limited time or that is advertised on late night TV infomercials. That said, experts have a lot to learn about natural, herbal, and alternative therapies.

### **Why does the person at the local organic food store or nutrition supply shop tell me that herbal products will work for my IBD?**

Diet supplements are a multi-billion dollar business in the United States. The FDA is not allowed to regulate these products long as they do not make specific health claims. Any supplement that claims it will reduce inflammation in Crohn's disease or ulcerative colitis would be very quickly taken off the market. Most of the products are said to have some benefits for digestion.

### **Are supplements dangerous?**

Many of these products are inactive and harmless. However, they can do a lot of damage to your pocketbook. It is easy to spend so much on these products that you cannot afford the medicines that have been clearly shown to work for IBD.

Some products do have active components. While these may be helpful, they can also be very harmful. For example, many can cause constipation. Others may interact with your other medicines and increase your risk for severe side effects. Some supplements work because they have ingredients that are not listed on the label, such as steroids. These

"secret ingredients" may have very harmful side effects.

In addition, many supplements are not tested or controlled by the FDA. Some of these have had poisons or toxins (for example, mercury or lead) but it was not known until people became ill or died. Also, the suppliers can change the formula without any warning or regulation, which may lead to new side effects. It is important to know that some of these companies take advantage of people who want to get better.

Please tell your doctor if you are taking supplements and which ones you are taking. Certain products with Echinacea, cats' claw, and alfalfa are known to interact with many medicines used to treat IBD. They interfere with their action or increase the likelihood that you will have side effects.

### **Can probiotics help IBD?**

Probiotics are now widely marketed with little or no proof to support their use. A few probiotics have been tested and can be obtained with a prescription. One example is VSL #3, a probiotic that has been shown to help prevent pouchitis in patients with an ileal-pouch anal anastomosis after a colectomy. VSL#3 has also been shown to be helpful in patients with ulcerative colitis if used at very high doses. Most probiotics have not been shown to work for Crohn's disease.

Probiotics are most helpful in preventing antibiotic-associated diarrhea. It is reasonable to use a probiotic when you are prescribed a course of antibiotic for an infection. Another area where probiotics may be helpful is in preventing recurrent C. Difficile infection. This is a common infection that occurs in patients with

IBD after being hospitalized or after receiving a course of antibiotics.

Probiotics have been shown to be harmful in rare cases for people who are very sick. One well-done study of probiotics used in severely ill patients with severe acute pancreatitis was stopped early because those taking probiotics were dying at a much higher rate than those taking the placebo.

### **Can fish oil help IBD?**

Fish oil, which is high in omega-3 fatty acids, has not been shown to be effective in the treatment of patients with Crohn's disease. On the plus side, fish oil may have other health benefits and has few side effects, although some people notice a fishy body odor or taste when they take high doses.

There are very few side effects, but it may be costly. Also, there is no way to know if the capsules you buy actually contain fish oil, due to the lack of FDA oversight. It may be cheaper and safer to eat cold-water fish that are high in omega-3 (for example, salmon, mackerel, herring) 2 to 3 times a week than to pay for fish oil capsules.

### **Can bowel cleansing (high colonics or cleansing enemas) help IBD?**

No. There is no evidence that purging the colon can help IBD.

### **Where can I get good information about alternative therapies for IBD?**

The best source is the National Center for Complementary and Alternative Medicine, which is funded by the National Institutes of Health. This is the web address:

<http://nccam.nih.gov/>

The CCF also has information:

<http://www.crohnscolitisfoundation.org/resources/complementary-alternative.html>

## **Preventive Care and Medication Monitoring**

### **Medication Monitoring**

If you take an immunosuppressive medicine such as azathioprine, mercaptopurine, tofacitinib, or methotrexate, you will be enrolled in our monitoring program for people who take these medicines.

Lab tests (blood tests) will be done for as long as you take the medicine. This will usually include a complete blood count with differential and peripheral smear (CBC/D/P) and a comprehensive metabolic panel (CMP). These blood tests give us early clues about any side effects, such as a low white blood cell count (WBC) or increases in the liver function tests (LFTs). You will get baseline lab tests before starting to take the medicine. We will work together to make a plan for your blood work.

It is common to have lab tests done frequently for the first 2 months as we figure out the best dose for you. Once you are taking a steady dose of the medicine and your blood tests are normal, you will have lab tests on a set schedule every 3 months.

### **Preventive Care**

#### **Preventing Infections with Vaccines**

Vaccines are used to reduce our risk for infections. Some vaccines are made with a live virus and others are made with an inactivated form of the virus. Vaccines that are made with a live virus may cause some symptoms of the virus. However, they lower your risk for getting a more serious form of the infection.

People with IBD often need to take immunosuppressive medicines, which put them at increased risk for certain infections. People taking thiopurine medicines (like azathioprine and mercaptopurine) are at a high risk for infections with viruses that stay in the body for a long time and become active again. For example, the virus that causes chickenpox can return much later in life as shingles. The virus that causes mononucleosis (Epstein Barr virus or EBV) can also become active again. The human papilloma virus (HPV), which contributes to cervical cancer, is more likely to cause an infection in women taking thiopurine medicines.

People taking anti-TNF medicines, including infliximab, adalimumab, certolizumab pegol, and golimumab have a higher risk for diseases such as tuberculosis and fungal infections. There is also an increased risk for bacterial infections of the skin and soft tissues. Pneumonia is the most common, serious, and sometimes fatal infection that can occur while a person is taking an anti-TNF medicine.

#### **Vaccines**

The pneumonia vaccines (Pneumovax and Prevnar) can protect people against 23 of the most aggressive types of pneumonia with just one shot. It is not a live vaccine and will not give you pneumonia. These vaccines are advised for all adults age 65 and older and also for anyone who is taking immunosuppressive medicines (including prednisone).

- If you have never had a pneumonia shot, you will get the Prevnar and then the Pneumovax at least 8 weeks later. You will get a Pneumovax booster in 5 years

- If you have had the Pneumovax, you will get the Prevnar at least one year after the Pneumovax. You will get a booster Pneumovax 5 years after your first.

The flu vaccine can prevent the flu or shorten the time the flu lasts and ease its symptoms. A flu shot is advised each fall for older people with IBD as well as those on immune suppressants, steroids, and/or biologics.

Anyone who takes immunosuppressive medicines or biologics should get the shot and avoid the nasal spray. The shot is made of inactivated virus and the nasal spray is made of the live virus.

The hepatitis B vaccine is given to prevent severe infections of the liver. These infections can be more serious, and even fatal, among people who are taking anti-TNF medicines. This vaccine is now a part of the routine childhood shots. It is a good idea for everyone with IBD to get it because an anti-TNF medicine may be needed in the future. You need three (3) shots over 6 months for the vaccine to work. This vaccine is inactivated and safe to get while taking immunosuppressive medicines. You will need to have this done through your primary care physician.

The human papilloma virus (HPV) vaccine (Gardasil and Cervarix) is recommended for young women and men between ages 11 and 26 to reduce their risk for cervical cancer and genital warts respectively. It is a good idea for young women and men with IBD to have this vaccine because taking an immunosuppressive medicine can increase your risk of HPV infection. A total of three (3) shots are required over 6 months for the vaccine to work. This vaccine is inactivated and safe to get while

taking immunosuppressive medicines. You will need to have this done through your primary care physician or gynecologist (if you are a woman).

Chickenpox and shingles are caused by the same virus – varicella zoster. This virus lives on in the body after chickenpox and can occur again as shingles. Having the vaccine for both chickenpox and shingles is advised for adults. But because these vaccines are made of the live virus, they may not be safe for someone who is taking biologics (anti-TNF, natalizumab, or vedolizumab) or corticosteroids.

It is best to have one of these vaccines at least 1-2 months after stopping biologic medicine, and to not start taking biologic medicine for about 1-2 months after having one of these shots. Patients on azathioprine, 6-MP, or methotrexate may be able to take a shingles vaccine but you should talk to your doctor first.

Injectable polio vaccine is not a live virus and will not cause polio. This vaccine is advised for children. The oral form is a live vaccine and is not considered safe for people who take immunosuppressive medicines or biologics.

Please tell your doctor if you are not up to date on childhood or other vaccines.

### **Problems with live vaccines (planning ahead)**

Many vaccines work better if they are alive but weak. They cause a better immune response. However, if you are taking an immunosuppressive medicine or biologic these vaccines can cause infections. It is **very important** to avoid active virus vaccines while taking corticosteroids or biologics. The vaccines listed below only come in live forms and should be given at least 1-2 months before starting to take corticosteroids or biologics. Live vaccines

should not be given while you are taking immunosuppressive medicines or biologic, or within 2 months after these medicines are stopped.

### **Common live vaccines**

Nasal spray (Intranasal) flu – remember the shot form is inactivated vaccine but the nasal spray is a live vaccine

Varicella (chickenpox and shingles)

MMR (measles, mumps and rubella) –this vaccine is used in children only and as a booster for health care workers who have negative blood tests for immunity to the disease.

Rotavirus – this vaccine is used in children only. Babies born to mothers on biologic therapy during pregnancy should not get the rotavirus vaccine as they should not get a live vaccine before 1 year of age. All other recommended vaccines before 1 year of age are inactivated and fine to give to baby.

Oral polio – this vaccine is used in children only. The injectable polio vaccine, which is not live, is also good for children

### **Uncommon live vaccines**

Smallpox

Yellow fever

Oral typhoid – can use injectable typhoid

Talk to your doctor if you are on immunosuppressive medications before getting any of these uncommon live vaccines.

### **Preventing Skin Cancer**

People who have IBD and take immunosuppressive medicines such as

azathioprine have an increased risk for basal cell and squamous cell skin cancers and perhaps melanoma. Patients on biologic medicines may have an increased risk of melanoma.

Using sunblock, especially in the summer and at any time you will be out in the sun will help lower your risk. If you take immunosuppressive medicines or biologics for a long period of time, you may be advised to see a dermatologist for a complete skin exam every year.

### **Preventing Bone Loss (osteopenia and osteoporosis)**

#### **What is osteoporosis and what causes it?**

Osteoporosis is the loss of bone minerals such as calcium. It can lead to broken bones, often of the hips and spine. Other risk factors include a family history of osteoporosis, high alcohol intake, low calcium and vitamin D intake, limited physical activity, smoking, and age. The highest risk for osteoporosis is among women after menopause (natural or after surgery).

#### **What is osteopenia?**

Osteopenia is the milder stage of bone loss that occurs before osteoporosis. If you have osteopenia, you have a much higher risk for osteoporosis than if your bone density is normal. Children who have osteopenia are at high risk for osteoporosis in adulthood.

#### **Why is vitamin D so important?**

Your body needs calcium to make strong bones, and vitamin D plays a key role in helping your body use calcium. That is why many calcium pills also contain vitamin D. Vitamin D is made in the skin from the sun's ultraviolet rays. To make enough vitamin D, the skin needs to be

exposed to sunlight for 15 minutes a day for a few days each week.

While it is a good idea to use sunblock to prevent skin cancer, sunblock also prevents the skin from making vitamin D. People who live in the northern states are at increased risk for not getting enough vitamin D because of the long winters.

### **Why does IBD increase the risk for osteoporosis?**

People with IBD who have decreased bone density are at increased risk for osteoporosis. They are also more likely to get osteoporosis at a younger age. The Crohn's & Colitis Foundation of America estimates that between 30 and 60 percent of patients with IBD have decreased bone density. Low bone density in IBD is caused by the general risk factors mentioned above, along with risk factors related to the IBD.

### **Why is it important to prevent bone loss?**

Hip and spine fractures can greatly decrease the ability to walk and move around and to care for oneself. In the United States, 50 percent of women and 25 percent of men will have a fracture due to osteoporosis.

### **How is osteoporosis measured?**

A bone density scan, also called a DEXA (dual energy x-ray absorptiometry) scan, is an x-ray that measures bone loss. It is the standard test for bone density. You doctor will order a DEXA scan when you are first diagnosed and periodically to monitor any changes. The goal of the test is to see if you are at risk for osteoporosis so that you can get the help you need to treat or prevent osteoporosis.

### **Will I need any other tests to detect bone loss?**

You may have a blood test to check your vitamin D level. If your level is low, you may need to take vitamin D pills. The usual daily dose is 400 to 1,000 international units (IU), although older people need at least 1,000 IU per day. People with Crohn's disease may need higher doses for weeks to months. Your doctor may prescribe even higher doses for you.

### **Treatments for low bone density**

There are things you can do to treat low bone density and lower your risk for fractures. Some of the things you can do are to get regular weight-bearing exercise, such as walking or dancing, stop smoking, and make sure your diet gives you enough calcium and vitamin D.

You may also take calcium and vitamin D supplements, or other medicines such as bisphosphonates, biologics, calcitonin, hormone replacement, or parathyroid hormone therapy. Steroid medicines will only be used as needed and in the lowest dose possible to manage your IBD and keep your bones healthy.

- Calcium-rich foods include low-fat milk, yogurt, cheese, ice cream, sardines, salmon, shrimp, broccoli, collard and turnip greens, and sesame or sunflower seeds
- Calcium pills – 1,000 to 1,500 mg/day.
- Vitamin D pills – 800 to 50,000 international units, as indicated.
- Daily weight-bearing exercise – such as walking.
- Medicines-may be needed if you have osteoporosis or if you have had a broken bone in the past along with low bone density.



Your doctor may have you see a bone specialist to decide on the correct treatment.

## **Preventing Colon Cancer**

Some people with IBD have a slightly higher risk for colon cancer than those without IBD. Not everyone with IBD has the same risk. Having a colonoscopy as often as advised can help to detect early signs of cancer or pre-cancer, when it can be treated most easily. Everyone with IBD in the colon requires a colonoscopy starting 8 years after the first symptoms of IBD, and then every 1 to 3 years.

### **Understanding your risk for colon cancer:**

1. People with ulcerative colitis have an increased risk for colon cancer 8 to 10 years after diagnosis.
2. People with a limited form of ulcerative colitis that involves just the rectum do not have an increased risk for colon cancer.
3. Taking your IBD medicines regularly can help reduce your symptoms and can also decrease your risk for colon cancer.
4. Some medicines, supplements, and vitamins can protect a person from getting cancer. No medicine, supplement, or vitamin has been definitely shown to prevent cancer, but several show promise. These include IBD medicines related to mesalamine (Asacol HD, Pentasa, Lialda, Colazal, Azulfidine). Ask your doctor about new advances in this area.
5. Ask your doctor if you have an increased risk of colon cancer because you have IBD.

## **Smoking and IBD**

There is no doubt that smoking will make your Crohn's disease much worse. It makes your symptoms worse and can make it harder for medicines to work. Smokers are also more likely to develop recurrent Crohn's disease after surgery. If you smoke and you have Crohn's disease, stopping is one of the best things you can do for yourself. It is hard to quit, but there is help. Talk to your doctor or attend a smoking cessation program.

If you have ulcerative colitis you may have a flare when you quit smoking. Using a nicotine patch may help to prevent or relieve the flare. Please speak with your doctor about this.

## Reproductive Health and IBD

### Can I have a normal sex life if I have Crohn's disease or ulcerative colitis?

Sexual health is an important part of your overall health and quality of life. Crohn's disease and ulcerative colitis can affect your sexual health. Some medicines may get in the way of your desire for sex.

When the disease is active, you may feel very tired and have little desire for sex. Major abdominal or pelvic surgery (for example, removal of the colon) increases the risk for erectile dysfunction (impotence), which means not being able to have or keep an erection.

Surgery can also affect body image and how a person feels about their sexual appeal. Some people with Crohn's disease develop a fistula. If it is an anal fistula (infected tunnel between the skin and anus), intercourse can be painful. Please talk to your doctor if you are concerned about any of these issues.

A sexually transmitted disease (STD) can make it harder to treat IBD. For example, if you get genital herpes while you are taking an immunosuppressive medicine, you may have to stop taking the medicine until the herpes is treated.

Women with IBD who are taking an immunosuppressive medicine may have a higher risk for infection with the human papilloma virus (HPV). Many people are exposed to HPV, and in some women it causes cervical cancer or genital warts. In addition to a regular PAP test and getting the HPV vaccine, always use condoms to protect yourself from STDs.

## Fertility, Pregnancy, and Breast-Feeding with IBD

### Can I have a baby if I have Crohn's disease or ulcerative colitis?

Yes, most women who have IBD are able to get pregnant and carry a baby to term. In general, having IBD does not reduce the chances you will get pregnant.

The effect of IBD on pregnancy depends on how severe the disease was before and during pregnancy. If the disease is in remission at the time the baby is conceived it will likely stay in remission during pregnancy. If your IBD is well controlled, you can expect to have a normal pregnancy. Women with more severe IBD have a greater risk of early delivery and of having a baby with low birth weight.

Major abdominal or pelvic surgery increases the risk of not being able to get pregnant. It may affect a woman's ability to carry a pregnancy to term. The most common problem is caused by the growth of scar tissue that blocks the fallopian tubes. If this occurs, in vitro fertilization may be an option. In men, major abdominal or pelvic surgery increases the risk for erectile dysfunction.

Sulfasalazine, a common medicine used to treat IBD, causes a decrease in sperm count and fertility in 10% of men who take it. If you are taking sulfasalazine and your partner is having a hard time becoming pregnant, talk to your doctor about switching to another 5-ASA medicine. The sperm count will return to normal when the sulfasalazine is stopped.

The risk of having a miscarriage or of birth defects is higher for women who become pregnant while taking methotrexate. Both men

and women must stop taking methotrexate 6 months before trying to conceive a baby.

### **How can I make sure my IBD is well controlled before I get pregnant?**

The best way to control your disease is to get regular care from your health care team and take your medicines faithfully and in the prescribed doses. Tell your doctor about your symptoms and any side effects, so you can work together to find the best treatment that works for you.

If your IBD is not treated using your maintenance medicines, the inflammation can get out of control very quickly. This increased inflammation causes your disease to get worse and you will have symptoms such as diarrhea, blood or mucous in the stool, and abdominal pain. If you have ever had a flare of your disease, you know these symptoms.

Many people lose their appetite and are unable to gain or even maintain a healthy weight when they have these symptoms. Or, because they associate food with painful bowel movements or increased diarrhea, they stop eating. This is a big concern if you get pregnant during a disease flare. If you are not able to take in enough calories, your baby will not grow as it should.

IBD that is not controlled may cause fistulas (infected tunnels between organs), abscesses (infections), and perforations (tears). These are severe and need special treatment and maybe even surgery.

### **Will I have to go to the doctor more often when I am pregnant?**

If you are taking immunosuppressive medicines, biologics, or having disease flares while you are pregnant, you will need to see your obstetrician

and IBD doctor more often. Your baby's growth will be closely monitored by your obstetrician with ultrasound scans over the course of your pregnancy. You may need to see a doctor who specializes in high-risk pregnancies.

### **Will my IBD get worse when I am pregnant?**

IBD does not always get worse during pregnancy. Women whose IBD is in remission when they get pregnant are likely to stay in remission. Women with active disease when they get pregnant are likely to have active disease during pregnancy. Many women try to conceive only when they are in remission.

Some women notice their symptoms improve while they are pregnant. This is due to changes that occur in the mother's immune system so that her immune system will not attack the baby. Some women have flares shortly after giving birth when the immune system returns to normal.

Symptoms do not improve for every pregnant woman with IBD. New research suggests patients with ulcerative colitis are more likely to flare than Crohn's disease during pregnancy, even if they are in remission at conception.

### **Should I keep taking my medicines for IBD while I am trying to get pregnant or if I become pregnant?**

You will do better if your disease is under control before and during pregnancy. Most medicines used to treat IBD are generally safe to take during pregnancy. So it is a good idea to keep taking the medicines to treat your IBD while you are pregnant. Stopping a medicine that is working to control your disease can make your IBD worse. A flare during pregnancy is a big risk to you and your growing baby.

One of the things to think about is whether the effects of a flare are worse than the risk of side effects from the medicines. You and your doctor need to talk about the risks and benefits of using medicines during pregnancy before you try to get pregnant. If you find out you are pregnant, don't stop your IBD medicines. Call your doctor right away to discuss whether you should keep taking your medicines.

Methotrexate and thalidomide are the only medicines that you **absolutely cannot** take during pregnancy.

### **Will IBD medicines harm my baby?**

Most medications used to treat patients with IBD are safe and should be continued through pregnancy.

The U.S. Food and Drug Administration decides the safety level of drugs taken during pregnancy.

- Category A includes medicines like acetaminophen (Tylenol), which have been shown to be of very low risk to the baby during pregnancy.

- Category B medicines are the next safest medicines to take. These are generally considered very low risk to the baby during pregnancy. Examples of category B drugs used to treat IBD include sulfasalazine (Azulfidine) and mesalamine (Asacol, Canasa, Lialda, Pentasa, Rowasa). Infliximab (Remicade), adalimumab (Humira), and certolizumab (Cimzia) have now been extensively studied in large groups of pregnant women and are considered safe in pregnancy and during conception.

Vedolizumab (Entyvio) is considered category B, but more studies regarding its use in pregnancy are needed.

- Category C means there are no studies to show if the medicine is safe or not safe to take during pregnancy.

However, the benefits of taking the medicine often outweigh the risks of not taking the medicine. Prednisone and Entocort are category C drugs that have been used in pregnancy and are thought to be safe.

- Category D means that there is some proof that the drug can cause a problem during pregnancy. But the benefit of taking the medicine may still outweigh the risk of not taking the medicine. Azathioprine (Imuran) and 6-mercaptopurine (Purinethol) are category D drugs.

While the official ruling by the FDA is that these drugs are not recommended during pregnancy, these drugs have been used by large groups of pregnant women in multiple countries and found to be of very little risk and are safe in pregnancy. These groups include people with kidney transplants, autoimmune liver disease, and IBD.

- Category X means the drug should **absolutely not** be taken during pregnancy and should be stopped for several months before getting pregnant. Methotrexate is Category X and that means that this drug should **never** be used during pregnancy or the 6 months before trying to become pregnant. There is a very large risk for

birth defects if you use methotrexate during pregnancy.

Special safety measures are always needed when using methotrexate during childbearing years. Double contraception is required while taking this medicine. Both the man and the woman need to use birth control. This is also true for couples when only the man is taking methotrexate, because this drug can affect the sperm. Men who take methotrexate should also stop taking the medicine 6 months before trying to conceive with their partner.

Women with IBD often need antibiotics during pregnancy. Two common antibiotics are metronidazole (Flagyl®), a category B drug, and ciprofloxacin (Cipro®), a category C drug. Metronidazole is generally used during pregnancy instead of ciprofloxacin.

Diphenoxylate plus atropine (Lomotil®), a drug often used for diarrhea, is considered category C and should not be taken during conception and pregnancy. Loperamide (Imodium®), which is also used to treat diarrhea, is considered a safer choice because it is a category B drug.

### **Can I breast-feed my baby while taking my IBD medicines?**

Most IBD medicines are safe to continue while breast-feeding. These include mesalamine, sulfasalazine, prednisone, azathioprine, 6-mercaptopurine, and anti-TNF medicines. Methotrexate is **never** to be taken while breast-feeding.

### **Genetic Risk for IBD in Childbearing**

#### **Will my children get IBD?**

Experts are still trying to figure out the exact cause of IBD. There seems to be more than one cause. Your genes may play a role, as well as other things such as infection. If you have Crohn's disease, the risk that your child will develop Crohn's disease is about 5%. If you have ulcerative colitis, the risk that your child will develop ulcerative colitis is about 2% to 8%.

Although your children are at a higher risk for IBD than the general public, they are not likely to develop IBD. If your child has symptoms of IBD or is not growing as expected, tell your child's doctor that you have IBD.

## Medication Guidelines

<u>5-ASA's</u>	<u>Lab Requirements</u>	<u>Clinic Visit Requirements</u>
Lialda	CBC/Plt; ESR; CMP; CRP	Every 6-12 months
Apriso	Every 6-12 months	
Asacol HD		
Delzicol		
Colazol		
Giazo		
Pentasa		
Sulfasalazine		

<u>Immunosuppressants</u>	<u>Lab Requirements</u>	<u>Clinic Visit Requirements</u>
Azathioprine (Imuran)	CBC/plts; hepatic function panel	Every 3 months
6MP (purinethol, mercaptopurine)	every 2 weeks for 6 weeks	
Methotrexate	After this, CBC/plts; hepatic function panel every month for 1 yr. Also, BMP; CRP; ESR every 3 months	
	After one year, CBC/plts, CMP, CRP, ESR every 3 months.	
Xelganz (tofacitinib)	CBC/plts; CMP; lipids at start TB Testing prior to start and yearly	Every 3-6 months
	CBC/plts; CMP; lipids after 4 wks	
	CBC/plts; CMP; CRP; ESR after 8 weeks and then every 3 months	

<b>Biologics</b>	<b>Lab Requirements</b>	<b>Clinic Visit Requirements</b>
<u>Injection medications:</u> adalimumab (Humira) certolizumab (Cimzia) golimumab (Simponi) ustekinumab (Stelara)	CBC/Plt; ESR; CMP; CRP every 6 Months TB Testing prior to start and yearly HepB panel prior to start baseline chest x-ray prior to start	6-8 weeks after start then every 3 months

<b>Biologics</b>	<b>Lab Requirements</b>	<b>Clinic Visit Requirements</b>
<u>Infusion medications:</u> Infliximab (Remicade) Natalizumab (Tysabri) Vedolizumab (Entyvio)	CBC/Plt; ESR; CMP; CRP are drawn at every infusion TB Testing prior to start and yearly HepB panel prior to start Histoplasmosis testing prior to start Baseline chest x-ray prior to start	6-8 weeks after start then every 3-6 months
Vedolizumab (Entyvio)	CBC/Plt; ESR; CMP; CRP are drawn at every infusion	



## Therapeutic Studies in Clinical Research

### Why should I join a clinical study?

Many people with IBD join clinical studies, and there are many good reasons to do so. These include:

#### 1. Wanting to find a therapy that works better than current options

- Taking part in clinical studies gives you a chance to try new treatments that are not FDA approved or on the market.
- Basic research is finding new methods and medicines that may control IBD. We won't know if these work well until people with IBD try them.

#### 2. To be monitored more closely

- People who take part in clinical studies are checked more closely than in usual clinical care. This is due to safety rules and the need to keep track of things for the FDA.
- People in clinical studies (mainly cancer studies) do better than people who are not in clinical studies. This may be due to closer monitoring.

#### 3. Wanting to contribute to progress in IBD research

There are 1.4 million people with IBD in the United States. This is not a huge number. So, in order to make progress in IBD research, people need to join clinical studies. Unlike more common diseases like diabetes, progress in IBD needs many people with IBD to join in clinical studies.

### Why do people not want to join a clinical study?

#### 1. Worried about getting placebo

To truly test if a drug works, it must be compared to a placebo (an inactive substance, i.e. 'sugar pill'). Some people will be assigned by chance to get a placebo, along with their usual medicines. Most studies allow people to 'cross-over' to the medicine being tested if they don't get better after a period of time. Other studies allow people to receive the test medicine after the study ends.

#### 2. Worried about committing to a study and not being able to get out

You can change your mind and stop being part of a study at any time. This is based on federal rules for research. If you decide to stop taking part in a study, your care will not be affected in any way.

The only way to know if new medicines work is to give them a try.

## Resources

### Crohn's and Colitis Foundation

We encourage you and your family to become members of the Crohn's & Colitis Foundation (CCF). The CCF is a very helpful resource for anyone living with inflammatory bowel disease. Your nurse or doctor can tell you more about this group.

The CCF is the largest grassroots organization devoted to finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases.

It is a nonprofit, volunteer-driven organization with over 50,000 members and 40 chapters in the United States that:

1. Provides information and support groups for patients with Crohn's disease and ulcerative colitis. The Information Resource Center (<http://www.crohnscolitisfoundation.org/living-with-crohns-colitis/talk-to-a-specialist/>) provides information, support, and guidance on Crohn's and colitis. Call between 9am and 5 pm eastern time on weekdays 1-888-MY GUT PAIN (1-888-694-8872). Interpreters are available for more than 20 languages.
2. Maintains Disease Information web pages at <http://www.crohnscolitisfoundation.org/what-are-crohns-and-colitis/> with information about tests, medications, and treatment options in IBD.
3. Puts together educational workshops and symposia, and a scientific journal to help medical professionals to keep pace with the newest research discoveries in IBD.
4. Funds cutting-edge studies at major medical institutions, and nurtures investigators with grants at the early stages of their careers.

### Recommended Books about IBD

If you want to learn even more about Crohn's disease and ulcerative colitis, please visit the CCF bookstore where you will find a list of books recommended by CCF staff and volunteers.

### Useful Websites

- **Crohn's & Colitis Foundation:**  
<http://www.crohnscolitisfoundation.org/>
- **Centers for Disease Control and Prevention:**  
[www.cdc.gov/ibd/what-is-ibd.com](http://www.cdc.gov/ibd/what-is-ibd.com)
- **American Gastroenterological Association:**  
[www.gastro.org/patient-center](http://www.gastro.org/patient-center)
- **Vanderbilt IBD Clinic Twitter Account:**  
<https://twitter.com/VUMCibd>
- **Information about research studies:**  
[www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)