CROHN'S & COLITIS
FOUNDATION OF AMERICA

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A Guide for Parents

INTRODUCTION: GETTING THE DIAGNOSIS

You have just learned that your child has a chronic form of inflammatory bowel disease (either ulcerative colitis or Crohn's disease). Quite possibly, you have never even *heard* of that condition before. And now your child has it. Your level of concern grows since the doctor has said this disease doesn't go away.

If you feel overwhelmed and scared right now, that is only natural. You probably have a ton of questions. You're wondering how your child got this disease and, more important, how much of an impact it will have — both now and down the road. For example, you'll want to know:

- Will my child be able to go to school and play with friends as before?
- Is a special diet necessary?
- Will surgery be needed?

That is the purpose of this brochure: to answer these questions and walk you through the key points about Crohn's disease and ulcerative colitis and what you may expect. You won't become an expert overnight, but gradually you'll learn more and more. And the more you know, the better you'll be able to become an advocate for your child. More than that: You'll be an active member of your child's healthcare team.

THE IMPACT OF THE DIAGNOSIS

When chronic illness is diagnosed during childhood or adolescence, the child isn't the only one who feels the effects. The entire family is touched. As a parent, you hate to see your child in physical or emotional distress. You'd gladly take on that pain if you could, but it just doesn't work that way. Instead, the most positive thing you can do for your child is to be supportive and get the best healthcare available.

If there are other children in the family, they need to understand their sibling's condition and the impact it's likely to have on their lives. It's important to reassure them that you still love them and want to be as involved in their lives as you've always been, although you may have to devote more time to the child who is ill. Finally, you'll want to share information about the illness with other family members, as well as friends and school personnel. We hope you'll take advantage of additional brochures in this series ("A Guide for Children and Teenagers" and "A Guide for Teachers and Other School Personnel"), as well as the other materials and programs prepared by CCFA that have helped thousands of families over the years cope with Crohn's disease and ulcerative colitis.

WHAT ARE CROHN'S DISEASE AND ULCERATIVE COLITIS?

Crohn's disease and ulcerative colitis are the two most common types of inflammatory bowel disease (IBD). In both diseases, the inner surface of the intestine becomes raw and eroded.

- Crohn's disease may affect any part of the gastrointestinal (GI) tract, from the mouth to the rectum and even the skin outside the anal opening. However, the areas most often affected are the lower part of the small intestine (ileum) and the large intestine (colon). The inflammation of Crohn's disease usually extends through the full thickness of the intestinal wall.
- In ulcerative colitis, only the colon is inflamed; all or just part of it may be affected. The bowel injury of ulcerative colitis does not extend through the full thickness of the intestinal wall, affecting just the inner lining of the colon.

There may be at least 100,000 children under the age of 18 in the United States who suffer from IBD.

HOW COMMON IS IBD?

It is estimated that there are more than *1.4 million* Americans with IBD.

- Males and females appear to be equally affected.
- Although Crohn's disease and ulcerative colitis affect people of all ages, they are primarily diseases of younger persons, with adolescents and young adults between the ages of 15 and 35 being the most susceptible.
- There may be at least 100,000 children under the age of 18 in the United States who suffer from IBD.

ARE ULCERATIVE COLITIS AND "SPASTIC COLON" THE SAME DISEASE?

No. "Spastic colon" is a term used to describe a disorder called *irritable bowel syndrome,* or IBS. A child with this disorder may have symptoms (such as diarrhea and pain) that look a lot like IBD. However, irritable bowel syndrome results from alterations in bowel motion (motility) rather

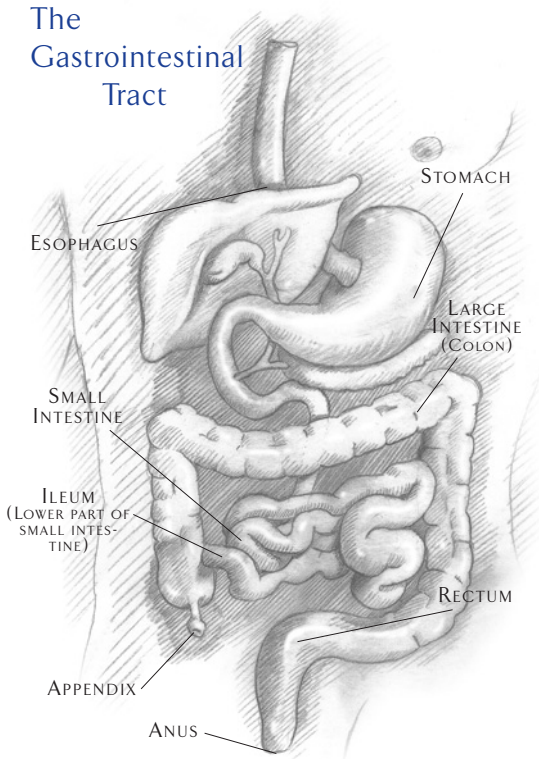
than inflammation of the bowel. It is possible to have IBD *and* IBS, but it's more likely to have just one or the other condition.

WHAT ARE THE SIGNS AND SYMPTOMS OF ULCERATIVE COLITIS AND CROHN'S DISEASE?

Despite the differences between Crohn's disease and ulcerative colitis, both forms of IBD cause similar symptoms—all brought on by chronic inflammation. Persistent diarrhea, abdominal pain, rectal bleeding, fever, and weight loss are the hallmarks of Crohn's disease and ulcerative colitis. And they are the same in both adults and children affected by IBD.

Symptoms may appear gradually or develop very suddenly. Occasionally, severe symptoms appear to be "set off" during a mild illness, such as the flu. In retrospect, some people realize that the symptoms actually may have been present for a long time.

- In Crohn's disease, abdominal pain and diarrhea are often the earliest signs. Obvious rectal bleeding is a little less common in Crohn's than in ulcerative colitis. Lack of appetite, weight loss, and slowed growth also are common. Other signs of Crohn's disease include sores in the anal area, extra folds of skin around the anal opening, and anal fistulas (tiny openings or pores from which pus-like fluid can seep).
- Most young people with ulcerative colitis develop loose bloody stools. Crampy abdominal pain is common, as is the persistent urge to have a bowel movement. Some children may awaken from sleep with the urge to move their bowels. But symptoms vary; some children with ulcerative colitis have little or no diarrhea, just rectal bleeding with an occasional cramp.



- Symptoms of the two diseases are not always limited to the GI tract. They also can produce rashes, mouth sores, joint pain and swelling, and rarely, liver disease. These are known as *extraintestinal symptoms*.

IS IBD INHERITED?

We know that Crohn's disease and ulcerative colitis tend to run in families. Although studies have shown that perhaps 15% to 20% of affected individuals may have a close relative with one of these diseases, there does not seem to be any clear-cut pattern to family inheritance.

- Caucasians tend to get IBD more than other racial groups. They are followed by blacks, Hispanics, and Asians.
- The highest incidence of IBD in the United States is found among Ashkenazi Jews (of Eastern European descent).

- Scientists have already identified one gene, called NOD2 / CARD 15, which is involved in at least 20% of Crohn's cases. Researchers are actively working to identify other genes that influence the tendency to develop IBD.

WHAT CAUSES IBD?

At this point, researchers are still uncertain about what causes these diseases. They do know, though, what does *not* cause Crohn's disease and ulcerative colitis, and that is tension, anxiety, or diet (all of which were once thought to play a role). Furthermore, neither of these diseases is contagious; one person cannot infect another.

What are some of the likely causes? Most experts think there is a *multifactorial* explanation. That simply means that it takes a number of circumstances working together to bring about IBD—including these top three suspects:

- Genes
- An inappropriate reaction by the body's immune system
- Something in the environment

It's quite likely that one or more genes sets the stage for the development of IBD. Then, it takes some kind of "trigger" in the environment to enter onto the scene. That could be a virus or a bacterium, but not necessarily. Whatever it is, it prompts the person's immune system to "turn on" and launch an attack against the foreign substance. That's when the inflammation begins. Unfortunately, the immune system in a person with IBD may be poorly regulated and doesn't "turn off." So the inflammation continues, damaging the lining of the gastrointestinal tract and causing the symptoms of ulcerative colitis or Crohn's disease.

It takes a number of circumstances working together to bring about IBD.

MAKING THE DIAGNOSIS

There is no single test that can secure the diagnosis of Crohn's disease or ulcerative colitis. In addition to a thorough medical history and physical examination, children must undergo blood tests, barium X-rays, and endoscopy of the upper and lower GI tract.

- Blood tests are done to check for a low red cell count *(anemia)* or high white cell count *(inflammation)*. Other blood tests may be performed to look for evidence of inflammation in the intestine and elsewhere. These include the erythrocyte sedimentation rate (ESR or "sed rate") and C-reactive protein (CRP). More recently, various antibody tests have been discovered that can show the altered GI immune process in some people with IBD. These are called anti-saccharomyces cerevisiae antibody (ASCA) and perinuclear anti-cytoplasmic antibody (pANCA).
- Barium X-rays include the *upper GI* and *small-bowel series.* (The lower GI series, or barium enema, has been replaced by colonoscopy.) During the upper GI series, the child swallows a chalky liquid containing barium that coats the upper intestinal tract so it will show up on an X-ray. Areas of swelling, narrowing, or other signs of intestinal inflammation are identified. The upper GI series is done on an empty stomach, which usually requires the child to fast overnight and skip breakfast.
- Endoscopy is a test that involves inserting a lighted viewing tube through either the mouth

into the upper intestine (*upper endoscopy*) or through the anus into the colon (*colonoscopy*). Like a small bowel X-ray series, upper endoscopy is done on an empty stomach. However, the child is given some sedation in order to ensure complete comfort during the examination. Colonoscopy is done in much the same way. The child is placed on a clear liquid diet and given laxatives for one to two days before the colonoscopy to allow good visualization of the inside lining of the large intestine. In addition to looking for inflammation, the doctor removes tiny pieces of tissue, a procedure called *biopsy,* during both upper endoscopy and colonoscopy. The biopsy samples are viewed under a microscope to see any abnormalities not clearly visible to the naked eye.

Physicians who perform endoscopies in children usually have certain preferences regarding laxatives and sedation. If you have questions or concerns about these matters, discuss them with your doctor. Without appropriate testing, IBD can be difficult to diagnose, because both Crohn's disease and ulcerative colitis may mimic other conditions.

In some individuals, it is difficult to determine whether their IBD is Crohn's disease or ulcerative colitis — even after extensive testing. Doctors may order additional blood tests to help distinguish between the two forms of IBD. Very rarely, people are given the diagnosis of "indeterminate colitis." Such uncertainty is more common in the youngest patients — those under five years old at the time of diagnosis.

DO CHILDREN EVER OUTGROW THESE ILLNESSES?

No. Crohn's disease and ulcerative colitis are considered *chronic* diseases. Chronic conditions are ongoing ones that persist throughout life. They can be controlled with treatment but cannot be cured. That means the disease is long-term, but it does *not* mean it is fatal. It isn't. Most children who have IBD go on to lead full and productive lives.

- It should be noted that both Crohn's disease and ulcerative colitis are marked by periods of disease activity *(flares)* alternating with symptom-free periods *(remission).*
- Some people have only mild symptoms and many respond well to drug therapy — whether the initial symptoms are mild or severe.
- Occasionally, a child with ulcerative colitis may become so ill that surgical removal of the entire large intestine, including the rectum, is necessary. Surgery provides a permanent cure for ulcerative colitis. Surgery for Crohn's disease is not considered a cure, however. It usually involves removal (resection) of a particular region or regions of diseased intestine. Although this surgery is not a cure, it can provide the child with many disease-free years, with reduced need for drug therapy. (See "**What is the role of surgery?**" on page 14.)

WHAT MEDICATIONS ARE USED TO TREAT IBD?

The two basic goals of treatment for children with IBD are to achieve remission (the absence of symptoms) and, once that is accomplished, to maintain remission. Some of the medications used for these two aims may be the same, but they are given in different dosages and for different lengths of time.

Often, the same drugs are used to treat both Crohn's disease and ulcerative colitis. There is

no "one-size-fits-all" treatment for every child or adolescent with IBD. The treatment approach must be tailored to the individual, as each child's disease is different. Broadly speaking, five different categories of drugs are used in IBD, both for children and adults:

- **Aminosalicylates:** These include aspirin-like compounds that contain 5-aminosalicylate acid (5-ASA). The best known medication in this group is sulfasalazine. These drugs, which can be given either orally or rectally, alter the body's ability to launch and maintain an inflammatory process. They reduce inflammation in the intestine, similar to the way aspirin works against inflammation in other parts of the body such as the joints (arthritis). Mesalamine-containing agents, which include mesalamine and balsalazide, are effective in treating mild-to-moderate episodes of IBD. They also are useful in maintaining remission. For more severe disease, the 5-ASA compounds can be used together with other drugs.
- **Corticosteroids:** These medications, which include prednisone and prednisolone, also affect the body's ability to launch and maintain an inflammatory process. In addition, they work to suppress the immune system. Corticosteroids are used for children with moderate-to-severe IBD. They can be administered orally, rectally, or intravenously (through a vein). Prednisone and similar drugs are like cortisone, a hormone made by the adrenal glands. They have powerful anti-inflammatory effects. However, prednisone is at least five times stronger than naturally occurring cortisone. Effective for short-term control of acute episodes (that is, flare-ups), corticosteroids are not recommended for long-term or maintenance use because of their side effects. Budesonide is a newer steroid that does not have systemic side effects and may be used to help treat mild-to-moderate Crohn's disease. If a child cannot come off steroids without suffering a relapse of symptoms, the doctor may need to add some other medications to help manage the disease.
- **Immunomodulators:** These include azathioprine, 6-mercaptopurine (6-MP), cyclosporine, and methotrexate. This class of medications basically overrides the body's immune system so that it cannot cause ongoing inflammation. Usually given orally, immunomodulators generally are used in children in whom aminosalicylates and corticosteroids haven't been effective or have been only partially effective. They may be useful in reducing or eliminating dependency on corticosteroids. They also may be effective in maintaining remission in young people who haven't responded to other medications given for this purpose. Immunomodulators may take six weeks to three months to begin to work. This class of drugs is used earlier in some children —particularly when growth is an issue, the upper GI tract is involved, or perianal problems (complications like fistulas that occur around the anus) are present. These drugs have a well-established role in treating IBD, with many years of experience proving their effectiveness and safety in appropriate pediatric patients.
- **Antibiotics:** Metronidazole, ciprofloxacin, and other antibiotics may be used when infections, such as abscesses, occur in IBD. The most commonly used antibiotic in IBD is metronidazole, which is helpful in treating perianal complications of Crohn's disease. Antibiotics also may be necessary when intestinal inflammation extends into the abdomen. In particular, abscesses (pockets of fluid containing bacteria) may accumulate outside the intestinal wall. This is more likely to occur in Crohn's disease than in ulcerative colitis.
- **Biologic therapies:** The newest class of drugs to be used in IBD, biologics include infliximab, the first biologic drug approved for Crohn's disease. It is indicated for people with moderately to severely active Crohn's disease who haven't responded well to conventional therapy. It also is effective for reducing the number of fistulas. Infliximab is an antibody that binds to tumor

necrosis factor (TNF), a protein in the immune system that plays a role in inflammation. Use of the drug may be an effective strategy for tapering children off steroids, as well as for maintaining remission.

- Yet another form of therapy for IBD is dietary intervention. Strictly speaking, altering the diet is not a drug therapy, but it may have the same practical effect as taking medicine. Dietary therapy for IBD may include a predigested (elemental) formula given by mouth or through a feeding tube. It also may call for the delivery of nutrition through an intravenous (IV) line. Used in place of regular food, IV feeding allows the intestine a chance to rest. Another term for full intravenous feeding is *total parenteral nutrition (TPN).* Special diets and TPN are sometimes used when drug therapies have been ineffective or have caused too many side effects — particularly in children with Crohn's disease.

This is just an overview of the medications commonly used in the treatment of Crohn's disease and ulcerative colitis. You can find more specific information about these medications on our Web site at www.ccfa.org.

WHAT ARE THE MOST COMMON SIDE EFFECTS OF MEDICATIONS USED TO TREAT IBD?

All medications can have some side effects, and medications for IBD are no exception. Here are some of the possible side effects of the medications your child may be taking for IBD:

- **Aminosalicylates (5-ASA)** are generally tolerable and vary with the specific medication and formulation. Possible side effects may include diarrhea, headaches, and nausea. Some of these side effects can be reduced when the drug is given first in small doses, then increased gradually to a recommended daily dose. Doctors watch for the occurrence of side effects and decide whether the drug should be continued, reduced, or replaced with other medications.
- **Corticosteroids,** such as prednisone, may cause rounding of the face (facial "mooning"), acne, and increased appetite and weight gain. They may cause bones to lose their calcium and become more susceptible to fracture (osteoporosis). Additional side effects include development of diabetes, high blood pressure, and mood swings. Individuals on prolonged corticosteroid therapy should see an eye doctor regularly because these drugs can cause cataracts and glaucoma. Prednisone also can interfere with the body's ability to fight infection. If your child develops an infection — especially chicken pox—notify the doctor. But possibly the most worrisome side effect of corticosteroids is that they may interfere with growth. This is of particular concern, as children with IBD may already be shorter than their peers because of poorer absorption of food and nutrients.
- Another important effect of prednisone is that it puts the adrenal glands "to sleep." These glands can sense the presence of cortisone or prednisone in the blood stream. When prednisone is taken every day, the adrenal glands will respond by shutting down. Once shut down, they may take a while to start making cortisone again. The longer prednisone is taken, the longer it takes for the adrenal glands to begin producing cortisone. That is why prednisone therapy is reduced gradually. Prednisone should not be stopped without consulting with your child's doctor. During periods of stress — induced by such triggers as infections, surgery, dental work, or accidents — temporary increases in prednisone therapy may be necessary. Notify your doctor if any of these periods of bodily stress occur.

- Side effects of prednisone decrease when the dose is reduced; they usually disappear altogether when the drug is discontinued. High blood pressure usually can be prevented by a low-salt diet. In most cases, prednisone and similar corticosteroids can be administered safely with close supervision, and serious side effects are not as threatening as they may sound. Prednisone remains an extremely valuable *short-term* drug in the treatment of IBD. Your child's healthcare team must carefully weigh the benefits of long-term use with the risk of potential side effects.
- **Azathioprine** and **6-mercaptopurine** may cause nausea, a decrease in white and red blood cell counts, and inflammation of the pancreas (pancreatitis) or liver (hepatitis). **Metronidazole** may cause nausea and abdominal discomfort, a metallic taste in the mouth, and tingling in the hands and feet. It also may darken the urine. Blood tests can monitor for the side effects of 6-mercaptopurine and azathioprine, which are reversible and respond to lowering the drug dosage. In addition, new enzyme tests may allow some predictability as to who is at increased risk for these side effects.

Therapy for IBD is in a constant state of change. New drugs and new forms of drug delivery are being designed, tested, and introduced all the time. In fact, one day your child may be invited to participate in a *clinical trial,* a research study that evaluates one of these new medications.

WHAT IS THE ROLE OF SURGERY IN TREATING IBD?

In Crohn's disease, surgery becomes necessary when medication no longer controls symptoms. It also may be called for when there is an intestinal obstruction or other complication that cannot be managed by medication. In most cases, an irreversibly diseased segment of bowel is removed, and the two ends of healthy bowel are joined together. This is called *resection and anastomosis.* While this surgery may allow many symptom-free years, it is not considered a cure for Crohn's disease, as the disease may recur at or near the site of anastomosis.

With ulcerative colitis, the situation is different. Surgical removal of most of the colon and the lining of the remainder of the rectum (sub-total colectomy) offers a permanent cure. The surgery is usually performed in stages. First, an artificial opening is created in the abdomen and the remaining small intestine is attached to this opening, called an *ileostomy.* The ileostomy drains liquid waste into a small bag that is attached to the skin with a special adhesive. At a later surgery, the lowest part of remaining small intestine is reattached to the anal opening. The attachment is called an ileoanal anastomosis. Once the *ileoanal anastomosis* has healed, the ileostomy in the abdominal wall is closed. Bowel movements can then occur in the normal way, through the anus. This operation is rarely used in Crohn's disease because of the possibility of the disease returning in the bowel just inside the anal opening, the *ileal pouch.*

For more information on surgery in Crohn's disease, visit our Web site at www.ccfa.org.

WHAT IS THE ROLE OF DIET AND NUTRITION IN IBD?

Good nutrition is essential in any disease, but especially in illnesses like IBD, in which decreased appetite, digestive problems, and diarrhea are typical. Maintaining proper nutrition is a vital part of the overall treatment program. Most children with IBD require relatively little or no change in diet. However, since every child is different, there may be times when modifying the diet can be helpful, particularly during a flare. A few recommendations apply:

- Salt intake should be limited during corticosteroid therapy, because salt creates fluid retention.
- Occasionally, the ileum is severely inflamed, making its internal passageway quite narrow. In this situation, a low-fiber diet is recommended. "Chunky" high-fiber products, such as popcorn, should be avoided.
- Some children develop an increase in diarrhea and abdominal cramps when they consume dairy products because of an inability to digest milk sugar *(lactose intolerance)*. If this is the case, they should avoid dairy products.
- A registered dietitian can plan a low-fiber, low-sodium, or low-lactose diet when necessary. However, most children with IBD require relatively little or no change in diet.
- Children with IBD sometimes become deficient in certain vitamins and minerals such as vitamin B-12, folic acid, vitamin C, iron, calcium, zinc, and magnesium. Your child's doctor can identify and correct these deficiencies with supplements when necessary. However, most experts feel that simply providing adequate calories by encouraging children or teenagers to eat almost anything they desire is the first priority and is likely to prevent other problems.
- For children who have trouble eating, nutritionally complete liquid diets are available. These can be used alone or together with regular food to increase caloric intake. The decision to use one of these preparations should be made in consultation with your child's doctor.
- Another way to provide extra calories is through the use of continuous liquid diet infusion at night. While the child is asleep, the formula is pumped through a narrow tube that has been passed through the nose into the stomach, adding thousands of nutritionally packed calories that can help boost growth and physical development. The nasogastric feeding method is usually done at home for several months.

Probiotics and prebiotics

Researchers have been looking at other forms of intestinal protection for children and adults with ulcerative colitis and Crohn's disease. That's where *probiotics* and *prebiotics* come in.

- Probiotics, also known as "beneficial" or "friendly" bacteria, are microscopic organisms that assist in maintaining a healthy GI tract. Approximately 400 different types of good bacteria live within the human digestive system, where they keep the growth of harmful bacteria in check. A proper balance between good and bad bacteria is key. If beneficial bacteria drop in number or the balance is otherwise thrown off, that's when harmful bacteria can overgrow — causing diarrhea and other digestive problems. In children with already damaged GI tracts, like those with ulcerative colitis, symptoms may be particularly severe. Mounting evidence suggests that the use of certain probiotics — available in capsules, powders, liquids, and wafers — may represent another therapeutic option for people with IBD, particularly in helping to maintain remission. As with any other treatment, it is important to discuss the use of probiotics with your child's doctor and follow recommendations.
- Prebiotics are non-digestible food ingredients that provide nutrients to allow beneficial bacteria in the gut to multiply. They also stimulate the growth of probiotics.

Further information on diet and nutrition in IBD can be found on our Web site at www.ccfa.org.

CAN LIVING WITH A CHRONIC DISEASE LIKE IBD CAUSE EMOTIONAL PROBLEMS?

Yes, it can. The diagnosis of a chronic illness is a tough blow for anyone, but for children, it can be especially hard to bear. Still developing a sense of themselves (emotionally as well as physically), young people now must face an extra hurdle when a long-term disease enters the picture — whether it is IBD or diabetes or asthma. That is because a chronic disorder poses a threat to a child's sense of well-being and security. As a result, children may show signs of anxiety and become clingy and dependent. But these reactions are a *response* to the disease, and not its cause.

- Most young people experience some degree of agitation and depression in response to their illness. Some estimates say that as many as 50% of all children with IBD react by becoming depressed. Sometimes various treatments for IBD may make matters worse. For example, emotions can be affected as part of the side effects of medications such as corticosteroids.
- The emotional support provided by healthcare professionals goes a long way toward reassuring the child.
- At times a counselor or child psychologist may be helpful, enabling the child to regain the self-confidence that is sometimes affected by chronic illness.
- When there are indications of more severe emotional disturbances — social isolation, an inability or unwillingness to attend school, or other signs of inability to cope — consultation with an experienced psychologist, psychiatrist, or psychiatric social worker may be useful.

There is no reason for either the affected child or any member of the family to feel guilty about causing the disease.

DO CHILDREN OR THEIR FAMILIES EVER EXPERIENCE FEELINGS OF GUILT THAT THEY CAUSED THE ILLNESS?

Yes. It is natural for people to feel this way, especially if a parent also has IBD. However, there is no scientific evidence that IBD is brought on by diet, psychological factors, or other causes within the family's control. It was nothing that you or your child did that brought on the illness. Obviously, a parent cannot choose the genes they pass on to their children. There is no reason for either the affected child or any member of the family to feel guilty about causing the disease.

ARE THERE THINGS I MAY DO AS A PARENT THAT CAN MAKE THE SITUATION WORSE? HOW CAN I PREVENT THAT?

Again, there is nothing you have done as a parent to cause your child's chronic disease. However, parents may become overly protective when a child has such an illness. That is only natural. As soon as your child is old enough, it is a good idea to foster independence by encouraging him or her to assume responsibility for various medical routines, such as taking medications or calling the doctor when necessary. The illness also can become a source of tension between parent and child, coming at an age when independence is a major issue. In particular, parents may become alarmed when their child loses weight or eats poorly. Children and adolescents need to voice their fears about changes in their

bodies brought on by illness and treatment. You and your child should openly discuss these concerns with the healthcare team.

HOW CAN I TELL IF MY CHILD IS NOT GROWING ADEQUATELY?

Growth failure may occur in children with Crohn's disease when disease onset occurs before puberty.

- Signs of growth failure include a lower-than-expected increase in height and weight. Children with IBD may be aware that they are shorter than most of their classmates. Moreover, parents may notice that the size of a child's clothing and shoes remains the same for a long period of time.
- Your child's doctor can plot a growth curve on a chart. This should be done at six to 12 month intervals. The chart will show the rate at which your child is growing, compared with the average growth rate of other children of the same age across the country. This is a simple technique, and the doctor may show you how to keep track of your child's growth rate at home using these same charts. An alert parent is often the first to spot these changes in a child's development.
- Other signs of failure to grow are delayed bone development (which can be measured by X-ray) and an onset of puberty that appears delayed compared with the family pattern.

WHAT ABOUT DELAYED ONSET OF PUBERTY? WILL MY CHILD BE NORMAL?

Even though puberty may be delayed by several years because of IBD, most teenagers do reach maturity and function normally. Some continue to grow in height into their 20s, after the onset of puberty and long after their peers have stopped growing. Many reach their "normal" height in this way. Moreover, fertility is generally not affected by IBD in either sex.

HOW MUCH INFORMATION SHOULD I GIVE MY CHILD ABOUT THE ILLNESS?

Your child or teenager will probably indicate to you just how much information about the disease he or she wants to have. Parents should encourage children to ask questions and discuss concerns with their healthcare providers. Doctors can manage the illness better when they have a working dialogue with the child. Similarly, most children feel much more in control when they know the facts. That does not mean, though, that you need to overwhelm your child with all the details.

HOW DO CHILDREN COPE WITH IBD?

You'll learn about numerous strategies that can make living with IBD easier for your child. Coping techniques for dealing with the disease may take many forms:

- Attacks of diarrhea or abdominal pain may make children fearful of being in public places. But that isn't necessary. All it takes is some practical advance planning. Encourage your child to find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation.
- Carrying along extra underclothing or toilet paper is another smart maneuver.
- Encourage children or adolescents to find practical ways of dealing with the illness in school. In addition to learning where the nearest bathrooms are, the child should also be advised to visit the school nurse's office when needed. When school attendance is a particular problem,

testing may be necessary to determine whether the disease is flaring or if perhaps depression or other emotional problems are responsible.

SHOULD MY CHILD'S TEACHERS AND FRIENDS BE TOLD ABOUT THE ILLNESS?

Children spend most of their waking hours in school. It's where they learn, play, and socialize. In short, school is the center of a child's world. That is why teachers, school administrators, and the school nurse should be told matter-of-factly about the child's illness.

- Such explanations can make life a lot easier when a child needs to make frequent trips to the bathroom. The nurse can be especially helpful in dealing with bathroom and gym issues.
- This information is particularly important if there are hospitalizations or frequent absences from school. Educational needs, like getting homework assignments and taking make-up tests, must be addressed. Catch-up plans can be arranged if necessary.
- Your school system should be willing to work with you to ensure your child's continuing education. Keeping the lines of communication open between you and your child, the school, and your child's healthcare team is key to avoiding major difficulties.

For more on this topic, see CCFA's brochure, "Crohn's Disease and Ulcerative Colitis: A Guide for Teachers and Other School Personnel."

Your child should decide whether to tell friends about the disease. The disease may seem difficult to explain, and children can often be cruel about such things. Therefore, your child may choose not to tell friends about the problem in the beginning. However, as young people develop a better understanding of their disease, this may change.

Most people with IBD continue to lead active and productive lives.

You should respect your child's wishes whenever possible.

SHOULD A CHILD WITH IBD PARTICIPATE IN SPORTS?

Yes. Young people with IBD should be as active as possible. There is generally no reason not to participate in sports if the disease is under control. Some limitations may be necessary if strenuous sports cause fatigue or aggravate abdominal pain, arthritis, or other symptoms. Furthermore, prolonged high-dose steroid therapy may make bones more susceptible to fracture during contact sports, such as football and wrestling. In these instances, a modified exercise program may be advisable.

IS IT POSSIBLE TO LEAD A NORMAL LIFE WITH IBD?

This is perhaps the most important question of all. While Crohn's disease and ulcerative colitis are serious chronic diseases, they are not considered fatal illnesses. Most people with IBD continue to lead active and productive lives, even though they often need to take medications regularly and may occasionally have to be hospitalized. Sometimes the disease flares or becomes worse, requiring temporary increases in drug therapy or the use of additional medication. Nonetheless, between these flares, many people feel fully well and are relatively free of symptoms.

Although there is no medical cure for Crohn's disease or ulcerative colitis, research and educational programs funded by CCFA have improved the health and quality of life of people with IBD. Through CCFA's continuing research efforts, much more will be learned and a cure will be found.

Membership Application

YES, I want to be part of the solution by becoming a member of CCFA at the level indicated below:

PLEASE CHECK ONE:

- ❑ Individual $30
- ❑ Family $60
- ❑ Supporting $100
- ❑ Contributing. $250
- ❑ Patron $500
- ❑ Benefactor. $1,000

I am a: ❑ New Member ❑ Renewing Member

I do not want to be a member, but want to support CCFA's programs. Enclosed is my donation of $_____.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home #: _____

Email address: _____

Optional & confidential (for CCFA use only):
CCFA does not sell, lend or exchange its member information with anyone. All information is kept strictly confidential.

Employer/
Business Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Work #: _____

Email: _____

- ❑ Crohn's patient ❑ Colitis patient
- ❑ My child has Crohn's
- ❑ My child has colitis ❑ Other_____

METHOD OF PAYMENT

- ❑ Check enclosed (please make your check payable to CCFA)
- ❑ Credit card (please include the following information):
- ❑ Visa/Mastercard ❑ American Express
- ❑ Discover

Account #: _____

Expiration Date: _____

Signature: _____

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NOTES