CROHN'S & COLITIS FOUNDATION OF AMERICA

Diagnosing and Managing IBD

What's Inside?

When you or a family member experience severe gastrointestinal symptoms that do not respond to over-the-counter treatments or resolve on their own, you know that you need to get help quickly. While patients will often see their primary care provider first, sometimes it is necessary to see a specialist in gastrointestinal disease (a *gastroenterologist*) to aid in making a diagnosis and initiating proper treatment. If there is a reasonable suspicion of inflammatory bowel diseases (IBD), such as Crohn's disease or ulcerative colitis, it is best to seek out a gastroenterologist who specializes in treating IBD. CCFA can help you identify such a physician in your local area through our website, www.ccfa.org.

If your health plan does not provide access to a gastroenterologist, find a primary care provider with the most experience in diagnosing gastrointestinal (GI) illness. These health care providers can refer you for the tests and procedures discussed in this brochure, which will be the basis for making your diagnosis, finding the best therapies, and managing your condition.

Finding out if you have IBD may require many tests, including blood work, colonoscopy with biopsies, and radiology (X-ray) tests. This brochure explains which tests you may need to undergo to make a clear diagnosis, as well as to monitor the ongoing status of your Crohn's disease or ulcerative colitis. Although it is not possible to cover every diagnostic test in a brochure, the most common tests have been included. If you have a question about a test not mentioned here, contact CCFA for more information at www.ccfa.org or 1.888.694.8872 (MY. GUT.PAIN).

Finding out if you have IBD

Crohn's disease (CD) and ulcerative colitis (UC) belong to a group of conditions known as inflammatory bowel diseases (IBD).

IBD also includes indeterminate colitis (IC), a term used when it is not clear if inflammation is due to Crohn's or colitis, constituting about 15% of all cases. It is unclear why people get IBD, however, research shows that a combination of genes, an overactive immune system, and environmental factors all play a role.

Many new treatments have made IBD more manageable today than it was only ten years ago. It is important to bear in mind that IBD is a chronic illness and requires proactive care. Successful disease management begins with an accurate diagnosis and assessment of disease activity, including its precise location in the gastrointestinal tract. Choices for both medical and surgical treatment options will be guided by ongoing clinical and diagnostic monitoring. As you learn about the diagnostic tests and procedures, you will also become familiar with the tools that will help manage IBD for the long term.

Crohn's disease or ulcerative colitis?

Crohn's disease may involve inflammation in any part of the gastrointestinal tract (from mouth to anus) while ulcerative colitis is confined to the large intestine (the colon and rectum). Some of the medications available for treatment can be used for either ulcerative colitis or Crohn's disease, however, some medications are used

for *only* Crohn's disease or *only* ulcerative colitis. Also, some medications are used for cases involving specific areas of the intestinal tract. Your physician will need to locate the sites of active disease and complications to help select the most effective therapies for your IBD.

Could it be something else?

Typical symptoms of IBD include abdominal pain, cramping, diarrhea, rectal bleeding, and extreme fatigue. These are the result of inflammation of the intestine and may be similar in both Crohn's disease and ulcerative colitis.

In 25-40% of patients, the classic signs and symptoms of IBD may be accompanied by symptoms in the eyes, joints, skin, bones, kidneys, and liver. These non-bowel symptoms are called *extraintestinal manifestations* or EIMs. Children who develop IBD often experience growth problems, without outward signs of an inflamed bowel.

Because the gut has only a limited number of ways to show distress, many of the above symptoms of IBD are non-specific and could also be related to other gastrointestinal condi-

tions. These include: infectious gastroenteritis, traveler's diarrhea, celiac sprue, gallbladder disease, pancreatitis, stomach ulcers, irritable bowel syndrome (IBS), and colorectal cancer. Ruling out other possible diseases is part of the diagnostic process, starting with patient history and physical examination.

Patient history and physical exam

The first diagnostic step will be taken during your initial doctor's office visit. A gastroenterologist (or pediatric gastroenterologist, if the patient is a child) is the most qualified healthcare specialist to diagnose IBD. You will need to provide as much information as possible about your symptoms and when they occur. It helps if you can keep a diary listing your symptoms, including bowel movements, bleeding episodes, waking up at night from pain or diarrhea, fevers, joint aches, or other symptoms. The diary should include when symptoms started, how often they occur, how long they last, and what makes them better or worse.

Genes and genetic testing

It also helps to investigate the family tree to identify relatives who may have had IBD or other serious, chronic GI issues. Having an immediate family member with IBD is the number one risk factor for developing Crohn's disease or ulcerative colitis, although most patients with IBD do not have a family history of IBD.

However, there is evidence that suggests genetic testing may play a role in identifying a Crohn's patient's likelihood of developing complications over time. Therefore genetic testing may aid your physician in making appropriate treatment decisions.

The diagnostic process

Your physician will take your history and perform a physical exam.

The physical exam will focus on the GI tract, including inspection of the anus and possibly a rectal examination. Your physician may order various tests in order to make a diagnosis of IBD and help identify whether you have Crohn's disease, ulcerative colitis, or indeterminate colitis (IC). These tests fall into several categories. Some are *invasive*—performed inside the body—while others are non-invasive and require only access to blood or stool samples or radiographic images of the suspected disease site.

Although tests may seem intimidating at first, all are well tolerated by the vast majority of patients. Children will need extra support and coaching, but remember that pediatric specialists routinely perform these tests and can advise you on how to make the process easier for your child.

Blood and stool tests

Physicians commonly use blood tests as part of your diagnostic work-up. Blood tests involve a blood draw, called a *venipuncture*, from a vein in your arm, although some tests, particularly for pediatrics, may be done from a capillary fingerstick. Your physician's office staff may perform the blood draw, but based on the practice and your insurance, you may sometimes be required to go to a laboratory collection site to have your blood taken.

There are no blood tests that can directly diagnose IBD. However, blood analysis can determine inflammation in the body. Inflammation may be detected through a number of measurements involving blood cells and proteins in the blood or stool. These tests will not reveal what's causing the inflammation, and best serve as an indicator that the physician needs to perform other types of tests to identify the inflammation's source.

In addition to being markers of inflammation, blood tests are useful in several other ways. A *complete blood count* (CBC) can also show signs of inflammation or infection through an increased white blood cell count. Anemia may be detected through red blood cell measurements. Blood tests may also assess liver and kidney functions, which can be affected by IBD or the medications used to treat the disease. An *electrolyte panel* is important to check for dehydration and side effects of medications. Your physician may also order blood tests to predict how well you may respond to a particular medication moving forward.

Blood tests are part of both the initial work-up and ongoing follow-up and monitoring of your condition. They usually do not require any special preparation.

The blood tests described previously are considered "routine," and will usually be ordered when IBD is suspected. The same tests will be required to monitor your disease while in periods of both remission and active disease, or *flare-ups*. See the "Routine Blood and Stool Tests" table on page 18.

Markers of inflammation

Proteins found in blood and stool, also called *biomarkers*, may be useful tests for detecting inflammation. They can help in diagnosis and may predict the course of IBD.

The use of some biomarkers is relatively new; they are not used by all physicians. Stool biomarkers include *calprotectin* and *lactoferrin*. Blood biomarkers include *CRP* & *ESR*. Research has shown that these biomarkers are useful in predicting IBD activity, but they are also present in other GI diseases. These blood and stool tests may be more helpful for guiding invasive testing, detecting flares, and optimizing medical therapies than for diagnosing IBD.

Ruling out other diseases with routine stool-based tests

Gastrointestinal infections with similar symptoms may be identified by testing small stool samples. These tests may look for *C. difficile, E. coli, Campylobacter, Yersinia, Salmonella, Shigella*, and other infections.

Specialized blood tests

Specialized tests include *serology* tests for biomarkers that researchers have associated with IBD. *pANCA, ASCA*, *CBir1*, and *OmpC* are examples of biomarkers that may be included in serology tests. Approximately 80% of patients may have biomarkers associated with IBD while 15-20% of patients may not have these markers. However, these tests will not be necessary for all IBD patients, as in most cases, the physician can make the diagnosis without them. In addition, these biomarkers are not

present in a significant number of patients with documented IBD and may also be present in those without IBD.

It is important to realize that many biomarkers are the result of more recent research and have varying degrees of acceptance by the medical community. There are a number of tests that help physicians diagnose and monitor IBD; your physician may not order every one. The perspective is changing based on research and experience. Keep up with current information by speaking with your doctor and checking the CCFA website.

Tests for optimizing therapy

TPMT testing may be ordered when physicians are considering the use of *mercaptopurine* or *azathioprine* for patients. Testing can help to determine whether you would be an appropriate candidate for these medications and what the optimal starting dose would be for each person.

An additional specialized test is the tuberculosis (TB) skin test or *PPD*, required for all patients prior to beginning a therapy called "TNF blocker." The test looks for inactive TB which may become active in patients receiving TNF blocker therapy. Specialized blood tests are summarized in the table on page 18.

Monitoring your health with laboratory tests

If you have been diagnosed with IBD, even if there are no disease symptoms or extra-intestinal manifestations, you will undergo periodic blood testing for evidence of active inflammation and complications of your disease or medical therapy.

Physicians will tell you that IBD can fool you. You may feel well while inflammation is building in your intestine or other complications are underway. It is also important to understand that the test results will change over time, reflecting your condition. Tests are a snapshot of where you are today, and not a long-term view of your health. Tests that your physician may order on a regular basis will include the following:

- **Complete blood count**—identifies anemia, infection, inflammation, and monitors certain medications
- **ESR (sedimentation rate)**—identifies inflammation
- **C-reactive protein**—identifies inflammation
- **Liver enzymes**—screens for liver complications
- **Electrolytes**—checks for dehydration and medication side effects

- **Stool markers and cultures**—identifies inflammation and infectious complications

With a specific disease diagnosis like IBD, health insurance plans will generally cover the cost of monitoring tests as they can contribute to maintaining your health, reducing complications, and finding the right treatments.

The standard for diagnosis of IBD: endoscopy and biopsy

Endoscopy is a procedure that lets your doctor look inside your body. It uses an instrument called an *endoscope*, or "scope" for short. Scopes have a tiny camera attached to a long, thin, flexible tube. When you have an endoscopy, your physician will be able to see images of your intestine magnified on a screen during the procedure, allowing him to evaluate different areas of the gastrointestinal tract, to assess the intestinal lining, and to guide biopsies (*see Figure 1*). In the course of performing diagnostic endoscopy, your physician will take multiple biopsy samples of the intestinal lining to evaluate for microscopic inflammation.

Endoscopy also allows the physician to utilize different types of scopes. Colonoscopes, sigmoidoscopes, and endoscopes are all forms of scopes.

Although laboratory tests support the diagnosis of IBD, endoscopy plays the most important role. It helps your physician to see if inflammation is present, where it is located, assess its severity, and obtain biopsies to confirm the diagnosis. Endoscopy is also vital for monitoring your therapy. Healing of the lining of the intestine is a sign that your medication is effective.

Colonoscopy

Given that the colon and end of the small intestine are the most frequently involved in IBD, *colonoscopy* will be the type of endoscopy most often performed to both diagnose and monitor IBD. A specially trained physician will guide a

colonoscope into your rectum and through the entire length of the colon and end of the small bowel (*terminal ileum*). Typically, you will receive sedation prior to the procedure to minimize discomfort. Many patients sleep through the procedure and do not even recall that the test took place. You should tell your physician if you experience discomfort during the procedure so immediate adjustments to the sedation might be made.

The preparation for a colonoscopy is the greatest challenge you have to face. In order for your physician to see the intestinal lining, it is important to wash out fecal material prior to the procedure. For a colonoscopy, you should expect to:

- Receive restricted diet instructions and follow them
- Drink a bowel preparation (prescribed by your physician)
- Dedicate the night before your test to the bowel purging process
- Wear loose, comfortable clothing to your procedure
- Have a friend or family member drop you off and pick you up after the procedure

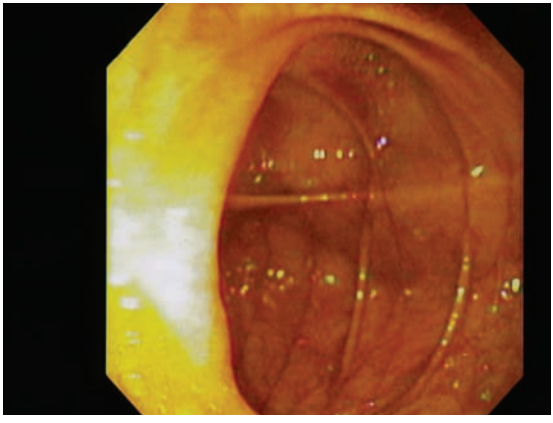

Figure 1

Before your test, you will typically drink a preparation fluid that purges your colon of stool and debris by causing diarrhea. Follow the directions from the pharmacy closely. The preparation fluid may have an unpleasant taste. The colon preparation is time-consuming and can be uncomfortable; however, the result will be a clean intestine, with an unobstructed view of the intestinal lining for a successful colonoscopy.

Colonoscopies are generally very safe procedures, but there is an extremely small risk of bowel perforation during the exam. You may want to discuss the risk with the physician performing the test.

Many patients ask about the usefulness of less invasive "*virtual colonoscopies*." Although these radiology-based tests are an exciting new development, they are not recommended for suspected IBD, where biopsies and direct viewing of the colon and small bowel are required.

Other endoscopic tests

Other types of endoscopic tests can be ordered to evaluate patients with suspected or established IBD. These include:

- **Sigmoidoscopy:** an endoscopic evaluation of the lower one-half to one-third of the colon. This is useful when your physician wants to confirm the presence of inflammation in this segment of the colon. In patients with ulcerative colitis, inflammation begins in the rectum. Therefore, a sigmoidoscopy can be a good diagnostic test to confirm the disease and to monitor your response to therapy. It is usually performed without sedation, because it is a very short procedure and is associated with less discomfort than colonoscopy. The preparation for this procedure is less complex than colonoscopy, usually requiring only one or two enemas the day of the procedure.

- **EGD or upper endoscopy:** a common procedure that physicians use to evaluate a wide variety of symptoms, including, but not limited

to, upper abdominal pain, nausea, vomiting, and difficulty swallowing. An endoscopy requires fasting after midnight until the test. Crohn's disease can occasionally affect the esophagus, stomach, and upper small bowel, which are investigated with an EGD. A longer upper endoscope, called an *enteroscope*, can be used to look for inflammation further into the small bowel. A standard enteroscopy can typically evaluate the first one-third of the small bowel.

- **Capsule Endoscopy (CE):** a newer procedure that allows your physician to obtain pictures of the entire small bowel. The capsule or "pill" camera contains a light source and camera surrounded by a protective outer shell. It also requires fasting after the evening meal and sometimes bowel preparation prior to the procedure. The patient is fitted with a belt recorder, swallows an endoscopy capsule, which is about the size of a penny, and goes about regular activities. The capsule then travels through the small intestine and transmits approximately 60,000 images to the recorder. At the end of the day, the patient returns to the doctor's office for downloading of images. The capsule is excreted in the stool normally.

  Capsule endoscopy is not recommended for patients with strictures or bowel obstructions as the capsule can become "stuck" or retained in the small bowel, resulting in symptoms of bowel obstructions and, rarely, requiring surgery. In addition, biopsies cannot be taken with the capsule.

- **EUS or endoscopic ultrasound**: a relatively new technique that uses an ultrasound probe attached to an endoscope to obtain deep images of the gut below the surface. With IBD, physicians use EUS most often to look at fistulas in the rectal area. *Fistulas* are abnormal connections from the intestine to another part of the intestine, another organ of the body, or the surface of the skin.

The role of biopsy and the surgical pathologist

A *pathologist* is a physician who will examine biopsy tissue under the microscope for specific features that help make the diagnosis of IBD. In addition, the pathologist may identify findings that can determine whether the disease is ulcerative colitis or Crohn's disease. Results from evaluation of biopsies can take as long as one week.

Radiology scans or diagnostic imaging

Traditional upper endoscopy and colonoscopy will not be able to evaluate about two-thirds of the small intestine.

In addition to capsule endoscopy, radiologic exams or diagnostic imaging are performed to evaluate these segments of intestines as well as to evaluate areas outside the bowel.

Radiology involves taking pictures that reveal the inside of the body. There are many types of radiological tests used in IBD, including:

- Barium enema
- CT scan and CT enterography (CTE)
- Leukocyte scintigraphy (white blood cell scans)
- MRI and MR enterography (MRE)
- Small bowel follow-through and small bowel enteroclysis

- Ultrasound
- X-rays

How tests work together to tell your story

Your physician will order additional tests based on your symptoms and laboratory test results. The Imaging Tests chart on page 18 discusses the areas of interest in the intestine and the radiology and endoscopy tests that you may undergo to confirm the presence of disease at these sites or complications.

A closer look at diagnostic imaging

- **X-rays**
  No preparation required. The test exposes you to a small amount of radiation.
  X-rays are the oldest way of imaging the inside of the body. X-rays are cost-effective and useful for detection of blockages in the small or large intestine. Patients with Crohn's disease, for example, can have inflammation and/or scarring of the small bowel that narrows the intestine and prevents the easy passage of stool and air. This is called a *small bowel obstruction*. The large bowel can also become blocked and dilated. Rarely, people with ulcerative colitis can develop a widening of the large bowel called *toxic megacolon*. These are serious complications that can be seen on a plain X-ray.

- **Small Bowel Follow-Through (SBFT)/ Small Bowel Series (SBS), Enteroclysis and Barium Enema**
  Preparation: Expect to spend at least a half-day at the hospital, ambulatory care center, or physician's office for the small bowel or large bowel evaluation. Your healthcare provider will provide specific instructions for preparing for the test. The test exposes you to small amounts of radiation.

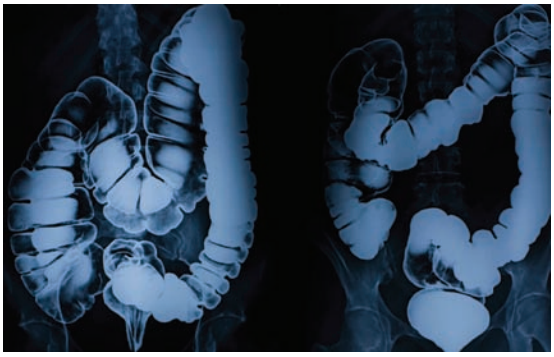

Figure 2

The contrast used for these tests is usually barium. It is a thick, chalky liquid that can be given by mouth or via the rectum. There are two types of contrast X-rays of the small intestine: *small bowel follow-through (SBFT)/small bowel series (SBS) and enteroclysis*. The large bowel X-ray is called a *barium enema*.

When you arrive for the test, you will change into a hospital gown and the technologist will take a plain X-ray or scout film. For a small bowel follow-through, you will drink several cups of barium and then have an X-ray taken every 15-30 minutes as the barium travels down the small intestine and enters the large intestine. The time required is variable but may be as long as four to five hours.

An *enteroclysis* is similar, except that the barium is placed directly into the small intestine through a tube in the nose or mouth.

During a barium enema, the barium is placed directly into the colon using a tube inserted into the rectum. During the exam, the colon is distended with air to provide better images.

- **CAT Scan or CT Scan and CT Enterography (CTE)**
  A CAT scan, also known as a *CT scan*, takes simultaneous X-rays from several different angles to reconstruct a realistic image of the internal organs (see Figure 2). It may involve a contrast material delivered orally, rectally, or

intravenously to improve the quality of the test. During the test, you will be on a special table that advances through the scanner to take images at each level of your abdomen. Newer scanners have an open design to minimize claustrophobia. A CT of the abdomen takes five to 20 minutes to complete. The CT scan is used to rule out complications of IBD, such as intra-abdominal abscesses, strictures, small bowel obstructions or blockages, fistulas, and bowel perforation.

A variation of this exam is called *CT enterography (CTE)*. During this exam, a special oral and/or intravenous contrast agent is given to better outline the intestines. In addition, CTE reconstructs images in 3-D to better visualize the small bowel in relation to other organs. The physician may perform this exam to identify areas of inflamed bowel and more subtle obstructions or blockages.

This test emits significant amounts of radiation. You may discuss with your physician whether imaging alternatives, such as MRI, are more appropriate for you. (See "Radiation Risks," page 21, for more information.)

Be aware that some patients are allergic to the contrast agent in intravenous form. Let the technician know if you think you have an allergy. Patients with kidney disease, diabetes, or dehydration are at increased risk for kidney side effects from the intravenous contrast material.

- **Magnetic Resonance Imaging (MRI)**
  Magnetic resonance imaging (MRI) is useful for viewing internal organs, muscles, soft tissue, and the brain. It does not involve radiation. It converts a signal into a realistic image of the body, giving clear images free of interference from overlying bowel loops. MRI is also useful in seeing disease outside the intestine.

Routine Blood and Stool Tests*

Test	Descriptive Name	Helps to Diagnose
CRP	C-reactive protein	Inflammation (non-specific)
ESR	Erythrocyte Sedimentation Rate	Inflammation (non-specific)
CBC	Complete Blood Count	Anemia, infection, inflammation
Electrolytes	Sodium, Potassium, Chloride, CO_2	Dehydration
Liver Function	Liver Enzymes	Medication side effects, PSC (primary sclerosing cholangitis)
Vitamin B12		Anemia, nutritional status
Vitamin D		Bone mineral status
Calprotectin	Stool protein	Active intestinal inflammation
Lactoferrin	Stool protein	Active intestinal inflammation

Specialized Blood Tests*

Test	Descriptive Name	Potential Usefulness
pANCA	perinuclear anti-neutrophil antibody	Distinguishes UC from CD
ASCA	anti-Saccharomyces cervisiae antibody	Distinguishes CD from UC
CBir1	anti-flagellin antibody	Indicative of Crohn's disease
OmpC	anti-OmpC antibody	Indicative of Crohn's disease
TPMT	thiopurine methyltransferase	Safety and starting dose of azathioprine or 6MP

Imaging Tests*

Suspected IBD Location or Complication	Possible Tests
Ileocolonic disease	Colonoscopy, SBFT/enteroclysis, CTE, MRE, capsule endoscopy (CE)
Upper tract Crohn's disease	EGD-Upper GI Series (UGIS)
Perianal Crohn's disease	MRI-EUS
PSC (primary sclerosing cholangitis)	ERCP
Pancreatic and bile ducts	MRCP
Perforations, blockages, abscesses	Plain X-ray and CT scan

*This is not a complete list of all possible tests. Speak with your healthcare provider regarding other tests.

During an MRI, you will lie on a table inside the scanner while the magnet generates images. Some patients are uncomfortable with being enclosed inside the scanner; however, newer machines have open scanners to address this issue. Tell your physician if you have concerns about enclosed spaces.

Evolving technology has increased the power of MRIs to investigate IBD, making it a more frequent choice for high quality images of the small intestine. *MR enterography (MRE)* has emerged as an alternative to small bowel follow through and *CT enterography (CTE)* for small bowel evaluation. In addition, MRI of the pelvis can be very useful in documenting the extent of disease and presence of abscess or infection in patients with perianal Crohn's disease.

Inform your physician if you have a pacemaker or any metal implants in order to avoid a complication from the MRI.

- **White Blood Cell Scan or Leukocyte Scintigraphy**
  A tagged white blood cell scan called *leukocyte scintigraphy* is occasionally used to detect the white blood cells that have migrated to the intestinal tissue and caused inflammation. A tagged white cell scan can be useful to determine the presence of active inflammation and the site of inflammation.

- **Ultrasound**
  Ultrasound technology is used to study many organs in the abdomen, typically the liver, gallbladder, and those in the pelvic area. Currently, endoscopic ultrasound and MRI are both used to diagnose perianal Crohn's disease. Physicians in the US do not typically use ultrasound to evaluate the small bowel; however, in Europe, they use ultrasound more often to assess for blockages in the small bowel. Ultrasound emits no radiation, and relies on the shadows cast by inaudible sound waves. Although ultrasounds do not

usually require preparation other than not eating for a few hours before the test, you should check with your physician.

The multiple roles of diagnostic imaging

As is the case with laboratory tests, diagnostic imaging may also play multiple roles in treating and managing IBD. Not only will the radiology scans help to determine if you have Crohn's disease, but they will also reveal the extent and severity of the inflammatory process and assess complications of disease such as an obstruction, fistula, or abscess. This information will allow your physician to recommend the best course of therapy. For more information on medication options, review CCFA's brochure, "Understanding IBD Medications and Side Effects." Even after diagnosis, imaging studies may be used to determine how well you are responding to therapy and confirming that your disease is in remission. This is what is called "monitoring" your IBD and it is a critical part of getting and staying well.

Radiation risks

There is research that indicates radiation as a risk factor for cancer. It is clear that health-related radiological scans contribute the most to radiation exposure for the majority of patients. CT scans currently generate the largest amount of radiation among the types of scans discussed in this brochure. Despite the radiation exposure associated with CT, it is a still a very useful test for diagnosing IBD and its complications. However, other exams such as MRI and ultrasound are being used increasingly to decrease radiation exposure for patients.

You and your physician will discuss the risks and benefits of all your decisions, diagnostic and therapeutic. There are no risk-free options; however, the absolute risk associated with radiation from imaging is much lower than the risk of having poorly controlled IBD because of inadequate monitoring of your disease.

If you think you may be pregnant, inform your physician, as it is important to avoid all tests that can expose your fetus to radiation.

When the patient is under 18

Although IBD most typically appears in young adulthood, there are increasing numbers of cases in patients under 18 years of age.

Children are not miniature adults and the process of diagnosing and treating IBD or any other illness must be tailored to their biology and anatomy.

You will need the advice of a *pediatric gastroenterologist*, a subspecialist in the field who treats IBD in kids. Symptoms of concern in children include:

- Abdominal pain
- Diarrhea
- Failure to gain weight or grow
- Fatigue
- Fever
- Rectal bleeding
- Relapsing gastrointestinal illness over several months
- Weight loss

A pediatric gastroenterologist will order the diagnostic tests and procedures that are the safest and most appropriate for your child and discuss all treatment goals with you. Clearly, you want your child to be free from his or her symptoms as soon as possible. This would indicate good response to the treatment. However, your child may require ongoing use of laboratory tests, endoscopy, and diagnostic imaging to assess for complete healing and for complications of medical therapy. Your physician may make changes in medications as a result of these tests.

Your child's doctor may also direct you to counseling and support to help your child through what could be a challenging time. CCFA has child-specific literature available to help you teach your child about diagnosing and living with IBD. Available reading material for kids may even help them get over the fears of blood testing and procedures. Contact our Information Resource Center at www.ccfa.org or 1.888.694.8872 (MY.GUT.PAIN) for free copies of this literature.

Concerns specific to children

Recurrent diagnostic imaging should be minimized to reduce lifetime exposure to radiation. MRIs are becoming a more common choice, because they do not involve radiation, but this technology is evolving and may not be available

in every location. Also, an MRI is more costly. Stool tests for lactoferrin and calprotectin may help identify patients that need additional diagnostic testing. Blood tests require only about two teaspoons of blood from a child and most children do well with blood draws. If a child is anxious, formal relaxation techniques can be taught and anesthetic creams can numb his or her arm.

Another concern in pediatric IBD may be the use of endoscopy. As with adults, colonoscopy plays a central role in diagnosing children. Children receive general anesthesia rather than conscious sedation, as in adults. Complications are extremely rare, especially when performed in a specialized setting like a pediatric IBD center.

Keep in mind that your physician will only order diagnostic tests if the clinical picture leads him or her to believe that IBD is a possibility—which is one you cannot afford to overlook. In addition, the risk of not knowing that your child has IBD or inadequate monitoring of IBD is far greater than the risk from diagnostic testing.

Surveillance colonoscopy

Ulcerative colitis and Crohn's disease are risk factors for development of colon cancer.

About 5% of patients with ulcerative colitis develop colon cancer. The risk increases with the duration of the disease and the extent of colon involved.

Colorectal surveillance through colonoscopy, a process of looking for signs of cancer as a preventive measure, is generally recommended

8 to 10 years after the diagnosis of ulcerative colitis or Crohn's disease. Your physician may recommend routine surveillance colonoscopy to obtain biopsies throughout the colon. These biopsies will help to identify *dysplasia*, or pre-cancer in the colon. Guidelines for surveillance change over time, so you should ask your doctor about what is new in detection of colon cancer. With proper treatment and monitoring of your IBD, you should be able to maximize your chances for good health over the long term and not miss signs of additional disease.

Scheduling tests

Scheduling of diagnostic tests and procedures can be challenging in a busy IBD Center.

There is usually no specific order of tests, but rather a need to have all the information generated in a reasonable period of time. If you are ill and undergoing an initial evaluation, or experiencing a serious flare, the timing is certainly more pressing than for a routine, elective, monitoring procedure, which you may schedule months in advance. The physician may want the results as soon as possible. A flexible schedule will be helpful in making yourself available for testing. Remember, there are lead times built into obtaining results of biopsies and beginning treatment. At times, diagnostic tests may be clustered together for your convenience.

You will want to work with your employer to take advantage of available sick days to cover testing requirements. If you already have utilized available sick time, you will have to consider short term disability or family leave. Remember that this is a serious health issue and you will want to get your disease in remission as soon as possible so you can return to work.

If the patient is your child, make sure to speak with your child's teacher or guidance counselor to discuss any necessary school accommodations that may be required so that ongoing diagnostic testing may take place.

Questions for Your Doctor or Nurse:

1. What is the purpose of the test? What will happen if we get a positive result?
2. Do I need to fast or prepare otherwise?
3. How long will it take?
4. Can I go alone or must I have a companion?
5. When will I learn the results? Who will be giving them to me? May I have a hard copy for my records?
6. Will we be repeating this test or procedure? How often?
7. Will health insurance cover the cost of this test, and if so, how frequently?

Health insurance considerations

In the health care reform era, things are changing quickly.

It is crucial to evaluate your coverage when you face the prospect of chronic disease. It is good news that health plans are now required under federal law to cover all patients, including those with serious medical conditions. However, levels of coverage vary and you may well want to make changes going forward with a chronic disease diagnosis like IBD. To find out how the new law will affect you, the US Depart-

ment of Health provides information at www.healthcare.gov.

High-deductible health plans may require you to absorb much of the cost of the initial diagnostic work-up including endoscopy, radiology, and laboratory work. It may be more cost-effective to pay higher premiums and reduce out-of-pocket costs if you need ongoing tests and procedures. Costs of procedures vary by location and sometimes insurers require prior approval before you undergo a test. This is particularly true when a test of the same type is repeated within a specific time frame. You will need to speak with your health insurance provider about the provisions of your plan.

If you are uninsured and cannot cover the cost of insurance premiums, you can look at resources available in your state for the uninsured and consider enrolling in a plan that permits access to the basic diagnostic requirements and treatments for IBD.

Support and resources

If you suspect you have IBD, consider finding a support group as early as possible; other patients can be valuable in helping you deal with a diagnostic process that is new and unknown.

Particularly, parents of youngsters who are ill may find the experiences of other parents educational and reassuring. Your gastroenterologist can guide you to local hospital-based resources and CCFA chapters.

CCFA makes available much information for support of the newly diagnosed patient through our website, www.ccfa.org. Or, call our Information Resource Center directly at 1.888.MY.GUT.PAIN (888.694.8872) and speak to an Information Specialist who can offer helpful suggestions and resources. One such resource is the "Diagnostic Test Log" included in this brochure. The log can be used to help you keep track of tests and results. To use the log, fill in the information about your tests under each category.

We suggest you keep it somewhere handy so you can access it easily. The log also serves as a convenient reference for when you meet or speak with a health care provider.

Living your life

Ongoing monitoring of your IBD should not interfere with your daily life and activities. It is simply an additional aspect of how you live and take care of your body. By having accurate diagnosis and adequate monitoring of Crohn's disease or ulcerative colitis, you have the best chance of living your life as normally as possible and pursuing all of your dreams and goals.

The future of diagnostics

We look forward to a future when diagnostic testing will provide better guidance for choosing therapies and telling us whether a patient will have a mild or more serious disease course.

Scientists are currently studying biomarkers in combination with newer genetic tests to see how they might accurately forecast the progression of IBD or development in family members. CCFA's Risk Stratification Initiative in our Pediatric Network, the largest financial investment in our four-decade history, is involved in this type of clinical research.

Diagnostic imaging is also an area where scientists are attempting to improve technology for IBD assessments. For example, a molecule called MAdCAM-1 is currently under investigation in MRI; the molecule will help target inflammation in the intestine, and may enable non-invasive diagnosis and monitoring of IBD.

CCFA has also committed heavily to researching the *gut microbiome*, the collective study of intestinal bacteria and their genes. It is our plan to make new scientific tools accessible to scientists to help figure out how the inflammation of IBD happens and how we might stop or prevent it.

In addition, CCFA has an active IBD DNA Databank serving the community of scientists who depend on DNA samples from patients with active disease to study IBD.

Visit our website, www.ccfa.org, to learn more and see how you can get involved in supporting our research initiatives.

Glossary

Anti-OmpC (outer membrane protein C): the antibody to a specific protein on the outer membrane, recently identified as a significant biomarker. New data shows that anti-OmpC levels are high among members of families that have a history of both Crohn's and colitis.

ASCA (anti-saccharomyces cerevesiae): a serology test useful in distinguishing Crohn's disease from ulcerative colitis and predicting disease course.

Biomarkers: proteins in the body that may be measured by laboratory tests to assist in diagnosis and management of disease.

Biopsy: a tissue sample provided to a pathologist to help diagnose and classify disease.

Calprotectin: a stool test for intestinal inflammation that aids in predicting active disease.

CBC (complete blood count): a laboratory blood test that helps to detect anemia, infection, and inflammation.

CBiR1 (Anti-Flagellin): this antibody may be a marker of Crohn's disease complicated by fistulas, perforations, or other serious problems.

CRP (C-reactive protein): a laboratory test that indicates non-specific inflammation in the body.

CT (computed tomography): an imaging test that uses X-rays to make detailed pictures of structures with the body.

CTE (computed tomography enterography): a variation of the CT scan where the patient swallows special contrast agents to give a sharp outline of the intestines in the X-rays.

DEXA (bone densitometry scan): an X-ray that assesses the thickness of bones and risk for osteoporosis (thin bones) and fractures.

EIM (extraintestinal manifestations of IBD): signs and symptoms outside of the gastrointestinal tract associated with IBD.

Electrolytes: laboratory test panel including serum sodium, potassium, chloride, and carbon dioxide that may indicate dehydration and other complications or medication side effects.

ERCP (endoscopic retrograde cholangeopancreatography): a type of endoscopy that utilizes X-ray to diagnose a liver disease called *primary sclerosing cholangitis (PSC)*.

ESR (erythrocyte sedimentation rate): a laboratory blood test for non-specific inflammation.

Granuloma: a collection of cells in the intestinal lining, visible under the microscope, that indicate the body's attempt to get rid of a foreign material; sometimes seen in Crohn's disease, but not always present.

Gut: the intestine or bowel.

Hemoglobin and hematocrit: measurements of red blood cell number and volume, found in the CBC, useful in determining anemia.

Lactoferrin: a stool test for intestinal inflammation that aids in predicting active IBD.

MRCP (magnetic resonance cholangiopancreatography): a type of MRI that allows the physician to see images of the bile ducts, which are similar to ERCP images.

MRI (magnetic resonance imaging): an imaging test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures within the body.

p-ANCA (perinulclear anti-neutrophil cytoplasmic antibodies): a serology test that may aid in diagnosing ulcerative colitis, distinguishing it from Crohn's disease, and predicting disease course.

PPD: (purified protein derivative): tuberculosis (TB) skin test, advised for all patients taking biologic therapies, to assess the presence of latent and active TB disease.

Radiographic: Relating to the process that depends on X-rays.

Small bowel enteroclysis: an imaging test that evaluates the small intestine by infusing barium and air through a tube inserted into the small intestine via the nose.

Serology: a blood test to identify antibodies (proteins) which may have developed in response to an infection, other foreign proteins, or to one's own proteins.

SBFT/SBS: (small bowel follow-through/small bowel series): an imaging test that evaluates the small intestine, involving swallowing barium, after which serial x-rays are taken.

US (ultrasound): an imaging test in which high-frequency sound waves, not heard by the human ear, are transmitted through body tissues using a transducer, relaying information to a computer for display.

Toxic megacolon: an acute condition where the colon is dilated or enlarged, a complication associated with ulcerative colitis.

TPMT: (thiopurine methyl transferase): a laboratory blood test for the activity of an enzyme that helps in breaking down the medications azathioprine and 6MP, which helps to establish proper dosing of these medications.

Virtual colonoscopy: a less invasive, new version of colonoscopy, done without sedation and using X-rays and computer-based, virtual-reality technology to produce 3-D images of the lining of the colon. Virtual colonoscopy is not currently used to diagnose or monitor IBD.

Diagnostic Test Log

CROHN'S & COLITIS FOUNDATION OF AMERICA

Keep track of your test information by using this diagnostics log. Fill out important information under each category and leave some space to record any changes or new information.

Date of test	Type of test	Names of healthcare providers	Purpose of test	Outcome and follow-up

Diagnostic Test Log

CROHN'S & COLITIS FOUNDATION OF AMERICA

Date of test	Type of test	Names of healthcare providers	Purpose of test	Outcome and follow-up

About CCFA

Established in 1967, the Crohn's & Colitis Foundation of America, Inc. (CCFA) is a private national nonprofit organization dedicated to finding the cure for IBD. Our mission is to fund research; to provide educational resources for patients and their families, medical professionals, and the public; and to furnish supportive services for people with Crohn's or colitis.

Advocacy is also a major component of CCFA's mission. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Contact CCFA to get the latest information on symptom management, research findings, and government legislation. You can also become a member. Join CCFA today by calling 888.MY.GUT.PAIN (888-694-8872) or visiting www.ccfa.org.

We can help! Contact us at:

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(888.694.8872)
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The Crohn's & Colitis Foundation of America is a non-profit organization that relies on the generosity of private contributions to advance its mission to find a cure for Crohn's disease and ulcerative colitis.

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