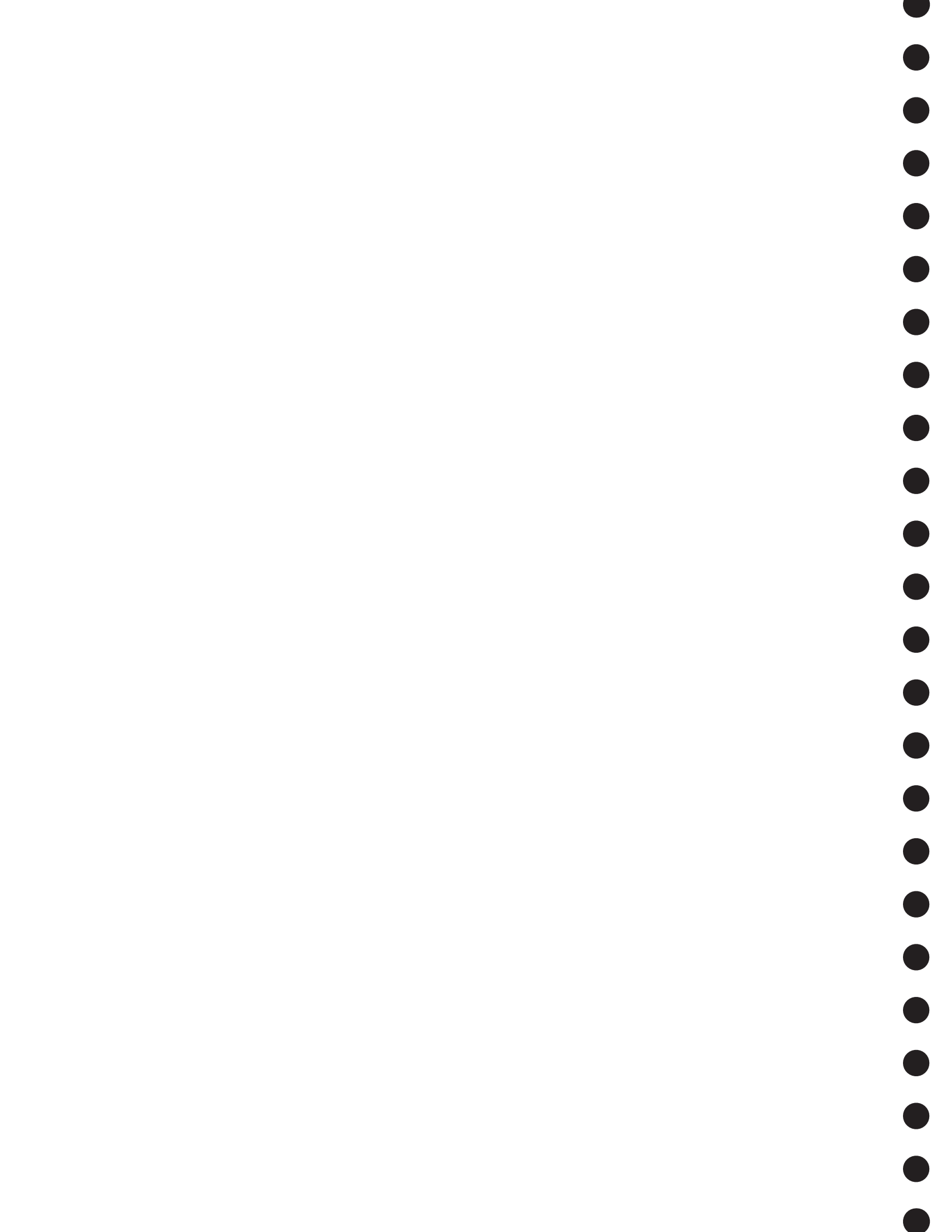


**WITH THANKS & GRATITUDE**

*This patient guide was made possible thanks to a donation by the Tabor Family  
in loving memory their daughter, sister and friend, Tracy Tabor Finstad.*





<b>CONTENTS</b>	1
<b>WELCOME!</b>	
Welcome Letter	3
Important Things to Know Up Front	4
Meet Your Crohn's & Colitis Team	6
<b>HOW TO CONTACT US</b>	
IBD Clinic Schedule	9
Physician and Nurse Contact Information	10
Appointment Scheduling and Other Contact Information	11
<b>THE BASICS OF IBD</b>	
Basic Information about Inflammatory Bowel Disease (IBD)	12
Frequently Asked Questions about Inflammatory Bowel Disease (IBD)	15
20 Questions to Ask Your Doctor about Inflammatory Bowel Disease (IBD)	17
<b>TESTING IN IBD</b>	
Colonoscopy and Flexible Sigmoidoscopy	18
Upper Endoscopy	19
Capsule Endoscopy and Deep Enteroscopy	20
Laboratory Tests	21
Imaging Test	23
<b>TREATMENT OPTIONS IN IBD</b>	
Medicines	26
Surgery for Inflammatory Bowel Disease	64
Therapeutic Studies in Clinical Research	68
Diet and Inflammatory Bowel Disease	69
Complementary and Alternative Medicine	78
<b>MAINTAINING MY HEALTH</b>	
My Information	81
Friends and Family Form	81
My Appointment Planner	82

My Medicines .....	83
Planning for My Next Visit .....	84
Bathroom (Bowel Movements) Tracker .....	85
Prednisone Taper Schedule .....	86
Characteristics of My Inflammatory Bowel Disease .....	87
Surgery on My Gastrointestinal (GI) Tract .....	88
Monitoring My Laboratory Tests .....	89
Preventing Complications by Monitoring My IBD Medicines .....	90
Preventing Infections with Vaccines .....	90
Vaccines.....	91
Smoking and Inflammatory Bowel Disease .....	94
Tuberculosis (TB) and Hepatitis B Testing .....	94
Preventing Skin Cancer .....	94
Preventing Bone Loss .....	95
Preventing Colon Cancer .....	99
Preventing Cervical Cancer (for Women) .....	101

## **SEXUAL HEALTH & PREGNANCY**

Sexual Health and Inflammatory Bowel Disease .....	102
Fertility, Pregnancy, and Breast-feeding with Inflammatory Bowel Disease .....	102
Genetic Risk for Inflammatory Bowel Disease in Childbearing .....	105

## **RESOURCES**

University of Maryland Crohn's & Colitis Program Web Site .....	106
Crohn's & Colitis Foundation of America.....	108
Maryland Support Groups .....	109
Clinical Research at the University of Maryland .....	110
Recommended Books about Inflammatory Bowel Disease .....	111
Useful Web Sites .....	114

## **MEDICAL RECORDS**

Place your test results and other documents here

# WELCOME TO THE UNIVERSITY OF MARYLAND INFLAMMATORY BOWEL DISEASE PROGRAM



## **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. We have included our contact information, as well as pages to record your test results and current medicines. You will also find information about treatment options and other helpful resources.

## **The quality of your care is our number one goal.**

We are a team of physicians, registered nurses, research coordinators, dietician, and administrative assistants. We want to partner with you to make sure you have the best quality of life possible. To do this, we ask you to come to all of your visits and take your medicines as prescribed by your physician.

## **We need to see you at least once every 4 to 12 months and maybe more often, if necessary.**

Your well-being is our number one concern. If it is easier, you may have some blood tests done in a lab close to your home. Please ask the lab to fax us the results. If you are not able to attend your scheduled clinic visits or have lab tests done as needed, we are not able to care for you safely and your health can be adversely affected. We look forward to getting to know you. We will work together toward your goals so that you can live your life to the fullest.

## **IMPORTANT THINGS TO KNOW UP FRONT**

- If you are ill or are having side effects between 8:30 AM and 4:30 PM on a weekday call your nurse (see phone number on page 10). **If you are thinking of going to the ER, call your nurse first because we will try to see you right away.** If you cannot reach us and you are seriously ill, go to the ER right away.
- When you call the Inflammatory Bowel Disease Program be prepared to tell us exactly what symptoms you are having or give specific details about your concerns. Please have your **date of birth** and a **list of your current medicines**. When you call, you will speak with the administrative assistant who will give the message to your nurse. We will make every effort to get back to you as soon as we can. Make sure we have your correct phone number and an alternate number so we can reach you.
- If you call before 12 NOON with an urgent issue, we will make every effort to return your call by the end of the day. If for some reason you cannot reach us, and you are seriously ill, please go to the ER right away.
- Routine calls will generally be returned within one business day.
- If you have an urgent question after 4:30 PM on a weekday or on the weekend, call the gastroenterology and hepatology on call service at (410) 328-5780 and ask for the gastroenterologist on call.
- Keep in mind that if **you are admitted to the hospital due to a flare of IBD, your outpatient IBD gastroenterologist may not see you day to day in the hospital.** One of the IBD specialists on our team will see you and oversee your care while you are in the hospital. This doctor will be in touch with your outpatient doctor about your care, as needed.
- **If you need to be seen right away, one of our five physicians may be able to see you the same day or within a day or two. All of our physicians** provide care for urgent visits as well as routine visits during clinic hours. Our physicians work closely with your IBD doctor, who will always be in charge of your care.

- 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.
- For medicine refills, call 410-706-3387. **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 you have a change in address, phone number or health insurance, please give the new information to our administrative assistants at toll free **410-706-3387** Monday to Friday 8:30 AM to 4:30 PM. If you are taking an immunosuppressive medicine we need to be able to get a hold of you quickly. For example, the results of your lab tests may indicate that the dose of your medicine needs to be changed. For this reason, please call our office **as soon as you can** to give us your new contact information.
- We encourage you and your family to become members of the Crohn's & Colitis Foundation of America (CCFA) [www.ccfa.org](http://www.ccfa.org). The CCFA is a very helpful resource for anyone living with inflammatory bowel disease. Your nurse or doctor can tell you more about this group.

## MEET YOUR INFLAMMATORY BOWEL DISEASE TEAM

Our **doctors** possess exceptional clinical skills and have a genuine interest in your treatment.

### Gastroenterology



Raymond Cross, MD, MS, AGAF  
Associate Professor of Medicine



Mark Flasar, MD, MS  
Assistant Professor of Medicine



Leyla Ghazi, MD  
Assistant Professor of Medicine



Seema Patil, MD  
Assistant Professor of Medicine



Sandra Quezada  
Assistant Professor of Medicine

### General Surgery



Jonathan Chun, MD  
Assistant Professor of Surgery



Stephen Kavic, MD  
Associate Professor of Surgery



Andrea Bafford, MD  
Assistant Professor of Surgery



Nicole Payne  
Administrative Assistant

Our **registered nurses** (RNs) are very knowledgeable and caring. They will help you manage your disease.



Holland Reidt  
Administrative Assistant



Janis Marcella, RN

Our **nutritionist** is very knowledgeable and will help answer any questions that you may have about nutrition.



Andrea Rey, RN



Allison Maurer, RD, LDN  
Nutrition Specialist



Dora Frank, MS, CRNP

If you would like to participate in clinical research, our **clinical research staff** will tell you about the current research studies and how you may be able to take part.

Our **administrative assistants** will help you schedule your appointments and make sure you are ready for your first IBD visit.



Katherine Osche-Dauvin  
Clinical Research Specialist



Linda Stein  
Administrative Assistant



Guruprasad Jambaulikar  
Clinical Research Specialist



Nuru Shabazz  
Administrative Assistant



Ashih Bhandari  
Clinical Research Specialists





# HOW TO CONTACT US



**INFLAMMATORY BOWEL DISEASE PROGRAM SCHEDULE**  
 University of Maryland Medical Center, Digestive Health Center  
 22 South Greene Street, Baltimore, MD 21201

## GASTROENTEROLOGY CLINICS

	RAYMOND CROSS	MARK FLASAR	LEYLA GHAZI	SEEMA PATIL	SANDRA QUEZADA
<b>MONDAY</b>		9-4pm			
<b>TUESDAY</b>			8-12pm every other week	8-12pm	
<b>WEDNESDAY</b>	8-1pm			1-4pm	
<b>THURSDAY</b>			8-12pm; 1-4pm every other week		8-12pm
<b>FRIDAY</b>	8-1pm	8-12pm every other week		8-12pm	8-12pm

## SURGERY CLINICS

	STEPHEN KAVIC	ANDREA BAFFORD	JONATHAN CHUN
<b>MONDAY</b>	12-4pm		
<b>TUESDAY</b>			
<b>WEDNESDAY</b>		12-4pm	
<b>THURSDAY</b>			1-4pm
<b>FRIDAY</b>			

## **SCHEDULING APPOINTMENTS**

### **Physician and Nurse Contact Information**

**How to Contact Your Doctor:** To contact your doctor, call the nurse who works with your doctor. Look below to determine who your nurse is and which phone number to use.

#### **Raymond Cross, MD, MS**

Nurse: Suzanne Baldivieso, RN

410-706-3398

Administrative Assistant: Nicole Payne

410-706-3387

#### **Mark Flasar, MD, MS**

Nurse: Dylan McLellan, RN

410-706-6009

Administrative Assistant: Nuru Shabazz

410-706-3387

#### **Leyla Ghazi, MD**

Nurse: Dylan McLellan, RN

410-706-6009

Administrative Assistant: Linda Stein

410-706-3387

#### **Seema Patil, MD**

Nurse: Suzanne Baldivieso, RN

410-706-3398

Administrative Assistant: Linda Stein

410-706-3387

#### **Sandra Quezada, MD**

Nurse: Dylan McLellan, RN

410-706-6009

Administrative Assistant: Holland Reidt

410-706-3387

## **OTHER CONTACT INFORMATION**

### **Inflammatory Bowel Disease Program**

410-706-3387

### **Digestive Health Center**

410-328-2877

### **GI Endoscopy Lab**

410-328-5780

### **Clinical Research Staff**

#### **Guruprasad Jambaulikar**

410-706-3397

### **Kathryn Osche-Gauvin**

410-706-5943

### **Ashih Bhandari**

410-706-3387

# THE BASIC OF INFLAMMATORY BOWEL DISEASE (IBD)



## 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. The bacteria cause 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 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. It is called Crohn's colitis when only the colon is affected. And it is called Crohn's ileocolitis when both the ileum and the colon are affected.

### 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. Remember, 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. Research suggests that 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 respectively.

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. This is called **malabsorption**. 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 (osteopenia or osteoporosis)**. 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. A decreased ability to absorb fat may lead to a specific type of kidney stones called calcium oxalate kidney stones. People with an ileostomy have no colon and do not develop oxalate kidney stones. A low oxalate diet may be helpful for someone who keeps getting oxalate kidney stones. To see the oxalate content of different foods go to this web site: [http://www.lowoxalate.info/food\\_lists/alph\\_oxstat\\_chart.pdf](http://www.lowoxalate.info/food_lists/alph_oxstat_chart.pdf). Crohn's disease also lowers the ability to

absorb bile salts, which can lead to gallstones. Poor absorption of bile salts leads to an increase in cholesterol in the bile, which may cause cholesterol gallstones.

### **What is primary sclerosing cholangitis (PSC)?**

Like IBD, PSC, is an autoimmune disease. PSC leads to inflammation and scarring of the bile ducts of the liver; PSC tends to get worse over time. The cause is unknown. About 2.5% to 7.5% of people with IBD develop PSC for unknown reasons. It is twice as common in men as women. Symptoms can include fatigue, itching, abdominal pain, fevers, weight loss, and jaundice (yellowing of the eyes and skin) that comes and goes. Many patients have no symptoms and the disease is found when a blood test shows high liver enzyme levels.

### **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 upper endoscopy, enteroscopy, or video capsule endoscopy.

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

**Cure** – There is no cure for IBD at this time, although this is an important area of current research. Treatment helps to eliminate or reduce symptoms, prevent flares, and decrease complications of the disease.

**Stop smoking** – If you stop smoking, the inflammation in your intestines will decrease and your symptoms may go away.

**Avoid NSAIDs** (Motrin, Ibuprofen, Naproxen, Aleve, etc.)-. 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 medications. Be sure to discuss the use of these medicines 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.

**Surgery** – 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.

**Diet** – Changing your diet, especially during flares, may ease your symptoms. It will not reduce inflammation, nor will it lower your risk for complications.

**Complementary treatment** – Herbal, alternative, or complementary therapies have not been shown to work 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 health care 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 are 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?

## FREQUENTLY ASKED QUESTIONS ABOUT INFLAMMATORY BOWEL DISEASE (IBD)

### 1. Is there a cure?

No, *currently* IBD cannot be cured. There will be periods of remission when the disease is not active. Medicines can reduce inflammation and increase the number and length of periods of remission.

### 2. How long will IBD last?

IBD is a lifelong (chronic) condition. A few patients find their disease becomes milder ("burned out") after age 60, but many do not.

### 3. Do I have to take medicine forever?

Probably. IBD is a chronic disease, and most patients need to take medicines to ease symptoms and reduce the number and severity of flares. You may need both maintenance medicines to prevent flares and rescue medicines

during the time of an active flare. Most maintenance medicines act fairly slowly, but rescue medicines act more quickly to reduce inflammation and ease your symptoms.

### 4. Are there some medicines that can get me out of a flare quickly?

Yes. Some of these are not used long term because of side effects. Examples include steroids like prednisone and cyclosporine. Patients will often change over from these rescue medicines to long-term maintenance medicines. Biologic drugs like adalimumab, certolizumab pegol, golimumab, infliximab, and natalizumab work fairly quickly and can be used long term to prevent flares of disease.

### 5. Why do I need to keep taking maintenance medicines when I feel well?

These medicines reduce the chances for a flare and the number of flares you will have. Some of these medicines (like adalimumab, certolizumab pegol, golimumab, and infliximab) need to be taken regularly or you can have a reaction and they will stop working for you.

### 6. Will surgery cure my IBD?

No, but surgery can be very helpful. For patients with ulcerative colitis, removal of the colon greatly reduces symptoms. Surgery has some risks associated with it, but it can often improve quality of life if you have severe colitis. There are several ways to reconnect the intestine after the colon is removed, each of which has benefits and drawbacks.

The effect of surgery for Crohn's disease can often be like pushing a giant reset button. The surgery can remove scar tissue and strictures, fistulas, and abscesses that cause a lot of symptoms for which medicines are not very effective. After surgery for Crohn's disease,

maintenance medicines often work better and may prevent the need for surgery in the future.

7. **Is it dangerous to suppress (weaken) the immune system for the rest of my life?**

There are some risks in taking medicines to suppress your immune system. Viruses that stay in your body, like the chicken pox virus, are more likely to be activated (cause shingles) in people taking immunosuppressive medicines like azathioprine and methotrexate. Bacterial infections of the skin and soft tissues are more likely in people taking anti-TNF medicines. However, for many, the benefits of avoiding IBD flares outweigh the risks that go with taking these medicines.

You can reduce some of these risks. Ask your doctor if vaccines would be helpful to you. If you are taking an anti-TNF medicine and you are going to have surgery, your dose may need to be adjusted.

8. **Could anything other than IBD be causing my symptoms?**

Yes, patients with IBD can get IBD-like symptoms for other reasons. Infections can cause diarrhea. Previous inflammation can cause increased sensitivity of the nerves in the intestine and make you very sensitive to abdominal cramps. Too much bacteria in the small intestine can cause bloating and gas. Because you cannot be sure, call your health care team if there is a change in your symptoms because it might be something other than a flare of IBD.

9. **Are narcotics used to treat my painful symptoms?**

Narcotics treat the symptoms, not the inflammation caused by IBD. Narcotics can make the inflammation worse. Research has

shown that patients with IBD who use narcotics are more likely to have severe infections and more likely to die. For this reason, narcotics are used only rarely.

10. **Why not just take prednisone whenever I have a flare?**

Prednisone has many side effects, including bone loss, diabetes, cataracts, emotional distress, and severe acne. That's why prednisone is only used when, and if, you really need it to rescue you from a flare. Maintenance medicines are used to reduce your number of flares and how severe your flare symptoms are. This way, you won't need prednisone as often if at all. There is also evidence that taking a maintenance medicine to reduce inflammation in the colon lowers your risk for colon cancer.

## 20 QUESTIONS TO ASK YOUR DOCTOR ABOUT INFLAMMATORY BOWEL DISEASE (IBD)

1. What is inflammatory bowel disease (IBD) and how is it diagnosed?
2. Do I have ulcerative colitis or Crohn's disease?
3. What specific area(s) of my intestine is (are) inflamed?
4. Could any condition other than IBD be causing my symptoms?
5. How is IBD different from irritable bowel syndrome (IBS)? Can I have both?
6. How is IBD treated?
7. What medicines are right for me? How soon should I expect relief?
8. What are the potential side effects of the medicines? What should I do if I notice any side effects?

9. Do I need to take my medicines even if I feel well?
10. Should I change my diet, take vitamins or other supplements, or make other lifestyle changes?
11. How might smoking affect my symptoms?
12. What are symptoms of IBD flares?
13. What are the possible complications of Crohn's disease and ulcerative colitis?
14. Will I need an operation, and if so will it cure my IBD?
15. Am I at increased risk for colon cancer?
16. How might my diagnosis of IBD affect my ability to have a baby?
17. Are my children at risk for developing IBD?
18. What should I do if my symptoms return? Which symptoms should I consider an emergency?
19. When should I have a follow-up appointment?
20. How can I get more information?



## 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. You can eat a light breakfast the day before the procedure but you can drink only clear liquids after that. You will need to have a driver with you because the sedatives will make you drowsy.

#### **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, 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 and any suspicious areas are biopsied to exclude 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 beforehand. 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. Colon cancer surveillance, however, requires 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 to assess 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 and 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. You must not eat any solid food the day of the procedure and stop drinking clear liquids 2 hours before the procedure. You will need to have a driver with you because the sedatives will make you drowsy.

### **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. 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 upper GI tract is inspected. Biopsies (tissue samples) obtained during the procedure do not cause pain. The actual procedure lasts only a short time, although 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 used currently 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 to open them up and improve symptoms.

### **TRANSRECTAL ENDOSCOPIC ULTRASOUND**

Crohn's disease occasionally involves the area around the anus, resulting in perianal fistulas and abscesses. Making sure that fistulas are accurately mapped out and that all areas of infection (abscess) are identified is very important to control symptoms and prevent recurrent 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 (abscess) does not form as the fistula heals.

#### **What is transrectal endoscopic ultrasound?**

Transrectal endoscopic ultrasound, often referred to as a "TRUS," 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 obtained from the rectal lining or from deeper tissues.

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

You will get detailed instructions when your appointment is made for the transrectal endoscopic ultrasound. You must not eat any solid food the day of the procedure and stop drinking clear liquids 2 hours before the procedure. If you receive sedation, you will need to have a driver with you because the sedatives will make you drowsy.

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

A transrectal 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. You may have an intravenous (IV) line started to give you a sedative if needed. 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 upper GI tract is inspected. Biopsies (tissue samples) obtained 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 transrectal endoscopic ultrasound?**

If you were given a sedative, you will be taken to the recovery room where your driver can join you. You will be given your transrectal endoscopic ultrasound results. The biopsy results will not be available for about a week.

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

A transrectal endoscopic ultrasound is done only if you have symptoms of perianal Crohn's. Many patients with Crohn's will never need one. A repeat transrectal endoscopic ultrasound may be

recommended if you do not respond well to therapy, if there are concerns for infection (abscess), and to assess your response to medical therapy.

### **What are the possible complications of transrectal endoscopic ultrasound?**

A transrectal 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 transrectal endoscopic ultrasound, contact your doctor as instructed on your discharge instructions.

## **LABORATORY TESTS**

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

### **Common Blood Tests**

- **Hemoglobin/Hematocrit** – A low count may suggest 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).

### Blood Tests For Diagnosis

The following blood tests may help to identify what type of IBD you have. These tests do not provide a firm diagnosis. The results of these tests are used along with your symptoms, colonoscopy results, and radiology exams to determine your final diagnosis.

- **ANCA antibodies** – More commonly positive in ulcerative colitis.
- **ASCA, I2, OMP-C, and CBir antibodies** – More commonly positive in Crohn’s disease.

### Testing for inflammation

- **Blood tests** – An increased erythrocyte sedimentation rate (ESR or “sed rate”) and an increased level of C-reactive protein (CRP) are markers of inflammation. These tests assess how severe your disease is and also measure your response to treatment.
- **Stool tests** – The levels of lactoferrin and calprotectin in stool are a measure of white blood cells. High levels mean your disease may be active. Low levels mean your disease may not be active.

### 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.

### Other Tests

- **PPD** – Skin test done before starting an anti-TNF medicine to make sure you do not have tuberculosis (TB).
- **QFTB** – 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 or perforated 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.

**Barium enema** – This test provides a detailed view of the inner surface of the colon. Problems with the structure of the colon, such as narrowed areas (strictures) can be detected with this test. Barium enemas also make it easier to monitor inflammation. A barium enema, or lower GI exam, is an x-ray exam of the large intestine (colon and rectum). To make the intestine visible on an x-ray, the colon is filled with a dye containing barium. This is done by pouring the dye through a tube inserted into the anus. The barium blocks the x-rays so the colon, which is filled with barium, will show up clearly on the x-ray. There are two types of barium enemas. In a single-contrast study, the colon is filled with barium. In a double-contrast or air-contrast study, the colon is first filled with barium and then the barium is drained out, leaving only a thin layer of barium on the wall of the colon. The colon is then filled with air.

**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. 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. As a result, CTE is becoming a first-line of test to evaluate the small bowel in patients with Crohn's disease and is also being used to monitor the disease over time.

**Computed tomography (CT)** – Routine CT is not as helpful as CTE for IBD, but it may be used in some cases, such as evaluating for a small bowel obstruction and to exclude an abscess or small perforation. Usually contrast material is given through an intravenous (IV) line so the intestines can be seen more clearly.

**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 and its channel (tract). 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 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 or abscesses around the anus. In this situation, a MRI can be performed to accurately identify all of

the fistulas and to identify abscesses that are not obvious on physical examination. This test is often done before a surgeon performs and exam under anesthesia to place setons (silk string or rubber band) around the anus so that an infection (abscess) does not form as the fistula heals. Also, 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 as it depends on how actively your intestinal tract is working. It may take longer if you have a blockage. You will drink several 7-ounce glasses of barium, although the final number of glasses depends on how long it takes the barium to travel through your small intestine. 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

*\*\*\* The medication guide below is meant for general information only. This information is not meant to cover all uses, directions, precautions, warnings, drug interactions, allergic reactions, or adverse effects. There may be additional medications your doctor will recommend. 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. \*\*\**

#### 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, whereas 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. This is why it is called both an induction and a maintenance medication. 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. Sadly, 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**<sup>®</sup>, **Sulfazine**<sup>®</sup>)
- Mesalamine (**Asacol HD**<sup>®</sup>, **Delzicol**<sup>™</sup>, **Pentasa**<sup>®</sup>, **Apriso**<sup>™</sup>, **Lialda**<sup>®</sup>, **Rowasa**<sup>®</sup>, and **Canasa**<sup>®</sup>)
- Balsalazide (**Colazal**<sup>®</sup>, **Giazo**<sup>®</sup>)
- Olsalazine (**Dipentum**<sup>®</sup>)

These medicines are all pills that should be taken with plenty of water. While these medications work similarly, they can differ in how many pills you need to take and how often you need to take them. Taking the right number of pills at the right times works best to prevent a flare of your disease. There are two forms of mesalamine made to be given per rectum: **Canasa**<sup>®</sup> (suppository) and **Rowasa**<sup>®</sup> (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 provider right away. You may need to stop taking the medicine. These medicines have rarely been shown to cause kidney problems (only 1 in 10,000 people). 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<sup>®</sup>) contains sulfa, and a common side effect of this medicine is an allergy to the sulfa. True allergic reactions include hives, swelling of the face, lips, or tongue, shortness of breath, tightness of the chest or throat, and wheezing. Anaphylaxis (vascular shutdown) 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 (Azulfadine<sup>®</sup>). Another common side effect of sulfasalazine is headache. This is directly related to the starting dose of the medicine so it is common to start with a lower dose and then slowly increase

to the needed dose. Enteric-coated sulfasalazine can reduce stomach upset but it costs more. Most people who cannot tolerate this medicine can still take other forms of 5-ASAs. Sulfasalazine (Azulfadine<sup>®</sup>) can cause anemia and low white blood cell counts. It is also known to reduce sperm counts in about 10% of men, which may affect fertility. Sperm counts return to normal after stopping the medicine. It is not known to cause birth defects.

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

As noted above, 5-ASAs can cause kidney problems. Your kidney function will be tested periodically while on this medication. If you are on sulfasalazine, your doctor will also periodically monitor your blood counts.

### **Will I have to take medicines in addition to a 5-ASA to treat my ulcerative colitis or Crohn's disease?**

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<sup>®</sup>, Uceris<sup>®</sup>). 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.

### **Azathioprine/Mercaptopurine**

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

Azathioprine (abbreviated AZA, brand names Imuran<sup>®</sup> and Azasan<sup>®</sup>) is a purine synthesis inhibitor used inhibitor used to treat moderate to severe

Crohn's disease and ulcerative colitis. Azathioprine 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?**

Azathioprine is a pro-drug. This means that after you take azathioprine, it is changed in the body to the active form of the drug, which is 6-mercaptopurine. 6-Mercaptopurine (or mercaptopurine) is also called Purinethol® (brand name) and is abbreviated 6-MP. Even though these medicines work the same way to help your disease, 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. Prednisone works very well in the short-term to reduce inflammation and symptoms. 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 may be used if you cannot stop taking prednisone without your symptoms getting worse. 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 medication, you can try splitting the dose (1/2 in the morning and 1/2 at night) or you can take the medication before going to sleep. The correct dose is based upon your weight. If you have impaired kidney function, your dose of azathioprine will be decreased. If you improve while taking azathioprine, you will take it for as long as you can. If you stop taking azathioprine, you can start it again anytime in the future, as long as you did not have side effects when you took it the first time.

### **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. However, you should not take allopurinol with AZA or 6-MP unless directed to do so because this can cause severe suppression of 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 have are taking an alkylating agent for cancer chemotherapy such as cyclophosphamide (Cytosan®). 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 azathioprine. The result of this test will show if AZA or 6-MP is safe for you and will help direct 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 medication, these monitoring blood tests will be done very frequently, every 1-4 weeks. After you are stable on the medication, these blood tests will be checked every 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.

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

**Allergic reaction:** Allergic reactions are rare and usually happen right away. True 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.

**Common side effects/risks:** You may have side effects such as nausea, vomiting, diarrhea, fatigue, and/or muscle pain. Some of these side effects can be improved by taking the medication at night,

or dividing the dose. A change from AZA to 6-MP may be another option to help decrease side effects.

AZA or 6-MP can lower your white blood cell count or platelet count and cause liver toxicity. You will be monitored closely for side effects and your dose may be adjusted based on the results of your blood tests.

**Uncommon side effects/risks:** 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.

**Lymphoma:** Because AZA or 6-MP is an immunosuppressive medicine there is a small risk for getting lymphoma, a type of cancer. However, it is not clear whether this risk is due to the medicine or to the IBD. You will be monitored closely while you are taking azathioprine. The risk for lymphoma in people who do not take AZA or 6-MP is about 2/10,000. In IBD patients taking AZA or 6-MP, it is about 4/10,000. As you can see, this means that there is a very small increase in your risk. 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.

**Skin cancer:** 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. Also,

do not use tanning beds. You will need to have a yearly skin exam by a dermatologist if you take AZA or 6-MP on a long-term basis.

**Infections:** AZA or 6-MP can increase your risk for infections. This risk is higher if you take another immunosuppressive medicine with AZA or 6-MP. 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. Methotrexate interferes with the metabolism of folic acid.

Methotrexate was first used in high doses to treat leukemia. High doses are needed to kill cancer cells, but only low doses are needed to treat IBD. Low-dose methotrexate (15–25 mg weekly) used to treat Crohn's disease does not kill cells, but instead reduces inflammation. Methotrexate 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 methotrexate?**

Methotrexate may be used if you cannot stop taking prednisone without your symptoms getting worse. You may also take methotrexate if you cannot take azathioprine or mercaptopurine, two other medicines often used to treat Crohn's disease and ulcerative colitis. Methotrexate can lessen the damage to the intestine, which can improve your health in the long-term. If you get better while taking methotrexate, you will avoid the side effects of prednisone, avoid the complications of untreated inflammation, and improve your quality of life.

### **How quickly does methotrexate 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 methotrexate?**

Methotrexate 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 methotrexate 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 this dose works, it may be lowered to 15 mg for ongoing therapy. The lower dose does not work for everyone and some people stay on the 25-mg injection in order to improve. If you have impaired kidney or liver function your dose will be decreased.

If you improve while taking methotrexate, you will take it for as long as you can. If you stop taking methotrexate, you can start taking it again anytime in the future, as long as you did not have side effects when you took it the first time.

### **May I take methotrexate 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 methotrexate. If an anti-TNF such as infliximab (Remicade®) has been added to your medicines, do not stop taking the methotrexate unless you discuss it with your doctor first. This combination of methotrexate and an anti-TNF may be prescribed if you have more severe inflammation. Other immunosuppressive medicines such as prednisone and budesonide (Entocort®) may also be taken with methotrexate. Remember that 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 and decide which plan is best for you.

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

**Non-prescription products:** Do not drink more than 2-3 alcoholic beverages per week while taking methotrexate 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 methotrexate. 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 methotrexate.

**Prescription medicines:** 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 methotrexate (usually in high doses) is taken along with certain nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen.

Do not take methotrexate 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 methotrexate?**

While you are taking methotrexate 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 4 weeks for the first few months. If the results of these blood tests are normal, your blood will be drawn every 3 months from then on. Your dose of methotrexate 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 methotrexate in your body.

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

**Allergic reaction:** Allergic reactions are rare and usually happen right away. True 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.

Stop methotrexate permanently if you have an allergic reaction.

**Uncommon side effects:** 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) or leucovorin can reduce nausea, vomiting, and stomach upset. Some people take an anti-nausea medicine just before the injection to prevent nausea and vomiting. Once your body is used to taking methotrexate, these symptoms may go away.

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

**Mouth sores:** If you get sores inside your mouth or on your lips, call your doctor right away. This may mean that the dose of methotrexate is too high. You will stop taking it and start again at a lower dose. Sometimes a medicine called leucovorin is given to

reverse the effects of methotrexate and to help the sores heal more quickly.

**Liver damage:** Liver enzymes spill into the blood if liver cells are damaged. These levels increase in a small number (8%) of people who take methotrexate. This is related to the buildup of methotrexate in your body over time. 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 when you are taking methotrexate.

**Kidney damage:** This usually only occurs when high doses of methotrexate are taken. Your kidney function will be checked by routine blood tests while you are taking methotrexate.

**Bone marrow suppression:** This occurs in a small number (5%) of people taking methotrexate. The result is a low blood cell count. This increases your risk for infections and bleeding.

**Skin conditions:** There is a rare risk of developing potentially fatal skin conditions, including Steven's-Johnson syndrome and toxic epidermal necrolysis, when you take methotrexate. Tell your doctor right away if you notice any new rash. Also, your skin may become more sensitive to light when you take methotrexate. Remember to use sunblock when you spend time outside and do not use tanning beds.

**Lung inflammation:** If you have chest pain, cough, difficulty breathing, or fever while you are taking methotrexate, call your doctor right away. A chest X-ray and CT scan may be needed to check your lungs. Prednisone may be used to treat lung inflammation.

**Infections:** Methotrexate can increase your risk for infections. The risk is higher if you take another immunosuppressive medicine with methotrexate.

*You need to have a working thermometer at home 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.*

**NO LIVE VACCINES:** You should *NEVER* be given a live vaccine while you are taking any immunosuppressive medicines. These vaccines include *MMR (measles-mumps-rubella), varicella (chickenpox), rotavirus, oral polio, and yellow fever.* Methotrexate can also increase your risk for having shingles. If you are older than 60, you should get a shingles vaccine 6 weeks before starting methotrexate. If you have never had chickenpox, you should get a chickenpox vaccine 6 weeks *BEFORE* starting to take methotrexate.

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

*NO WAY!!* Methotrexate 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 if you use methotrexate while you are pregnant. If you think you are pregnant, stop taking methotrexate *right away* and 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 methotrexate.

### **How to Inject Methotrexate**

1. Gather needed items: vial of medicine, syringe, and alcohol pad.
2. Wash and dry your hands.
3. Clean the top of the vial with the alcohol pad.
4. Use the alcohol pad to wipe the area you will inject, either the top of the thigh or belly.
5. Remove the cap from the needle.
6. Pull the plunger until the syringe has the same volume of air as the medicine you are going to give.
7. Put the needle into the vial of medicine and push the plunger down (to put air into the vial).
8. Turn the bottle over and slowly pull down the plunger to your dose.
9. Check for air bubbles and flick them out if needed.
10. Pull the needle out of the vial.
11. With your non dominant hand, pinch the skin around the area you cleaned.
12. With your dominant hand, insert the needle straight into the skin.
13. Bring your non dominant hand over to support the syringe and with your dominant hand, push the plunger all the way down to inject the medicine.
14. Pull the needle straight out.
15. Discard the needle/syringe unit into your puncture proof Sharps container.
16. Wash and dry your hands.

### **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 (75% to 80%). However, 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 and 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 may need to consider hospitalization for IV steroids and other treatments.

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

Take prednisone after meals or with food or milk to protect your stomach. 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 (40–60 mg for adults or 1–2 mg/kg for children) for 1 to 2 weeks to relieve the symptoms. Then you will decrease the dose by 5 mg every 1 to 2 weeks for about 4 to 12 weeks. This is called a taper. The speed at which you taper depends on the side effects, how severe the flare, and how quickly your maintenance medicine takes effect. 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. Because of the risk for serious side effects, you and your doctor will work together so you can avoid taking prednisone longer than you have to.

#### **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 while taking prednisone. Do not take any over-the-counter herbal products with Echinacea, cat's claw, or alfalfa because these can reduce the effect of all immunosuppressive medicines, including prednisone. You also need to avoid St. John's wort as it may decrease prednisone levels.

**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 in turn 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 (also called a DEXA scan) to be sure your bones are healthy. It is a good idea to take 1500 mg of calcium plus 1000

IU of vitamin D while you are taking prednisone. If you get osteoporosis you may need to take medicines called bisphosphonates. Regular weight-bearing 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?**

**Allergic reaction:** It is unlikely you will have an allergic reaction to prednisone because steroids are the medicines that work best to treat allergies. However, if you do have allergy-like symptoms while taking prednisone you may be allergic to one of the other things in the medicine. True 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) are rare. If you have an allergic reaction, go to the emergency room or call 911.

**Common side effects:** These 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:** These 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?**

**Adrenal crisis:** Never stop taking prednisone all of a sudden without tapering. Your adrenal glands normally make a certain amount of a hormone called cortisol every day. Because prednisone performs some of the same roles in your body as cortisol does, your adrenal glands stop making cortisol when you are on prednisone. If you slowly decrease the dose of prednisone, your adrenal glands will gradually start making cortisol again. 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.

### **Entocort®**

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

Budesonide (Entocort®, Uceris®) 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 (Entocort®, Uceris®)?**

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 medication.

#### **How quickly does Entocort® work?**

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

#### **How should I take Entocort®?**

When you take budesonide, 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 all immunosuppressive medicines, including budesonide.

**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?**

**Allergic reaction:** It is unlikely you will have an allergic reaction because steroids are the medicines

that work best to treat allergies. However, if you do have allergy-like symptoms while taking budesonide, you may be allergic to one of the other things in the medicine. True 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) are rare. If you have an allergic reaction, go to the emergency room or call 911.

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

**Rare side effects:** These include weight gain, fatigue, muscle weakness, facial rounding, fragile or thin skin, dizziness, throat irritation, and cataracts. In general, budesonide can cause any side effect that prednisone does (see above); however the side effects are less likely and less severe when they do occur.

**Adrenal crisis:** This risk is much higher with prednisone but it is still possible with budesonide

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

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

Anti-TNF medicines are antibodies that bind to tumor necrosis factor (TNF). Antibodies are proteins made by our bodies to help get rid of foreign things that get into our bodies and can harm us. TNF is also a protein and it is made by our bodies to help cause inflammation. When antibodies are bound to TNF, the TNF cannot cause inflammation in the intestine. Anti-TNF medicines are often called biologic agents or biologics. They are immunosuppressive medicines. This means that they partially block the action of the immune system, but do not completely it turn off.

#### **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 infusions at 0, 2, and 6 weeks for induction therapy. Then, maintenance treatment is needed every 8 weeks. The dose and time between doses may be changed to get the best response. Each infusion 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 (subcutaneous injection). It comes as a single dose in a pre-filled syringe or pen. The makers of **Humira®** provide at-home injection teaching. You will first administer induction therapy, with the first dose of 160 mg (4 shots, 40 mg each) at 0 weeks, and the second dose of 80 mg (2 shots, 40 mg each) at 2 weeks. You will then administer 40 mg (one shot) every 2 weeks for maintenance. 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 (subcutaneous injection) of 400 mg (2 shots, 200 mg each) to start and then repeated at weeks 2 and 4. The maintenance 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 administer the injections.

**Golimumab (Simponi®)** is only used to treat ulcerative colitis. The first dose is given as a shot just under the skin (subcutaneous injection) of 200 mg at week 0 and 100 mg at week 2. The maintenance dose is 100 mg every 4 weeks.

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

If you cannot tolerate or have not gotten a lot better with azathioprine or mercaptopurine you may need to take an anti-TNF. You may be started on an anti-TNF agent as your first therapy for Crohn's disease if you have perianal involvement or severe disease. 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. About 60% to 70% of patients who take these medicines notice that their symptoms decrease and their test results improve (endoscopy and blood tests measuring inflammation). Up to 40% 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 of anti-TNFs. Anti-TNFs work best if taken for the long-term. If you are able to tolerate 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?**

Clinical research studies have suggested that people with early Crohn's disease may do better if they take Remicade® and AZA or 6-MP together. You may take these two medicines together if you have more severe disease. It is believed that azathioprine helps to prevent your body from making antibodies directed against the anti-TNF medicine. This means you may benefit from taking an anti-TNF longer. Other immunosuppressive medicines such as

corticosteroids or methotrexate can be taken along with an anti-TNF as well. Remember that 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 all immunosuppressive medicines, including anti-TNF medicines.

**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 undergo 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.

**Allergic reaction:** An allergic reaction right away when you start taking an anti-TNF is rare. True 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 also 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 dry natural rubber (made from latex).

**Infusion/injection site reaction:** You may have an intravenous (IV) infusion-related reaction, which is a side effect that occurs within 2 hours of the start of an infusion of Remicade®. 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 rate of infusion and taking Benadryl®, Tylenol®, and/or prednisone. However, in a minority of patients, the reaction is too severe to continue the medication. Some people who take Humira® or Cimzia® experience an injection site reaction; the skin can become swollen, red and painful where the shot is given. These reactions can be reduced by taking Tylenol® as well as cooling the area with an ice pack before the shot is given.

**Resistance:** 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.

**Infections:** Anti-TNFs can increase your risk for infections, and 3% 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 reactivation of these into very serious infections. You will be tested for both of these infections with blood tests or a skin test before being started on an anti-TNF agent. If you test positive, you will need to be on treatment for these infections for a period of time before starting anti-TNF therapy.*

**Lymphoma and other cancers:** Because anti-TNFs suppress your immune system there is a small risk for getting lymphoma, which is a type of cancer.

However, 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. The risk is about 1/1,000 to 1/2500. This means there is a small increase in risk for having lymphoma. The risk may increase if you are taking a second immunosuppressive medicine in addition to 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.

**Other risks:** If you have congestive heart failure (CHF), you should not take anti-TNFs. People with multiple sclerosis or lupus should not take anti-TNFs. It is rare, but some people get elevated liver enzymes (especially if the anti-TNF is used with methotrexate), low blood count, or serious skin conditions such as erythema multiforme 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. Serum sickness-like reaction includes rash, welts (wheals), joint pain, fever, malaise, enlarged lymph nodes and should also be reported right away. About 5% of patients can develop a rash on their scalp, hands, and feet that resemble psoriasis. If this occurs, most patients need to stop the anti-TNF for the symptoms to resolve.

### **Tysabri®**

#### **What is natalizumab (Tysabri®) and how does it work?**

Tysabri® is used to treat Crohn's disease. Natalizumab is the generic name for Tysabri®. Tysabri® is an antibody that binds to and blocks the alpha 4 integrin protein found on white blood cells. By blocking this protein, Tysabri® prevents inflammation. It is an immunosuppressive medicine,

which means it partially blocks the action of the immune system but does not turn it off completely. While there are some side effects, most people do not get more infections when taking this medicine.

### **What is alpha 4 integrin?**

Alpha 4 integrin is a protein that is found on white blood cells. The alpha 4 integrin protein helps white blood cells to latch onto the inside of a blood vessel and then move from the bloodstream into the cells of the gut and the brain. Once these white blood cells have moved into the gut and the brain they tend to cause inflammation.

### **What are the benefits of taking Tysabri®?**

Some people cannot take or do not get better with immunosuppressive medicines commonly used to treat Crohn's disease. Tysabri® may be effective in controlling the disease for these people. It has been shown to ease symptoms and bring about a remission in Crohn's disease. The rates for getting better are about the same as an anti-TNF medicine such as Remicade®.

### **How quickly does Tysabri® work?**

Most people see a response within 12 weeks. Tysabri® (300 mg) is given as an IV (intravenous) infusion over 1 hour every 4 weeks. This medicine works best if taken continuously. Increasing the time between treatments may give your body time to make its own antibodies against the medicine, which may reduce or even completely stop it from working. Always talk to your IBD doctor before changing your medicine intervals or if you intend to stop the medicine altogether. If you cannot taper off prednisone or budesonide without the return of symptoms, you must stop taking Tysabri®.

### **May I take Tysabri® with other medicines used to treat Crohn's disease?**

You may take an aminosalicylate while taking Tysabri®. Tysabri® should not be used together

with other immunosuppressive medicines, such as azathioprine, mercaptopurine, methotrexate, anti-TNFs, or with long-term use of steroids. Taking Tysabri® with other immunosuppressive medicines may increase your risk for serious infections, especially herpes infections. It also increases your risk for progressive multifocal leukoencephalopathy.

### **Is there anything I should avoid while taking Tysabri®?**

**Non-prescription products:** Do not take any over-the-counter herbal supplements with Echinacea or cat's claw because these reduce the effect of all immunosuppressive medicines, including Tysabri®.

**Prescription medicines:** Do not take other immunosuppressive medicines or medicines given to treat cancer with Tysabri®, unless directed to do so by your doctor. *Be sure you 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. Do not start a new medicine prescribed by a different doctor without telling your IBD doctor. Also, do not stop taking the medicines prescribed for you unless you discuss it with your IBD doctor first.*

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

Your doctor will ask you if you have any side effects while taking Tysabri®. Your doctor will likely recommend testing every 6 months to one year to see if you have been exposed to the JC virus since starting Tysabri®.

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

Some people who take this medicine don't have any side effects.

**Allergic reaction:** An allergic reaction to Tysabri® is not common. If you are allergic to Tysabri®, the reaction will usually happen right away. The signs

are hives, swelling of the face, lips, and tongue, shortness of breath, tightness of the chest and throat, and wheezing. Anaphylactic shock, where you faint or lose consciousness (vascular shutdown), is rare. If you have an allergic reaction to Tysabri®, the infusions must be stopped right away and you must be treated for the reaction. Do not take Tysabri® again.

**Infusion reaction:** You may experience an infusion-related reaction, which is a side effect that occurs within 2 hours of the start of an infusion. The signs include headaches, being lightheaded, joint and muscle aches, rash, flushing, and nausea. Your doctor may choose to give you Benadryl®, Tylenol®, and/or prednisone before your infusion to decrease these reactions.

**Somewhat common side effects:** Other possible side effects are depression, fatigue, diarrhea, upper and lower respiratory infections, and urinary tract infections.

**Rare side effect:** You will be monitored closely for signs and symptoms of liver damage. If you have elevated liver enzymes while taking Tysabri®, the medicine should be stopped.

#### **What are the risks of taking Tysabri®?**

**Resistance:** There is a risk that your immune system will make antibodies against Tysabri®. If this occurs, the medicine may be stopped because it becomes less effective.

**Infections:** Tysabri® can increase your risk for infections, especially serious herpes infections. Call your doctor immediately if you are exposed to chicken pox or measles. This risk is higher if you are taking another immunosuppressive medicine while you are taking natalizumab (Tysabri®). *You need to have a working thermometer at home 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*.

**NO LIVE VACCINES:** You should *NEVER* be given a live vaccine while you are taking any immunosuppressive medicines. These include *MMR (measles-mumps-rubella), varicella (chickenpox), rotavirus, oral polio, and yellow fever.*

**Progressive multifocal leukoencephalopathy:** Tysabri® increases the chance of getting a rare viral brain infection called progressive multifocal leukoencephalopathy (PML). This is caused by reactivation of the JC virus, a common virus to which many people have been exposed to in the past. A blood test will be checked to determine if you have been exposed to the JC virus before starting this medication. If you have not been exposed to JC virus, the risk of PML is about 1 of 10,000 people or 0.01%. If you have been exposed to JC virus, the risk of PML is about 1% after you have been treated with Tysabri® for 2 years. Symptoms of PML include imbalance, difficulty swallowing, trouble with speech, weakness or paralysis, vision loss, and difficulty thinking. It almost always causes death or severe disability. There is no treatment to reverse the brain damage caused by PML. Some treatments can stop it from getting worse and therefore decrease the risk of death. Even though the increased risk for PML is very small while taking Tysabri®, this infection is very serious. That is why you can only be given this medicine through a special program.

## Cyclosporine

### What is cyclosporine?

Cyclosporine is an immunosuppressive medicine used to treat severe ulcerative colitis that does not respond to steroids. It is most often used by people who have had a kidney, liver, or heart transplant, but it also can be used to treat autoimmune diseases such as rheumatoid arthritis, psoriasis, and IBD. Brand names for cyclosporine include Gengraf®, Neoral®, and Sandimmune®. Cyclosporine works by slowing down the action of a type of immune cell called a T lymphocyte. It partially blocks the action of the immune system, but it does not completely turn it off. While there are some side effects, most people do not get more infections when they start taking this medicine.

### What are the benefits of taking cyclosporine?

If you have a severe ulcerative colitis flare and do not improve with prednisone you may go into the hospital to be given an intravenous (IV) steroid such as Solu-Medrol®. If the IV medicine does not ease your symptoms, it is said that you have steroid-refractory disease. IV cyclosporine is often given to those with steroid-refractory ulcerative colitis because it leads to a remission 80% of the time. If you improve with cyclosporine, you may be able to avoid surgery to remove the colon (colectomy). Cyclosporine is usually given for 3 to 6 months as you make the change to a maintenance immunosuppressive medicine such as azathioprine. Cyclosporine has not been shown to maintain long-term remission.

### How quickly does cyclosporine work?

You can expect to get better in 5 to 7 days. If cyclosporine does not work, the next step may be surgery to remove the colon.

### How should I take cyclosporine?

If you are in the hospital for severe ulcerative colitis, you may start with IV (intravenous) cyclosporine and then move to an oral dose as soon as possible.

### Can I take cyclosporine with other medicines used to treat Crohn's disease and ulcerative colitis?

You can take 5-aminosalicylic acid (5-ASA) while you are taking cyclosporine. Cyclosporine is taken for about 3 to 6 months as a bridge to another immunosuppressive medicine. It is used with caution when given along with other immunosuppressive medicines, such as azathioprine, mercaptopurine, methotrexate, or with long-term use of prednisone because of the increased risk for infection. If your disease is so severe that you need cyclosporine, you will likely need to take prednisone along with azathioprine or mercaptopurine for 1-2 months as you transition to taking only azathioprine or mercaptopurine. As you make the change, you will take trimethoprim-sulfamethoxazole (Bactrim®) to prevent an infection called *Pneumocystis jirovecii* pneumonia. Taking cyclosporine with other immunosuppressive medicines for a long time may increase your risk for serious infections and also increase your risk for lymphoma. You and your doctor will consider risks and the benefits to choose the best plan for you.

### Are there medicines I should avoid while taking cyclosporine?

**Non-prescription products:** Do not eat grapefruit or drink grapefruit juice while taking cyclosporine because it makes the cyclosporine stronger. Do not take potassium supplements or eat foods, for example bananas, or salt substitutes that are high in potassium. 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 cyclosporine. Also avoid St. John's wort as it may decrease cyclosporine levels.

**Prescription medicines:** There are many medicines that interact with cyclosporine. Ask your doctor or pharmacist if your other medicines are safe to take



with cyclosporine. Common medicines to avoid while taking cyclosporine include ACE inhibitors, calcium channel blockers, carbamazepine, colchicine, fluconazole and other anti-fungals. Some other medicines to avoid while taking cyclosporine include aliskiren, amiodarone, barbiturates, cardiac glycosides, carvedilol, dabigatran etexilate, doxorubicin, ezetimibe, fentanyl, griseofulvin, HMG CoA reductase inhibitors, methotrexate, mycophenolate, natalizumab, NSAIDs, phenytoin, protease inhibitors, rifamycin derivatives, sirolimus, somatostatin analogues, tacrolimus, and temsirolimus. Do not stop taking the medicines prescribed for you unless you are advised to do so by your doctor. *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. Do not start a new medicine prescribed by a different doctor without telling your IBD doctor. Also, do not stop taking the medicines prescribed for you unless you talk to your IBD doctor first.*

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

You will have routine blood tests to check your electrolytes, such as potassium and magnesium, and your liver and kidney function, which may be affected by the medicine. The level of cyclosporine in your blood will be measured, as well as the levels of inflammatory markers and lipids. Your blood pressure will also be checked at each visit. It is common to have your blood work checked every week for 4 weeks then every 2 weeks for a month and monthly thereafter. Your dose of medicine may change based on your blood tests. A change in your dose may mean a change in the schedule of blood tests. Your doctor will keep a record of the results of your blood tests. Be sure to tell your doctor about any other medicines you are taking because they may affect the level of cyclosporine in your body.

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

**Allergic reaction:** You are unlikely to have an allergic reaction to cyclosporine when you first start taking it. True allergic reactions such as hives, swelling of the face, lips, and tongue, shortness of breath, tightness of the chest and throat, and wheezing are rare. Anaphylactic shock, where you faint or lose consciousness (vascular shutdown), is rare. If you have an allergic reaction, go to the emergency room or call 911.

**Common side effects include** headache, tremor, numbness, tingling, seizures, increased hair growth, kidney problems, high blood pressure, swelling of the feet or ankles or general swelling, leg cramps, upper respiratory infection, other infections, nausea, increased triglycerides, diarrhea, abdominal discomfort, and stomach upset.

**Uncommon side effects** include increased blood potassium, decreased blood magnesium, enlargement of gum tissue, pancreatitis (inflammation of the pancreas), and change in liver function.

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

**Kidney:** Poor kidney function, including kidney damage, may occur when cyclosporine is used at high doses. Your kidney function will be checked with a blood test.

**Liver:** Levels of liver enzymes and bilirubin may rise when cyclosporine is used at high doses. They usually go back to normal when the dose of medicine is reduced.

**Hypertension:** Your blood pressure will be closely monitored while you are taking cyclosporine.

**Seizures:** If you have low lipid (blood fat) levels you may be at risk for seizures.

**Lymphoma:** Because cyclosporine is an immunosuppressive medicine there is a small risk for getting lymphoma, which is a type of cancer. It is not clear if this risk is due to the medicine or to the IBD. You will be monitored closely while you are taking cyclosporine. 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 had cancer in the past.

**Infections:** There is an increased risk for infection, such as *Pneumocystis carinii* pneumonia. This risk is higher if you are taking another immunosuppressive medicine while you are taking cyclosporine. *You need to have a working thermometer at home 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*.

**NO LIVE VACCINES:** You should **NEVER** be given a live vaccine while you are taking any immunosuppressive medicines. These include *MMR (measles-mumps-rubella), varicella (chickenpox), rotavirus, oral polio, and yellow fever.*

*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.*

## **SURGERY FOR INFLAMMATORY BOWEL DISEASE**

### **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.

**Ileal pouch–anal anastomosis** – 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 and connecting it to a small amount of rectal tissue. An ostomy bag is worn for about 12 weeks so that the internal pouch can heal.

**Subtotal colectomy** – This involves removing most, but not the entire colon. The rectum or the rectum and part of the sigmoid colon (last 10–20 cm) are not removed.

### Crohn's Disease

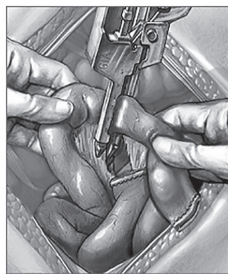
Possible reasons for surgery:

- Symptoms do not get better OR unable to tolerate medicine
- Complications, including strictures (narrowed areas of intestine), perforations, or bleeding
- Abscesses or fistulas 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 and the two healthy ends



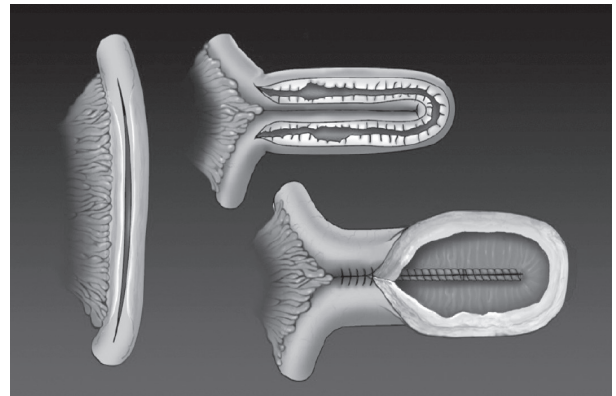
of the intestine are attached. Putting the two ends together is called an anastomosis.

*Photo: A.D.A.M.*

**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 into the abscess through the skin, or the abscess may be cut out with surgery.

**Strictureplasty** – 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.



*Reprinted with permission from the American Gastroenterological Association*

**Colectomy** – This involves removing the entire colon. Sometimes a permanent ileostomy is done. In selected, 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 selected, 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.

**Some information and tips:**

- Up to 70% of people with IBD will need surgery at some point.
- 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.**

Sometimes setons (silk string or rubber bands) and collagen plugs are used to treat perianal fistulas. Setons act like a wick to help a fistula continue to drain so that it does not form an abscess. 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.

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.

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.

Setons are used frequently as a supplement to medical therapy in patients with perianal fistulas.

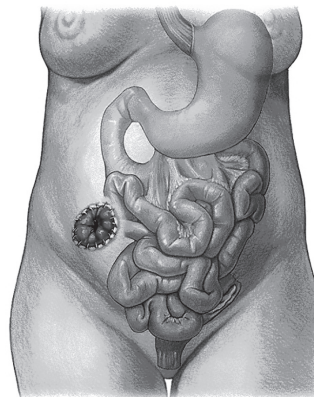
Plugs, glue, and advancement flaps are used rarely, primarily for patients with perianal fistulas that do not respond to conventional therapy. If you have any questions about these options, ask your doctor or nurse.

**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.

*Photo: A.D.A.M.*

**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.

#### ***The need for repeat surgery***

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.

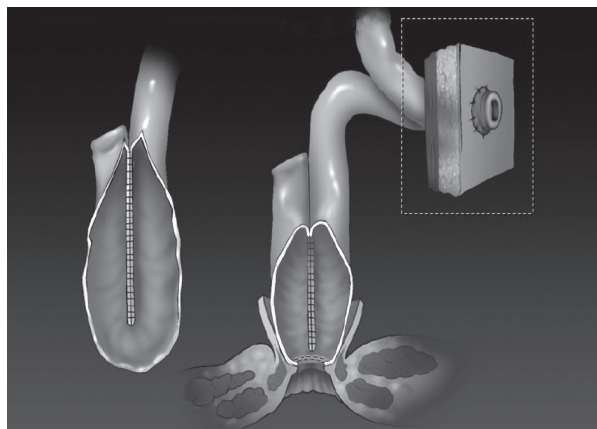
We will answer all of your questions before and after surgery. We want to do all that we can to make sure that both your quality of life and health are good after surgery.

#### ***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.

*Photo of J-Pouch*



*Reprinted with permission from the American Gastroenterological Association*

#### ***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 4 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 improves with time.
3. Inflammation of the J-pouch (pouchitis) occurs in 40% to 60% 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 with this surgery. It may be as low as 38% in the first years after 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.

### 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 (a randomization) 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.

### DIET AND INFLAMMATORY BOWEL DISEASE

#### Did my diet cause IBD?

No. 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, and the intestine stays inflamed. 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, and there is no proof that anything in a person's past diet caused his IBD.

### **How is food digested?**

Digestion is the process of breaking down food into smaller and smaller pieces so it can be used by the body or eliminated as waste. Here is how it happens: When the food you eat goes into your stomach, it is mixed with acid and enzymes (special proteins) that break it down into small pieces. Just past the stomach, in the small intestine, water is added as well as enzymes and bile from the pancreas and liver, which break these pieces down even more. The nutrients your body needs are absorbed through the lining of the small intestine into the blood vessels, where they travel through the bloodstream to the cells throughout the body. What cannot be digested in the small intestine (mostly watery food residue) moves into the large intestine, which is also called the colon. The colon absorbs and recycles much of the remaining water. The food residue is now solid (stool) and is passed from the large intestine as a bowel movement.

When the small intestine is inflamed in Crohn's disease, it is less able to fully digest and absorb the nutrients from food. This can lead to malnutrition because the nutrients pass through to the colon, causing watery diarrhea. When the large intestine is also inflamed, the diarrhea may become more severe.

In ulcerative colitis and Crohn's colitis (Crohn's disease affecting only the colon), the colon is inflamed and the small intestine continues to work normally. However, because the inflamed colon does not recycle water as it should, the diarrhea can be

severe. If the colon is very inflamed, proteins can leak out from the bloodstream into the stool. When the protein levels are very low in the bloodstream, fluid often leaks out into the soft tissues throughout the body, causing swelling. The swelling often starts in the lower legs and ankles.

### **Is IBD caused by allergies to foods?**

No. Although some people with IBD have allergies to certain foods, neither Crohn's disease nor ulcerative colitis is caused by food allergy.

### **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.

### **Can IBD be cured with a special diet?**

No. There is no proof that any diet will truly stop or prevent the inflammation of IBD. The goal is to try to eat a well-balanced, healthy diet. Healthy eating habits are good for everyone, but they are even more helpful for people with IBD. A healthy diet will give you the nutrients you need, which can help to heal the inflammation.

There are diets that have been shown to reduce the symptoms of IBD in some patients. These diets reduce the amount of different types of sugars in the diet that cause bacteria to create gas in the intestine, which can lead to pain, bloating, and cramping. The best proven diet is the FODMAP™ diet.

This diet was shown to reduce bloating and cramping in a well-done study among people with Crohn's disease. The FODMAP™ diet does not reduce inflammation, but does ease the symptoms. So, the bottom line is that it may be worthwhile to try the FODMAP diet, but be sure to keep taking your other medicines.

There are many other diets that are heavily marketed as a treatment or cure for IBD. There is no solid proof to support these claims. Some diets limit fermentable sugars, like the FODMAP™ diet, and may have similar benefits. Also, tell your health care team if you try a diet. They can help you to be sure that you are getting the nutrients your body needs.

An all-liquid diet of nutrients, called an elemental diet, has been shown to reduce inflammation in the intestine. It is usually given overnight through a tube that runs through the nose to the stomach. This approach eliminates eating all food by mouth for 8 to 12 weeks. It can improve symptoms and reduce inflammation, but it is very hard for most people to do.

### FODMAP™ Diet

#### What are FODMAPs?

- FODMAPs are Fermentable, Oligo-, Di-, Mono-saccharides, And Polyols in food.
- FODMAPs are short-chain carbohydrates (sugars) in food.
- FODMAPs are easily fermented by bacteria in the intestine.
- Fermentation is when bacteria in the intestine change sugar into alcohol and gas.
- When a lot of gas builds up in the intestine, it leads to crampy abdominal pain, bloating, increased belching, farting, and diarrhea.

#### Foods to AVOID:

- High in **fructose** – raisins, watermelon, apricots, honey, fruit juice, high-fructose corn syrup
- High in **fructans** – wheat, onions, artichokes, asparagus, green beans, leeks, garlic, inulin, legumes, lentils, soy,
- High in **lactose** – milk, yogurt, cheese, ice cream

- Contain **polyols** – apples, pears, plums, avocado, mushrooms
- Reduced **calorie sweeteners** – sorbitol, xylitol
- High in **raffinose** – legumes (peas, beans, lentils, carob), cabbage, Brussels sprouts
- **Wheat** as the *MAIN INGREDIENT* – bread, pasta, cereals, etc.

#### Foods to INCLUDE:

- **Wheat Alternatives** – Spelt, rice, corn, potato, oats, quinoa, non-wheat or gluten-free bread, pasta, and cereals
- **Sweetener Alternatives** – Maple syrup, jam, marmalade, peanut butter – these are all okay if they do not contain molasses or high-fructose corn syrup
- **Reduced Calorie Sweeteners** – Splenda®, Equal®, Sweet’N Low®

#### Fruits to INCLUDE:

- **Berries** – blueberries, blackberries, cranberries, raspberries, strawberries
- **Citrus** – kumquat, lemon, grapefruit, lime, orange, tangelo
- **Other** – banana, kiwi, pineapple, tomato
- **One portion** – honeydew melon, grapes

#### Vegetables to INCLUDE:

- Lettuce, spinach, celery, cucumbers
- Cauliflower, carrots, eggplant, turnips, green beans
- Corn, squash, sweet potatoes, potatoes, pumpkin, beets
- Olives, chili peppers
- **One portion** – broccoli



*Wheat products in small amounts, including wheat starch, thickeners, and caramel color, are OK!*

If the FODMAP™ diet reduces your symptoms, you may want to look at this book, *Low FODMAP™ Diet* by Sue Shepherd, ISBN 9780975195734.

### **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 intestinal motility (the movement of food through the digestive tract) and can cause diarrhea even among people with healthy intestines. Most people with IBD are able to tolerate moderate amounts of caffeine and alcohol in their diet.

A food diary can also show if your diet is providing the nutrients your body needs. You can review your food diary with your dietician to be sure that you are getting the recommended daily allowances (RDAs) for a person of your age, sex, and size. If not, the dietitian can suggest ways to change your diet so that you get what you need. That may mean increasing the amount of food you eat, changing what you eat, or adding vitamins or minerals to your diet.

Everyone needs enough calories, proteins, and nutrients in their diet. A balanced diet includes a variety of foods from all food groups. Meat, fish, poultry, and dairy products are sources of protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrate; butter and oils are sources of fat.

### **Do I need to avoid milk and dairy?**

Generally no. Lactose intolerance is not a part of IBD, so most people with IBD do not have to avoid foods that contain lactose (milk and dairy). Some people, especially those of Asian or African backgrounds, cannot tolerate lactose as they get older. However, they can often handle small amounts of dairy in their diet, and by taking lactase tablets with dairy foods they can often tolerate even more. Some people with Crohn's disease have severe flares that involve the duodenum (the first part of the small intestine), where lactose is digested. This inflammation can damage the lining of the intestine, and cause lactose intolerance for 1 to 3 months. This will resolve as the intestine heals.

This does not happen to people with ulcerative colitis or Crohn's colitis (Crohn's disease affecting only the colon) because the small intestine is not involved. If you think you are lactose intolerant, talk to your doctor. A lactose breath test, which is easy to do, is used to make the diagnosis. Your body needs dairy products because they provide calcium and vitamin D, as well as protein. Unless you have been told you have lactose intolerance, there is no reason to avoid milk and dairy products.

### **Do I need to avoid fiber?**

About 70% of people with Crohn's disease of the small intestine get a stricture (narrowing) of the intestine. When this happens, a low-fiber or low-residue diet may help to ease abdominal pain and other symptoms. This diet reduces the amount of food that cannot be digested (solid residue) in the stool. Foods to avoid include seeds, raw fruits, charred meats, and raw vegetables; especially apple peels and stringy roughage, like celery. These fibers are not digested and can tangle into a net and block or slow down the passage of other food through the part of the intestine with the stricture. Large, slowly digested pills (i.e. solid multivitamins or

some mesalamine products) should likewise be avoided. You will learn more about this diet at your clinic visit. It is likely that these changes in your diet will only be needed for a short time until the inflammation that caused the narrowing goes away.

It is important to note that many people with IBD do not have to worry about eating fiber, because they will not get strictures.

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

It is a good idea for all people with IBD to take a standard multivitamin every day. People with IBD who are doing well do 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. Vitamin D is absorbed in the small intestine. Vitamin D is needed to absorb the calcium from the diet, so it helps keep bones strong. A vitamin D supplement tablet in the range of 800 to 1,000 international units (IU) per day is needed, especially for those with active IBD and who live in the northern parts of the country. 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 IU daily).

Low iron levels are fairly common among people with IBD. It is caused by blood loss during inflammation, and by reduced iron absorption as a result of inflammation. Blood iron levels are easily measured. 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 after a large amount of the intestine is removed. 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 because they are lactose intolerant or because they think they are lactose intolerant. It can also happen to people who have enough calcium in their diets but do not absorb it as they should because of intestinal inflammation or because a large amount of the small intestine has been removed. In addition, medicines used to treat IBD may have a harmful effect on bone health. Long-term use of prednisone and other steroids, for example, slows the process of new bone formation and quickens the breakdown of old bone. It also interferes with calcium absorption. In addition to steroid use, Crohn's disease itself has been shown to be linked with bone thinning or osteoporosis. Therefore, screening with bone density studies (DEXA) is suggested for those at risk. People with bone loss should avoid steroids as much as possible to improve bone health. These people need to aim for at least 1,500 mg of calcium daily, either in food or in a pill taken three times during the day. 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?**

It is common to find that you 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. However, 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. If your urine is very yellow or you are not making much urine, you are likely dehydrated. Becoming lightheaded when you stand up quickly is a sign of severe dehydration. If this happens to you, drink additional fluids. If it does not get better, call your doctor or nurse or go to the nearest emergency room.

Although it may be hard to keep up your normal (about 2,000 calories) intake when you are feeling poorly, eating at least some food (about 1,000 calories) will help maintain the cells in the lining of your gut and also help heal ulcers. Many people switch to a bland diet or to an all-liquid diet during a flare. Bland foods like rice, toast, bananas, applesauce, and nutritional drinks like Carnation® Instant Breakfast™, Boost®, or Ensure® can help keep your caloric intake over 1,000 calories per day. A bland or all-liquid diet is only used during a flare. After a flare, slowly restart your normal diet (not a triple cheeseburger on the first good day). In the long term, be sure to eat a balanced diet with a wide variety of healthy foods to maintain your health.

### **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 in the form of products you can buy over the counter (for example, Ensure®). This diet can also be given via a feeding tube. This means 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 require 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.
- Limit FODMAP™ food sources.
- 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®.

#### **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.

- Limit FODMAP™ food sources.
- 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 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®.

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

- Keep using a low-residue diet and slowly add back a variety of foods.
- Begin with well-tolerated liquids and slowly move to soft solids, then solids (see below for liquid and solid food ideas).
- 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.

***Suggested first foods after a flare include:***

- Diluted juices
- Canned fruit
- Bread – sourdough or white
- Cooked eggs or egg substitutes
- Applesauce

- Oatmeal
- Mashed potatoes, white rice, or noodles
- Plain chicken, turkey, or fish

***Low-residue diet***

A low-residue diet limits the amount of fiber and other material that cannot be digested as it passes through your small intestine. A low-residue diet reduces the size and number of your stools and helps relieve abdominal pain and diarrhea.

***Foods to include during a flare:***

- Refined breads, cereals and pasta (with less than 1 gram of fiber in each serving)
- White rice
- Tender meat, poultry, fish and eggs
- Oil, margarine, butter, and mayonnaise
- Smooth salad dressings
- Broth-based soups (strained)
- Jelly, honey, syrup

***Foods to avoid during a flare or if a stricture is present:***

- Whole-grain breads, cereals, and pasta
- Whole vegetables and vegetable sauces
- Whole fruits, including canned fruits
- Yogurt, pudding, ice cream, or cream-based soups with nuts or pieces of fruits or vegetables
- Tough or coarse meats with gristle and luncheon meats or cheese with seeds
- Peanut butter
- Salad dressings with seeds or pieces of fruits or vegetables
- Seeds or nuts
- Coconut
- Marmalade

## **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. The FDA was created in 1913 to put an end to 'snake oil' salesmen and keep the public safe, but food supplements are not monitored by the FDA.

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.

A lot of probiotic research is now being done and some probiotics may be shown to be safe and effective for IBD in the future. At this point, trying probiotics on your own is probably not effective unless it is being used for the treatment of pouchitis or to prevent antibiotics associated diarrhea or recurrent *C. Difficile* infection. In rare cases, the probiotics may actually be harmful. In addition, probiotics are often expensive, so may be incurring out of pocket expenses without much benefit to you.

#### **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. A few small studies showed modest benefits with 4 to 5 grams per day. However, a larger study showed no benefit. 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. In animal studies, these oils seem to have some benefit for the immune cells. However, clinical studies have not always found the same effect in people.

Bottom line – fish oil has not been proven to help treat patients with IBD. 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 aloe vera help IBD?**

One small clinical study with 44 people who have ulcerative colitis showed that aloe vera gel (100 mL)

taken twice a day for 4 weeks had a modest benefit. This good effect has not been shown again, but it still may be of benefit. The form of aloe vera gel used in the study is not the same as what is usually sold in stores. Aloe vera juice, which is often seen, has a laxative effect and is therefore a problem for people who have diarrhea. Side effects of aloe vera include bloating, foot pain, sore throat, ankle swelling, acne, and eczema worsens.

Aloe latex (may be called aloe juice) contains strong laxative compounds. At one time, the FDA regulated laxative products with aloe as over-the-counter (OTC) laxatives. In 2002, the FDA ruled that all OTC aloe laxative products be removed from the U.S. market or be made without the aloe latex because the companies did not provide the needed safety data. At this time, aloe products are not regulated by the FDA so it is hard to tell if a product truly contains aloe vera gel or the laxative aloe latex.

#### **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/>. In addition, the University of Maryland has a Center for Integrative Medicine. Information on the center and how to make an appointment can be found at <http://www.compmed.umm.edu>.

# MAINTAINING MY HEALTH



## MY INFORMATION

Name \_\_\_\_\_ Medical Record Number \_\_\_\_\_

Primary Care Physician \_\_\_\_\_

Referring Physician \_\_\_\_\_

My Address \_\_\_\_\_

My email address \_\_\_\_\_

### My Phone Numbers

Cell \_\_\_\_\_ Home \_\_\_\_\_ Work \_\_\_\_\_

### Emergency Contact

Names \_\_\_\_\_ Emergency Contact Phone Numbers \_\_\_\_\_

1. \_\_\_\_\_

2. \_\_\_\_\_

### My Health Insurance and Pharmacy Information

Insurance Company: \_\_\_\_\_

Insured Person's Name: \_\_\_\_\_

Patient's Name: \_\_\_\_\_

Group Number: \_\_\_\_\_

Pharmacy Phone Number: \_\_\_\_\_

**Note: Ask your doctor for a 3-month prescription if you do mail order**

*If any of your information changes, please call our administrative offices:  
410-706-3387 • Monday to Friday 8am to 4:30pm*

## MY APPOINTMENT PLANNER

DATE	TIME	APPOINTMENT TYPE	APPOINTMENT LOCATION	DO I NEED TO BRING OUTSIDE RECORDS?	REFILLS NEEDED?	DO I NEED A DRIVER FOR THIS APPOINTMENT?
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO
				YES   NO	YES   NO	YES   NO



**MY MEDICINES**

MEDICINE	STRENGTH (example, milligrams or mg)	NUMBER TAKEN AT A TIME (example, 2 tablets)	FREQUENCY (example, 3 times per day)	START DATE	END DATE	WHY STOPPED?

**PLANNING FOR MY NEXT VISIT**

<b>QUESTIONS AND CONCERNS</b>	<b>ANSWERS AND COMMENTS</b>

**BATHROOM (BOWEL MOVEMENT) TRACKER**

DATE	TIME	CONSISTENCY (hard/soft/liquid)	URGENCY?	BLOOD PRESENT? AMOUNT?	MUCUS PRESENT?

## PREDNISONE TAPER SCHEDULE

DOSE	START DATE?	END DATE	NUMBER OF DAYS
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			
_____ mg prednisone by mouth daily			

**CHARACTERISTICS OF MY INFLAMMATORY BOWEL DISEASE (IBD)**

**What type of IBD do I have?**

If you are not sure, ask your doctor. This is important for you to know.

- Ulcerative colitis
- Crohn's disease
- Indeterminate colitis or IBD type undetermined
- I don't know

**Where is the location of my IBD?**

If you are not sure, ask your doctor. This is important for you to know.

SEGMENT OF GASTROINTESTINAL TRACT	YES	NO
Esophagus		
Stomach		
Duodenum		
Jejunum		
Ileum		
Ascending (right) colon		
Transverse colon		
Descending (left) colon		
Sigmoid colon		
Rectum		

## SURGERY ON MY GASTROINTESTINAL (GI) TRACT

DATE	HOSPITAL NAME	WHY WAS SURGERY DONE?	WHAT SEGMENT(S) OF INTESTINE WAS REMOVED? LENGTH REMOVED (IN. OR CM.)?	HOW WAS THE INTESTINE RECONNECTED?
		<input type="checkbox"/> inflammation <input type="checkbox"/> scarring or blockage <input type="checkbox"/> adhesions <input type="checkbox"/> other		<input type="checkbox"/> not connected <input type="checkbox"/> ileostomy <input type="checkbox"/> colostomy <input type="checkbox"/> connected <input type="checkbox"/> J pouch ----- connected to -----
		<input type="checkbox"/> inflammation <input type="checkbox"/> scarring or blockage <input type="checkbox"/> adhesions <input type="checkbox"/> other		<input type="checkbox"/> not connected <input type="checkbox"/> ileostomy <input type="checkbox"/> colostomy <input type="checkbox"/> connected <input type="checkbox"/> J pouch ----- connected to -----
		<input type="checkbox"/> inflammation <input type="checkbox"/> scarring or blockage <input type="checkbox"/> adhesions <input type="checkbox"/> other		<input type="checkbox"/> not connected <input type="checkbox"/> ileostomy <input type="checkbox"/> colostomy <input type="checkbox"/> connected <input type="checkbox"/> J pouch ----- connected to -----
		<input type="checkbox"/> inflammation <input type="checkbox"/> scarring or blockage <input type="checkbox"/> adhesions <input type="checkbox"/> other		<input type="checkbox"/> not connected <input type="checkbox"/> ileostomy <input type="checkbox"/> colostomy <input type="checkbox"/> connected <input type="checkbox"/> J pouch ----- connected to -----

### MONITORING MY LABORATORY TESTS

If you are not able to get your lab tests done on time, call your nurse.

DATE TESTS	TIME	DATE LABS	APPOINTMENT LOCATION

Please call your nurse if you have any questions about monitoring your lab tests.

## PREVENTING COMPLICATIONS BY MONITORING MY IBD MEDICINES

If you take an immunosuppressive medicine such as azathioprine, mercaptopurine, 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.

## 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 [Imuran®] and mercaptopurine [Purinethol®]) 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 (Remicade®), adalimumab (Humira®), certolizumab pegol (Cimzia®), and golimumab (Simponi®), 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 vaccine** (Pneumovax®) 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. This vaccine is advised for all adults age 65 and older and also for anyone who is taking immunosuppressive medicines (including prednisone). A booster is given at 5 years.

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 new, high dose, flu vaccine should be considered for patients 65 years of age and older and for patients on immunosuppressive medications.

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. It often comes in a form that combines both hepatitis A and hepatitis B vaccines in a single shot (although it is still three [3] shots total). This vaccine is inactivated and safe to get while taking immunosuppressive medicines.

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.

**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. However, because these vaccines are made of the live virus, they may not be safe for someone who is taking immunosuppressive medicines or biologics. It is best to have one of these vaccines at least 2 months after stopping an immunosuppressive medicine, and to not start taking immunosuppressive medicine for about 2 months after having one of these shots.

**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.

### **Vaccination plan**

**Childhood:** MMR, polio, rotavirus, Hib, Tdap, chickenpox, and hepatitis A and B long before immune suppressed

**Adolescence:** meningitis, Tdap, hepatitis B, and Gardasil.

**At diagnosis of IBD:** Consider a flu shot, Pneumovax, Shingles vaccine, and any other immunizations that are not up to date. Avoid live vaccines if it is anticipated that immunosuppressive medications and/or biologics will be started in the next two months. It is wise to check on coverage of these vaccines by your insurance plan before undergoing the vaccinations.

### **Other vaccines**

In special situations, you may consider having these other vaccines:

**Rabies** – Veterinarians, animal handlers, cave explorers, or after an animal bite

**Anthrax** – Anthrax laboratory workers, military personnel

**Tdap (tetanus/diphtheria/pertussis)** – Children (adults should have a Td booster shot every 10 years or deep wound. At least one of these booster shots needs to be Tdap).

**Hepatitis A** – Travel in Central or South America, Mexico, Asia (except Japan), Africa, and Eastern Europe; men who have sex with men; people who use street drugs; people with chronic liver disease; people treated with clotting factor concentrates; hepatitis A lab workers; also part of routine childhood shots

**Hib (Haemophilus influenzae type B)** – Children younger than 5 years; people without a spleen; people with sickle cell disease or HIV

- **Japanese encephalitis virus\*** – Travel in rural Japan
- **MMR\* (measles/mumps/rubella)** – Anyone born after 1956
- **Meningitis** – College freshmen, military recruits, children, travelers to Africa, people with a damaged spleen
- **Rotavirus\*** – Babies
- **Smallpox\*** – Military personnel
- **Live typhoid\*** – Travel to Africa
- **Varicella (chickenpox)\* Varicella (shingles)\*** – Children and adults who have not had chickenpox. Adults who are 60 or older
- **Yellow fever\*** – Travel to areas with yellow fever

#### 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 immunosuppressive medicines or biologics. The five vaccines that only come in live forms should be given at least 2 months before starting to take an immunosuppressive medicine or biologic (for example, prednisone, azathioprine, methotrexate, Remicade®, Humira®, Cimzia®, Simponi®, Tysabri®). Live vaccines should not be given while you are taking immunosuppressive medicines or biologic, or within 2 months after these medicines are stopped. The inactivated form should be used instead whenever possible. If you are taking an immunosuppressive medicine or biologic tell your primary care doctor before you get any shots.

#### 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) – these vaccines are used in children and adults to prevent chickenpox and shingles respectively. Remember, these are live vaccines and should not be given if you are on steroids, immune suppressants or biologics.
- **MMR** (measles, mumps and rubella) – this vaccine is used in children only and as a booster for health care workers who have negative titer
- **Rotavirus** – this vaccine is used in children only
- **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

## Vaccinations

VACCINE	DATE	RECOMMENDED
Influenza (flu)	_____ _____ _____	Annually for everyone on immunosuppressive medicine or biologics **If taking immunosuppressive medicine, only get the flu shot, which is inactivated, not the nasal spray, which is live. Consider the high dose flu shot.
Pneumovax® (pneumonia)	_____	Everyone 65 years and older, and at any age if taking immunosuppressive medicine Booster 5 years later
Hepatitis B	_____ _____ _____	Everyone Series of 3 shots at 0, 1, and 6 months
Td or Tdap(tetanus, diphtheria, pertussis)	_____ _____	Booster shot (Td) for everyone, every 10 years (at least once with Tdap for adults)
Varicella*** (chickenpox)	_____	If never had disease in childhood
Varicella*** (shingles)	_____	Advised for everyone 60 years and older to boost immunity
Oral typhoid*** Yellow fever***	_____ _____	Travelers to Africa, South America
Smallpox***	_____	Military personnel
Meningitis	_____	College freshmen, military recruits

\* Live vaccine - not recommended while taking immunosuppressive medicines

## SMOKING AND INFLAMMATORY BOWEL DISEASE

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, attend a smoking cessation program, or request to see our certified smoking cessation counselor in the Digestive Health Center (Dora Frank, CRNP).

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

## TUBERCULOSIS (TB) AND HEPATITIS B TESTS (REQUIRED BEFORE TAKING AN ANTI-TNF MEDICINE)

DATE	TEST	RESULTS (negative or positive)
_____	<input type="checkbox"/> TB skin test	_____
_____	<input type="checkbox"/> QuantiFERON® - TB blood test	_____
_____	<input type="checkbox"/> Hepatitis B surface antigen	_____
_____	<input type="checkbox"/> Hepatitis B surface antibody	_____

## 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 melanoma whereas patients on biologics 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 are 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. Up to 40% of the general population and 70% of patients with IBD have low levels of vitamin D.

#### **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. These include chronic inflammation, side effects of medicines used for IBD (especially steroids like prednisone), low ability to absorb calcium and vitamin D, and lack of exercise during times of flares. Small bowel surgery and liver disease (such as primary sclerosing cholangitis) also increase the risk for low bone density. People who develop pouchitis (inflammation where the small bowel is connected to the anus) after surgery are also at risk for low bone density.

#### **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.

This DEXA scan compares your bone density with bone densities of a large group of younger people. The test result is written as a T score for middle age and older adults. A T score between -1.5 and -2.5 represents osteopenia, which is the stage of bone loss that occurs before osteoporosis. Osteoporosis is a T score of less than -2.5. Bone density is usually measured in the spine and hip (with the hip being the most important area). There is a different standard of measurement for children and young adults called a Z score.

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

You may have a blood test to check your vitamin D level. The normal result is 30 to 74 nanograms per milliliter (ng/mL) for a 25-hydroxyvitamin D test. 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.

#### ***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, sesame or sunflower seeds, and dried figs. Some products, such as orange juice, are fortified with calcium. For a comprehensive list of calcium content in foods, go to this web page: <http://www.ars.usda.gov/services/docs.htm?docid=9673>
- Calcium pills – 1,200 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.
  - » Mostly work to prevent further bone loss.
  - » Bisphosphonates are usually used for women after menopause or for women with osteoporosis caused by steroid medicines. Alendronate (Fosamax®) or risedronate (Actonel®) are the most common for adults. Intravenous (IV) infusions or shots of bisphosphonates may be used for people who cannot tolerate oral medicines or who have severe bone loss or fracture.
  - » Teriparatide (Forteo®) – This medicine causes new bone to be formed. Teriparatide is a synthetic form of the parathyroid hormone. It is used by patients with multiple risks for fracture or who have had broken bones in the past. A bone specialist (endocrinologist) usually monitors this medicine, which can be used for up to 2 years.
  - » Denosumab (Prolia®, Xgeva®) – This medicine is a biologic that binds a molecule called RANKL. Blocking this molecule reduces the formation of

cells that breakdown bone. This drug has been shown to increase bone density and to prevent fractures in post-menopausal women.

***Risks associated with treatment for osteoporosis***

Most people with IBD are young, so the risk for fracture is usually low. Bisphosphonates are rarely used among women who could become pregnant because these medicines may affect the unborn baby. A rare complication of these medicines is osteonecrosis (dying bone tissue) in the jaw. This occurs most commonly with intravenous bisphosphonates and at the same time as dental work, injury to the jaw, or infection. As much as possible, major dental work needs to be done before taking bisphosphonates and avoided while taking bisphosphonates.

**Bone Health Tracker**

**Steroid (prednisone, Solu-Medrol®) History**

I have taken steroids for \_\_\_\_\_ months of my life.

If you have taken steroids for more than 3 months, ask your doctor if you need a bone density scan (DEXA).

Vitamin D blood test results

DATE	LEVEL

**Medicines used to increase bone density:**

Calcium: 1,200 to 1,500 mg by mouth daily

Vitamin D: \_\_\_\_\_ international units (IU) taken daily, twice daily, or monthly (circle one)

Bisphosphonates:

- Alendronate (Fosamax®): \_\_\_\_\_ mg taken daily or weekly
- Risedronate (Actonel®): \_\_\_\_\_ mg taken daily, weekly, or monthly
- Ibandronate (Boniva®): \_\_\_\_\_ mg taken daily or monthly
- Zoledronic acid (Reclast®): \_\_\_\_\_ mg taken yearly.
- Other: \_\_\_\_\_ : \_\_\_\_\_ mg taken \_\_\_\_\_

DEXA scan resultst

DATE	T SCORE	Z SCORE	INTERPRETATION
			<ul style="list-style-type: none"> <li>• Normal</li> <li>• Osteopenia</li> <li>• Osteoporosis</li> </ul>
			<ul style="list-style-type: none"> <li>• Normal</li> <li>• Osteopenia</li> <li>• Osteoporosis</li> </ul>
			<ul style="list-style-type: none"> <li>• Normal</li> <li>• Osteopenia</li> <li>• Osteoporosis</li> </ul>

## PREVENTING COLON CANCER

Some people with IBD have a slightly higher risk for colon cancer than those without IBD. The exact risk is not known, but new studies suggest that the risk is lower than had been thought in the past. Not everyone with IBD has the same risk for colon cancer. 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 and/or sigmoid colon 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 have a “chemopreventive” effect, meaning that they 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®). Azathioprine has also been shown to reduce your risk of colon cancer over time. Ask your doctor about new advances in this area.
5. If you have Crohn’s disease with inflammation involving more than 1/3 of your colon you may be at increased risk for colon cancer. Patients with Crohn’s disease that does not involve more than 1/3 of the colon are not at increased risk for colon cancer.
6. Ask your doctor if you have an increased risk of colon cancer because you have IBD.



### Preventing Colon Cancer Tracker

My colon  is  is not affected by IBD.

It has been \_\_\_\_\_ years since I started having symptoms of IBD.

- I have a family history of colon or rectal cancer.
- I have primary sclerosing cholangitis (PSC).
- I have had low-grade pre-cancerous cells (dysplasia) in the colon.
- I have had high-grade pre-cancerous cells (dysplasia) in the colon.

### What part of my intestine is affected by IBD?

- Only the rectum and/or sigmoid colon is affected (no increased risk for colon cancer).
- The rectum, sigmoid, and the left colon are affected (left-sided disease).
- The left colon, the transverse colon and possibly the right colon, are affected (extensive disease).

### For Crohn's disease:

- Less than one third of my colon is affected by Crohn's disease
- more than one third of my colon is affected by Crohn's disease

### Surveillance Colonoscopy Results

DATE	RESULTS	INTERVAL FOR NEXT SURVEILLANCE COLONOSCOPY
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	1 to 3 years, 6 months or when inflammation improved, 6 months (colectomy preferred), 3 months (colectomy preferred)
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	1 to 3 years
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	6 months or when inflammation improved
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	6 months (colectomy preferred)
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	3 months (colectomy preferred)
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	1 to 3 years
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	6 months or when inflammation improved
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	6 months (colectomy preferred)
	<input type="checkbox"/> No dysplasia <input type="checkbox"/> Indeterminate <input type="checkbox"/> Low-grade dysplasia <input type="checkbox"/> High-grade dysplasia	3 months (colectomy preferred)

## PREVENTING CERVICAL CANCER (FOR WOMEN)

### Risk factors:

- I no longer have a cervix OR I am older than 65.
- I am not taking any immunosuppressive medicines or biologics.
- I have been vaccinated for human papilloma virus (HPV).
- I have human papilloma virus (HPV) in my cervix.
- I have had an abnormal pap smear.
- I have had cervical cancer.
- I have never had a pap smear.

### Pap smear Surveillance Results

DATE	RESULT	INTERVAL FOR NEXT PAP SMEAR
	<input type="checkbox"/> Normal, not taking immunosuppressive medicine <input type="checkbox"/> Normal, not taking immunosuppressive medicine, but abnormal Pap smear in last 5 years <input type="checkbox"/> Normal, taking immunosuppressive medicine <input type="checkbox"/> Abnormal	
	<input type="checkbox"/> Normal, not taking immunosuppressive medicine <input type="checkbox"/> Normal, not taking immunosuppressive medicine, but abnormal Pap smear in last 5 years <input type="checkbox"/> Normal, taking immunosuppressive medicine <input type="checkbox"/> Abnormal	
	<input type="checkbox"/> Normal, not taking immunosuppressive medicine <input type="checkbox"/> Normal, not taking immunosuppressive medicine, but abnormal Pap smear in last 5 years <input type="checkbox"/> Normal, taking immunosuppressive medicine <input type="checkbox"/> Abnormal	
	<input type="checkbox"/> Normal, not taking immunosuppressive medicine <input type="checkbox"/> Normal, not taking immunosuppressive medicine, but abnormal Pap smear in last 5 years <input type="checkbox"/> Normal, taking immunosuppressive medicine <input type="checkbox"/> Abnormal	

## SEXUAL HEALTH AND CHILDBEARING ISSUES IN IBD



### SEXUAL HEALTH AND INFLAMMATORY BOWEL DISEASE

#### 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. Also, 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, 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 (PAP smear) and getting the HPV vaccine (see *Vaccines* in the section *Maintaining My Health*), 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 and 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 an abortion or of birth defects is higher for women who become pregnant while taking methotrexate. These risks also apply to men taking methotrexate because this medicine can alter the DNA in sperm. 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, abscesses, and perforations. These are severe and need special treatment and maybe even surgery. Surgery during pregnancy may harm both the mother and her baby.

### **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.

### **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. Therefore, 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, which is made of foreign cells. Remember, experts believe that the key problem in IBD is that the body's immune system fails to "turn off," which leads to unchecked inflammation. As a result, many women with IBD seem to get better from the "turning off" of the immune system that normally happens in pregnancy. Some women have flares shortly after giving birth when the immune system returns to normal. Of course, symptoms do not improve for every pregnant woman with IBD.

### **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. Therefore, 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

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

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

- Category A includes medicines like 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 (NOTE: What about other biologics? Shouldn't we list these? It is not really new) (Remicade®), a fairly new drug, is also category B, and has been safely used in pregnancy and during conception. 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 causes problems during pregnancy. However, 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, they have been used by large groups of people and found to be of very little risk. These groups include people with kidney transplants, autoimmune liver disease, and IBD. If you do not feel okay about taking these medicines, talk with your doctor. Together you will come up with the best and safest plan for you and your baby.
- 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. This means that **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, or anti-TNF medicines. Methotrexate is **NEVER** to be taken while breast-feeding.

### **GENETIC RISK FOR INFLAMMATORY BOWEL DISEASE IN CHILDBEARING**

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

Experts are still trying to figure out the exact cause of IBD. At this time there seems to be more than one cause. Your genes may play a role, and also 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%. This means that 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.

For more information, ask one of our nurses or providers about the University of Maryland Prenatal Genetics Counseling Program and the High-Risk Obstetrics Service.

## RESOURCES



### UNIVERSITY OF MARYLAND CROHN'S & COLITIS PROGRAM WEB SITE

<http://www.umm.edu/ibd>

The Crohn's & Colitis Program web site has many useful resources:

- Useful information about the treatment of the disease: [http://www.umm.edu/ibd/treat\\_options.htm](http://www.umm.edu/ibd/treat_options.htm)
  - Facts about IBD for friends and families
  - Facts for students with IBD
  - A glossary of some of the medical terms we use when talking about IBD
  - Details about clinical research studies
  - Facts about IBD research at the University of Maryland, including the research web sites of our faculty members
  - IBD Newsletter – a newsletter for patients published three times a year.
  - Webcasts of lectures on IBD
  - How to make an appointment (for patients)
  - How to refer a patient for an appointment (for physicians)
1. **IBD Symposium Lectures** – Versions of these lectures are provided online: <http://www.umm.edu/ibd/symposium-10.htm>
  2. **Patient Success Stories** – <http://www.umm.edu/ibd/success.htm>
  3. **UMD IBD Clinical Trials Website** – <http://www.umm.edu/ibd/research.htm#clinical>
  4. **IBD Program Patient Health Education Seminars** – [http://www.umm.edu/ibd/ibd\\_health\\_seminars.htm](http://www.umm.edu/ibd/ibd_health_seminars.htm)

### CROHN'S & COLITIS FOUNDATION OF AMERICA (CCFA)

The Crohn's & Colitis Foundation of America (CCFA) 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.

The CCFA 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 [www.cdfa.org/irc](http://www.cdfa.org/irc) provides information, support, and guidance on Crohn's and colitis. Call between 9 AM and 5 PM eastern time on weekdays 1-888-MY GUT PAIN (1-888-694-8872). Interpreters are available for more than 20 languages.
- Information about the Maryland/Southern Delaware Chapter can be found at <http://www.cdfa.org/chapters/md-southde/>
2. Maintains Disease Information web pages at [www.cdfa.org/info](http://www.cdfa.org/info) with information about tests, medications, and treatment options in IBD.
  3. The Maryland/Southern Delaware Chapter run an annual fundraising walk (Take Steps) in the spring and an annual fundraising Spotlight gala in the fall.
  4. Puts together educational workshops and symposia, and a scientific journal, Inflammatory Bowel Diseases, to help medical professionals to keep pace with the newest research discoveries in IBD.
  5. Funds cutting-edge studies at major medical institutions, and nurtures investigators with grants at the early stages of their careers.

6. Conducts a national research meeting each year, Advances in IBD, to promote the exchange of new research findings in Crohn's disease and ulcerative colitis.

**Find out more at <http://www.ccfa.org>.**

### **MARYLAND SUPPORT GROUPS**

**Please note:** All support group listings are subject to change. We suggest calling the contact person ahead of time as meetings may be changed or cancelled.

This is an ongoing support group open to all Crohn's disease and ulcerative colitis patients. The support group provides patients, their families and friends an opportunity to talk with others who are going through similar experiences.

**Date:** 1st Thursday of every other month

**Time:** 6:30 p.m.-7:30 p.m.

**Where:**

UMMC Patient Resource Center  
First Floor, Gudelsky Building  
22 S. Greene St.  
Baltimore, MD

Meetings will be cancelled if there are no confirmed attendees. For more information contact Dora Frank at 410-706-2877. Please RSVP to support group leader Laura Stephens at [LauraS@verizon.net](mailto:LauraS@verizon.net).

<http://www.umm.edu/ibd/ibdsupport.htm#ixzz2Chm0YmBi>

### **RECOMMENDED BOOKS ABOUT INFLAMMATORY BOWEL DISEASE**

If you want to learn even more about Crohn's disease and ulcerative colitis, please visit the CCFA bookstore where you will find a list of books recommended by CCFA staff and volunteers (<http://www.ezpromostore.com/ccfaretail/bookstore/>).

### **CLINICAL RESEARCH AT THE UNIVERSITY OF MARYLAND**

Physicians in the University of Maryland Medical Center's Inflammatory Bowel Disease (IBD) Program are actively involved in clinical research. For more information about current clinical trials or past publications, please visit <http://umm.edu/programs/ibd/research>.

### **USEFUL WEB SITES**

- **University of Maryland, Division of Gastroenterology and Hepatology:** <http://www.umm.edu/gi/>
- **University of Maryland, Crohn's & Colitis Program:** <http://www.umm.edu/ibd/>
- **IBD Program Faculty and Videos:** [http://www.umm.edu/ibd/phy\\_staff.htm](http://www.umm.edu/ibd/phy_staff.htm)
- **Crohn's & Colitis Foundation of America (CCFA):** [www.ccfa.org](http://www.ccfa.org)
- **Centers for Disease Control and Prevention:** [www.cdc.gov](http://www.cdc.gov)