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Interactive Qualifying Project

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IMPROVING THE QUALITY OF LIFE FOR PATIENTS WITH CROHN'S DISEASE AND ULCERATIVE COLITIS

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This project report is submitted in partial fulfillment of the degree requirements of Worcester Polytechnic Institute. The views and opinions expressed herein are those of the authors and do not necessarily reflect the positions or opinions of <u>MassGeneral Hospital for Children, Crohn's and Colitis Foundation of America</u> or Worcester Polytechnic Institute.

This report is the product of an educations program, and is intended to serve as partial documentation for the evaluation of academic achievement. The report should not be construed as a working document by the reader.

ABSTRACT

Over two million Americans suffer from an extremely debilitating disease called Inflammatory Bowel Disease. The purpose of this project was to improve the quality of life for children suffering from two forms of this disease, Crohn's Disease and Ulcerative

n interactive board game was created to aid the

ease and feeling comfortable with the inevitable

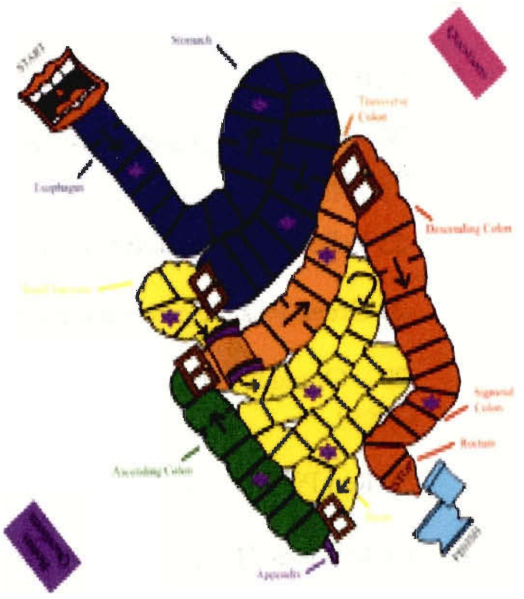
their lives.

THE
IBD GAME

RULES OF PLAY

For 2 to 4 players or teams

For ages 12 to 18



OBJECT

The object of the game is to move your game piece along the digestive tract from the start, at the mouth, to the finish, at the toilet, by rolling the die and to get rid of all of the pills for each section of the digestive tract by answering questions correctly.

EQUIPMNET

- IBD Game Board
- Questions / Answer Cards
- 4 Game Pieces
- 1 Die
- 5 types of pills

  -30 Blue Pills (Esophagus and Stomach)

  -25 Yellow Pills (Small Intestine)

  -20 Green Pills (Ascending Colon)

  -20 Orange Pills (Transverse Colon)

  -25 Red Pills (Descending Colon)
- 4 Pill Boxes (To store Pills while playing)

SETUP

1. Each player or team needs to choose one of the four game pieces. to use during the game.

2. Each player or team needs to choose the following number of pills:

   - 6 Blue Pills (Esophagus and Stomach)
   - 5 Yellow Pills (Small Intestine)
   - 4 Green Pills (Ascending Colon)
   - 4 Orange Pills (Transverse Colon)
   - 5 Red Pills (Descending Colon)

3. Each player or team needs to receive a pill box, so they can store all their pills in it during the game.

4. Place the bonus questions on the space labeled "Bonus Questions" and the regular questions on the space labeled "Questions".

5. Each player or team needs to roll the dice. The player or team with the highest roll goes first.

GAME PLAY

For each turn, a player or team rolls the die to determine the number of spaces to move. The player or team then proceeds the number of spaces shown on the die. When the player or team arrives at the space, an opposing player will then read the next question card. If the player or team landed on a space marked with a purple star, then the question is be drawn from the "Bonus Questions" pile. Otherwise the question is to be drawn from the regular "Questions" pile. If the player or team answers the question correctly, then the player or team will discard the designated number of pills, otherwise, no pills will be discarded and it will be the next player or team's turn. When the player reaches any one of the doors, and has not discarded all of his pills for that section, the player must go back to the start of the section. Once the player has discarded all of his or her pills for that section they may proceed through the doors.

NOTES

- Bonus questions do not have one correct answer. Any answer given by a player or team for a bonus question is considered correct.

ACKNOWLEDGEMENTS

There are many people who we would like to thank, but first we would like to thank our advisor Professor Leonard Polizzotto. Throughout this project he has been nothing but an incredible advisor and a friend to us all.

We would also like to thank Heather Peach for all the effort that she has most willingly put into this project. Without Heather this project would never have begun or became a reality. Thank you very much.

In addition, we would like to thank Theresa Murphy and the Crohn's and Colitis Foundation of America for all of their help and support throughout this project.

We would like to thank Kevin Keenaghan for all of the time and effort that he put in over his school break in helping the team editing the paper. Without Kevin this project would not look and sound as nice as it does today.

Lastly I would like to thank all of the patients suffering from Crohn's Disease and Ulcerative Colitis who have helped to make this project possible, and I would like to dedicate this paper to the millions of people that have to suffer with these diseases every day.

EXECUTIVE SUMMARY

Inflammatory Bowel Disease (IBD) is an intestinal condition that afflicts over two million Americans. Crohn's Disease and Ulcerative Colitis are two types of IBD, which are both mentally and physically debilitating. The goal of this project was to improve the quality of life for patients suffering from Crohn's Disease or Ulcerative Colitis.

The project team began by getting an understanding of the two diseases through research. Books and the Internet were used to help the project team to understand, through the words of patients, parents, and doctors, what the patients were going through and what kinds of things might help them get better both mentally and physically.

After the preliminary research was completed a better understanding was still needed of what the patients' needs and wants were if they were going to improve the quality of life of the patients. A survey was created to be given to the patients which asked questions that would help the project team to better educate themselves about the needs of the patient. During this period the members of the project group realized that they needed a larger sampling than just the patients, so a survey was created for parents and healthcare workers as well. Through the help of Heather Peach, an employee at MassGeneral Hospital for Children, and Theresa Murphy, an employee of Crohn's and Colitis Foundation of America (CCFA), the surveys were distributed to patients suffering from Crohn's Disease and Ulcerative Colitis, their parents, and their health care workers.

Once all of the surveys were returned to the project team, the results were analyzed and the team came to the conclusion that the patients were lacking in information about Crohn's Disease and Colitis, fun activities, and interaction with others.

Once this conclusion was reached, it was determined that there was a need for some type of design that would benefit the patients in all of the ways listed above. The initial thought was to create a computer game, a book or manual, or a video or skit. All of these ideas met some of the criteria, but not all. The fourth idea was to create a board game. The board game met all of the criteria, it was fun and enjoyable, it was interactive, and it was a wonderful learning tool.

The board game consists of a picture of the entire GI tract. The tract starts with a mouth, following all the way through and ending with a toilet, where the game ends. Each player, at the start of the game, is given a designated number of pills which are colored according to the colors on the board. The players move to different spaces on the board when the dice is rolled. Every time the player lands on a space, they are asked a question. If the question is answered correctly, they can get rid of the designated number of pills on the question card. Whichever player gets rid of all of his or her pills and reaches the toilet first wins.

This project, through its research and ultimate project design created from it, will help to educate patients suffering from Crohn's Disease and Ulcerative Colitis in an informative and enjoyable manner. It is the hope and expectation of the members of the project group that through their efforts, the quality of life of children suffering from these diseases will be improved.

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Chapter 1 Introduction (Esophagus)

Approximately two million Americans suffer from a group of diseases known as Inflammatory Bowel Disease (IBD). This class of disease afflicts mostly young adults, including thousands under the age of eighteen. There are two major types of IBDs. Ulcerative Colitis and Crohn's Disease are extremely debilitating both mentally and physically. The goal of this project was to improve the quality of life of patients suffering from Ulcerative Colitis and Crohn's Disease. The members of this project team do not have the knowledge or the expertise to improve the physical state of these patients. Therefore, the focus of this project was the improvement of the patients' mental status.

A patient's mental status is affected by many factors that play a role in Ulcerative Colitis. The initial mental hardship for a patient is when they are a diagnosed with a lifelong debilitating disease. Patients also have to begin to deal with abdominal pain, the difficulty of going to the bathroom frequently, as well as the anguish of not being able to do all of the physical activity that they are used. Often times patients will become very stressed which ultimately detracts from their mental state. Many other complications, such as procedures, surgery, and doctor's appointments, also affect a patients mental well being.

Patients identified discomfort about discussing their disease and lack of information about the diseases as two of the most significant issues related to their illness. In order to address these issues and therefore realize the goal of the project, the project team was able to design and implement an informative board game with Ulcerative Colitis and Crohn's Disease as its central theme.

The Interactive Qualifying Project (IQP) is described as "…challeng[ing] students to identify, investigate, and report on a topic examining how science or technology interacts with societal and structures and values. The objective of the IQP is to enable WPI graduates to understand, as citizens and as professionals, how their careers will affect the larger society of which they are a part." This project involved the study of two very debilitating diseases, Crohn's Disease and Ulcerative Colitis. Over the course of the project, the members of the project group were able to blend technology and society by creating an interactive device to improve the quality of life for children suffering from these two diseases.

Chapter 2 Background Information (Stomach)

Inflammatory Bowel Disease (IBD) is a term used to describe several gastrointestinal diseases. There are two major types of IBDs — Crohn's Disease and Ulcerative Colitis. These diseases, like all Inflammatory Bowel Diseases, affect the digestive system. Some of the symptoms associated with these types of diseases are intestinal inflammation, sores, bleeding, scarring and the loss of the smoothness of the inner lining of the intestinal tract. Symptoms can also include abdominal pain, cramping, fatigue, and diarrhea (CCFC, "The Facts About IBD," 2000). No cure currently exists for either disease. However, they can both be managed through nutritional therapy, medication, and surgery.

An estimated 1,000,000 Americans are afflicted with Inflammatory Bowel Disease. This number is not very exact since it is difficult to diagnose most IBDs. Although Inflammatory Bowel Diseases afflict people of all ages, most cases are diagnosed in patients under the age of 30. Males and females appear to be equally afflicted by the diseases. People who have family members with an Inflammatory Bowel Disease have an increased chance of being diagnosed with the disease (CCFA, "Questions and Answers," 2000). For this reason, researchers believe that Inflammatory Bowel Diseases have a genetic link. Research indicates that the some people have a genetic susceptibility that enables an agent such as a virus or bacteria to trigger an abnormal immune response (WebMD, "What is IBD," 2000). Most cases of Inflammatory Bowel Diseases occur in North America and Northern Europe. A much smaller number of cases occur in central Europe, the Middle East, and Australia, and practically none occur in Asia and Africa (CCFC, "The Facts About IBD," 2000). Researchers, because of this fact, also believe there is an environmental link.

2.1 Ulcerative Colitis

Ulcerative Colitis is one type of Inflammatory Bowel Disease. Ulcerative Colitis causes an inflammation of the colon and/or rectum, which is commonly known as the large intestine. It is described as the inflammation and ulceration of the innermost lining of the colon, known as the *mucosa*. With Ulcerative Colitis, the inflammation is localized in the large intestine and extends up from the rectum through the colon, without any areas of normal tissue intermixed with the diseased tissue (CCFA, "Question and Answers," 2000).

Presently, there is no cure for ulcerative colitis except for surgery. However, sometimes the post-surgery side effects outweigh the benefits of the surgery. As a result, doctors only advocate surgery as a last resort. As better surgical techniques are developed, surgery becomes a more viable solution early on in the progression of a patient's disease. However, right now keeping the disease under control is the first step in a patient's treatment process (Chipman, 1-30-2000).

Ulcerative Colitis is characterized by several main intestinal symptoms, which range in severity depending on the severity of the disease. These symptoms usually include diarrhea with or without rectal bleeding, which results in extreme abdominal pain. This diarrhea can be described as watery, loose stool or more frequent soft stool. This is due to the fact that Ulcerative Colitis interferes with the everyday functioning of the colon, including the absorption of fluids from the stool. The excess fluid is the underlying cause of the diarrhea. The severity of the patient's diarrhea has been found to coincide with his or her diet and the severity of his or disease (Rood and Stein, 1999).

Some patients may experience rectal bleeding, while others may not. This is dependent upon the severity of the disease. Abdominal pain is commonly seen in patients with Ulcerative Colitis, and is usually described as cramps that occur in the lower abdomen. It tends to occur in conjunction with an urge to have a bowel movement and tends to improve or is relieved by the completion of the bowel movement. The underlying cause for this pain is the spasms of the colon caused by inflammation (Rood and Stein, 1999).

Sometimes these symptoms progress to a critical point, called *Toxic Megacolon*. During Toxic Megacolon, the colon loses its muscular tone and becomes critically dilated. If the progression is not diagnosed at an early stage, perforation of the colon will occur. The perforation is usually followed by an infection of the abdominal cavity called *peritonitis*. Toxic megacolon is a medical emergency and, as a result, requires immediate surgery (Rood and Stein, 1999).

Ulcerative Colitis increases a patient's risk of developing colon cancer as much as three to five percent and increases with duration of the disease (Rood and Stein, 1999). When colon cancer is detected, a colectomy (refer to Section 2.12) is usually the prescribed course of action.

Of the patients who will develop extra-intestinal symptoms, one out of every five will develop joint and skeletal pain (Rood and Stein, 1999). The cause of the joint pain is linked to intestinal inflammation. Joint and skeletal pain often occur during active periods of the disease. Sometimes, joint problems are a precursor to intestinal pain. For example, arthritic pain can manifest in children long before Ulcerative Colitis is suspected. The large joints (knees, hips, shoulders, ankles, etc.) are typically affected. Most often, the joint pain subsides once the intestinal pain is gone. However, sometimes it will cause joint damage and, in turn, cause a chronic problem. In general, patients suffering from arthritic pain have to cope with decreased physical activity (Rood and Stein, 1999).

Similarly, the spine can be affected by Ulcerative Colitis. This condition is called *spondylitis,* and is characterized by lower back pain with morning stiffness. Spondylitis can usually be relieved through special exercises. A person who is affected by spondylitis often experiences a loss of flexibility due to problems with the spine's supporting ligaments. Over time, this could lead to a decrease in chest expansion; in late stages of the condition, the cervical spine can develop nerve problems similar to those seen in people diagnosed with a pinched nerve. A program of increased exercise and deep-breathing exercises can help minimize the disability associated with spondylitis (Rood and Stein, 1999).

It is now known that Ulcerative Colitis affects the metabolism of bone. This results in a thinning of bone, known as *osteopenia*. The severity of osteopenia has been observed to be greater in younger people. Progress has been made to correct this problem directly, but the best primary course of action is to control the inflammation, which is the underlying cause. This joint inflammation can lead to a less active lifestyle and even more severe complications if not detected early (Rood and Stein, 1999).

Skin problems can also be linked to the problems occurring in the intestines of a patient. The most common skin problem is called *erythema nodosum*. It is characterized by tender bumps on the skin, usually on the legs, and commonly precedes intestinal inflammation. Another complication of much greater concern is ***pyoderma gangrenosum***. Pyoderma Gangrenosum causes intense injury to small blood vessels and their lining cells. This is of great concern because it is not susceptible to conventional therapies, even steroids (Rood and Stein, 1999).

Other skin complications include canker sores in the lining of the mouth, cracks in the corners of the mouth (*cheilosis*), splitting of the lips (*fissuring*), and a reddening of the skin around the mouth. All of these problems can cause harsh changes to the outward appearance of a patient suffering from them. (Rood and Stein, 1999)

2.11 Medicinal Intervention for Ulcerative Colitis

Medication is usually the first option chosen by doctors to treat a patient with Ulcerative Colitis. This is due to the fact that effective medical treatment with medication has been found to help control the disease by suppressing inflammation, promoting intestinal healing and relieving the symptoms of diarrhea and abdominal pain. The medications prescribed by doctors can be separated into three categories: Anti-inflammatory medications, antibiotics, and anti-diarrheal medications (CCFA, "Medications," 2000).

Anti-inflammatory medications are used to suppress the harmful inflammation of the colon caused by Ulcerative Colitis, thereby relieving the abdominal pain caused by the inflammation. There are three major categories of anti-inflammatory medication, each with its own side effects. The first type is *Corticosteroids*, which includes drugs such as *Prednisone*, Hydrocortizone suppositories and enemas, *Methylprednisolone*, *ACTH*, and various other drugs. Corticosteroids are known to cause side effects in people who take high doses for extended periods of time. Possible side effects include weight gain, red blotches on the skin, increased facial hair growth, hypertension, severe mood swings, increased blood-sugar level (which can induce diabetes), weakness and cramps in the legs, and cataract formation and osteoporosis when a patient's treatment exceeds six to twelve months (Zukerman and Inglefinger, 1997).

The second type of anti-inflammatory medication is *sulfasalazine*, which includes drugs like *Azulfidine* and other generic forms. Sulfasalazine is commonly used to treat mild to moderate cases of Ulcerative Colitis. Its possible side effects include sulfa related allergies like fever, skin rashes, and joint pain, as well as nausea, headaches, fatigue, lowered white blood cell count, and temporary infertility in some men (CCFA, "Anti-Inflammatory Medications," 2000).

The third type of anti-inflammatory medication is *5-ASA* compounds, which includes drugs such as *Asacol*, *Dipentum*, *Pentasa*, and *Rowasa*. These drugs are usually prescribed to patients who cannot tolerate Sulfasalazine-type drugs. The drugs that fall into this category have only a few of possible side effects. These include loose bowel movements in patients in which the disease is active and the risk of long-term kidney damage in patients who are on doses that exceed 4000 mg a day (CCFA, "Anti-Inflammatory Medications," 2000).

The second category of medication is antibiotics. Antibiotics like *ampicillin* (Unasyn), *cephalosporin* (Keflex), and *tetracycline* (Achromycin) are used to treat the secondary infections that are caused by the penetration of bacteria into the damaged tissue of the intestinal wall. These antibiotics have side effects that are more commonly seen in patients with severe cases of Ulcerative Colitis who are on multiple medications. These side effects include yeast infections of the mouth and throat, which cause other symptoms such as white plaque on the lining if the cheeks, tongue, and throat, and pain in the throat or chest when swallowing (CCFA, "Antibiotic Medications," 2000).

The third type of medication that is prescribed for the treatment of Ulcerative Colitis is anti-diarrheal medication. Anti-diarrheal drugs such as *Loperamide* (Imodium) and *Diphenoxylate* (Lomotil) help reduce diarrhea by slowing down the rate of food traveling trough the digestive tract. This allows the digestive enzymes more time to break down undigested fats and fiber. Loperamide also helps prevent incontinence by tightening the anal sphincter muscles. Anti-diarrheal drugs, like any other type of drug, can cause side effects, including gas, bloating, cramps, and constipation (CCFA, "Antidiarrheal Medications," 2000).

Doctors generally prescribe these medications in conjunction with one another, because each drug has its own purpose. However, in some patients, medication might not be successful. When this is the case, doctors have to resort to the option of surgery (Chipman, 2000).

2.12 Surgical Intervention for Ulcerative Colitis

Twenty five to forty percent of Ulcerative Colitis patients require surgery. The usual disease complications that require surgery include hemorrhage, toxic megacolon, perforation, mild stricture, severe *dysplasia* (premalignant tumors), and cancer of the colon or rectum. Some patients who have Ulcerative Colitis are able to continue a completely normal lifestyle after surgery, while others do not respond well to surgery and develop other complications (Rood and Stein, 1999). Surgery can be classified as elective, urgent, or emergency. In most of the cases that require surgery, the surgery is needed immediately after the onset of complications. This is due to the fact that complications can sometimes be life-threatening or become life-threatening if left untreated (Rood and Stein, 1999).

Because Ulcerative Colitis is limited to the colon and rectum, there is a limited number of surgical procedures that can be performed. One type of surgery is a *proctolectomy*, the removal of the colon and the rectum with a permanent ileostomy that involves having an external "bag" to hold stool. During this procedure, the colon and rectum are removed and the end of the small intestine, called the Ileum, is connected to the abdominal wall by the way of a *stoma*. Then, a "bag" for collecting stool is attached to the abdomen on the outside of the patient's body. This procedure involves follow-up care for the patient, which includes regular emptying of the bag. This surgery is widely used if the patient is emotionally ready to cope with a permanent external ileostomy (Rood and Stein, 1999).

Another surgical intervention is a *continent ileostomy,* which was pioneered by Nils Kock. During this procedure the colon and rectum are removed and a pouch is made from the small intestine. This internal pouch is then connected to the wall of the abdomen by using a flat stoma with a valve. A catheter is then passed through the stoma and the valve when the pouch has to be drained. This is not usually the first chosen surgical procedure for patients, but is a good choice in certain cases (Rood and Stein, 1999).

Often patients find it difficult to tell when the pouch needs to be emptied, which is why a patient's follow-up care involves having a scheduled routine for emptying the pouch. Usually, a patient needs to drain his or her pouch two to eight times a day (Rood and Stein, 1999). This procedure also has some long-term complications. The valve that the catheter is passed though can develop slippage and prolapse, which requires additional surgery to correct. Patients are encouraged to follow some dietary restrictions after surgery. Their diet should not include any foods that do not digest fully because they are hard to drain out of the pouch. *Pouchitis* is also another concern. Pouchitis is an inflammation of the pouch, which may involve symptoms including pressure, pain, and cramping in the pouch. Pouchitis is accompanied by fever, malaise, or arthralgia, and is usually treated with medication, although it can reoccur after treatment (Rood and Stein, 1999).

A third surgical procedure is a "*proctocolectomy* (removal of the colon and rectum), with salvage of the anal muscles (sphincters) by construction of a new rectum (neorectum) from the distal small bowel (reservoir or pouch) and a temporary ileostomy. The loop ileostomy in closed after 6 weeks." (Rood and Stein, 2000; 156) The common name for this procedure is the *ileal pouch-anal anastomosis*, or *J-pouch*. The procedure usually requires two different stages, which means two separate operations. This type of surgery is not restricted to one age group (Rood and Stein, 1999).

The J-Pouch procedure is usually associated with long and short term complications, like any other major surgery. Conversion to a permanent ileostomy is required in seven to ten percent of patients with J-pouches. (Rood and Stein, 1999) The reasons for this include Crohn's disease of the pouch, chronic pelvic infection, and overall poor tolerance to the pouch. Bowel obstruction and pouchitis are the most common long-term complications. Some of these complications can be treated with medications, while others may require additional surgery (Rood and Stein, 1999).

A fourth procedure involves the colon, but not the rectum. During this procedure, only the colon is removed and the small intestine is connected directly to the rectum. This procedure is only useful in certain cases of Ulcerative Colitis (Rood and Stein, 1999).

The two procedures involving ileostomies were the surgeries of choice before the creation of the J-Pouch. The J-Pouch has become the more commonly used procedure because it does not induce some of the emotional strain attributed to having an ileostomy. Likewise, more procedures are being developed everyday to improve the lives of patients with Ulcerative Colitis and help them feel "more normal," although any surgery is difficult for a patient due to the many risks involved.

2.2 Crohn's Disease

Crohn's disease is a serious chronic inflammatory disease of the gastrointestinal tract. The disease predominately affects the lowest portion of the small intestines (ileum) and the large intestine (colon), but can also occur in other parts of the digestive tract, such as the esophagus or stomach. Crohn's disease usually afflicts all layers of the intestinal wall. The most common forms of Crohn's disease are *ileitis,* small-bowel Crohn's disease, and *ileo-colitis*, Crohn's disease affecting the ileum and colon. In approximately one in four cases of Crohn's disease, the disease affects the anus.

The disease can be hard to diagnose because its symptoms are similar to those of other Inflammatory Bowel Diseases (Lewis, 2000). Symptoms of Crohn's Disease can flare up after periods of remission, or they can be continuous. The most common symptom is diarrhea. Another symptom is constipation, which is usually caused by an obstruction in the small intestines. Abdominal pain, or cramps, can be caused by intestinal contractions and are usually related to diarrhea. Other common symptoms of Crohn's disease are fever, fatigue, and a loss of appetite, which may result in weight loss. *Tenesmus*, a painful urge for a bowel movement, can occur because of the inflammation in the rectum (WebMD, "What is IBD," 2000).

There are many complication associated with Crohn's Disease. Some potential complications are malnutrition and malabsorption. Toxic Megacolon is a serious complication that can occur when deeper layers of the colon become inflamed. This condition can cause the colon to enlarge or become paralyzed, and in extreme cases may cause it to rupture. If this happens, emergency surgery is necessary. A rupture of the colon is associated with a 30% mortality rate. Symptoms of Toxic Megacolon include weakness, abdominal pain, bloating, grogginess, and disorientation (WebMD, "What is IBD," 2000).

Abscesses and fistulas develop when there is a microscopic break in the intestinal lining, which allows germs to cultivate and infections to develop. An abscess may begin as a pimple-like boil that may expand and become very painful. Surgery for an abscess involves a surgical cut in the abscess, which allows the liquid inside to drain away. A rectal fistula is an abnormal opening that connects the rectum to the skin (external fistula), or connects the rectum to an organ (internal fistula). Surgery may be needed to drain away infected fluid and close the opening (WebMD, "What is IBD," 2000).

Another common complication of Crohn's disease is intestinal blockage. Segments of scar tissue caused by inflammation, called *strictures,* can contract the passageways of the digestive tract, such as in the intestines. This causes a bowel obstruction, which is associated with symptoms such as cramps and vomiting (WebMD, "What is IBD," 2000).

Patients with Crohn's disease have an increased risk of cancer of the digestive tract, especially colon cancer. Crohn's disease can cause complication outside the digestive tract, as well. Patients often suffer from stiffness of the joints and arthritic symptoms. Mouth sores, complications in the eyes, hepatitis, and kidney failure can also occur, along with gallbladder disease and gallstones. Blood loss due to ulcers resulting from the illness often causes anemia. In children, Crohn's disease may impair physical growth and postpone puberty.

Along with the physical complications that occur as a result of Crohn's disease, patients often also face emotional and neurological issues. Patients suffering from Crohn's Disease often associate eating with fear of abdominal pain. Attacks of diarrhea and anal leakage can cause a sense of humiliation, which in turn can result in social isolation and lowered self-esteem (Bowers, 9-25-2000).

2.21 Medicinal Intervention for Crohn's Disease

Medication plays an important role in treating Crohn's Disease. Most of these medications have serious side effects because of their potency. There are three reasons that people take medication if they have been diagnosed with Cohn's Disease: to reduce inflammation in the gastrointestinal tract, to reduce symptoms of the disease, and to treat the complication of the disease (CCFC, "Medication for IBD," 2000).

The first major category of medication that is prescribed to patients with Crohn's Disease is anti-inflammatory drugs. Anti-inflammatory drugs are used to reduce the inflammation caused by Crohn's Disease, thus relieving painful symptoms (CCFC, "Anti-Inflammatory," 2000). One commonly prescribed anti-inflammatory drug is Sulfasalazine, used to treat mild to moderate attacks of Crohn's disease. It reduces the production of diarrhea-causing chemicals, thus decreasing inflammation and allowing healing to occur. It also removes oxygen radicals that are released during inflammation, which can cause tissue damage and can kill cells (WebMD, "Medication for IBD," 2000).

The most common side effects of Sulfasalazine are nausea, reduced appetite, and vomiting. Another less common side effect is the shortening of the lifespan of the red blood cell, called *hemolysis*. The most unlikely, although most serious, side effect is bone marrow shutdown, which is called *marrow aplasia*. Patients who take this drug may need a vitamin supplement, because sulfasalazine reduces the ability of the intestine to absorb folic acid. 5-Aminosalicylate (5-ASA) is Sulfasalazine without the sulfa as a carrier. It is used as an alternative to Sulfasalazine, mostly for patients who are allergic to sulfa. The side effects of this drug are the same as for Sulfasalazine (CCFA, "Anti-Inflammatory Medication," 2000).

Another commonly prescribed anti-inflammatory drug is *Glucocorticosteroids* (steroids). Examples of commonly prescribed steroids are Prednisone, hydrocortisone, Betamethasone, Tixocortol, and Budesonide. These medications are used to treat moderate to severe cases of Crohn's Disease, to reduce inflammation. Patients with Crohn's Disease may need to take steroids continuously to control chronic symptoms of the disease.

Steroids have major side effects, including rounding and redness of the face, hair growth on the face, and acne. In children, reduced growth rate or delayed puberty can be associated with steroid use. In cases of malnutrition, swelling of the ankles may occur due to increased fluid levels in the body. Patients who use steroids for long period of time may develop fatty deposits in the arms, legs, and sometimes in the middle or upper back. Muscle weakness in the thighs and upper arms can also occur. Patients on steroids usually have an increased appetite and suffer weight gain because of this increase.

The "invisible" side effects of steroids include softening of bones, thinning of the skin in the arms and legs, a reduction of the body's fatty cushion-making veins more fragile and increased susceptibility to bruising. Another side effect is increased blood sugar, which can aggravate diabetes. Steroid use can sometimes cause peptic ulcers. It can also have psychological side effects, including changes in people's moods. A patients' psychological reaction to the steroids and the side effects can vary. They can become more energetic or they can become more depressed (WebMD, "Medication for IBD," 2000).

Another category of medication used to treat Crohn's disease is immunosuppressives. Some of the major immunosuppressives are *Azathioprine*, 6-

mercaptopurine (6-MP), *methotrexate*, and *cyclosporine* A (CCFA, "Medications," 2000). Immunosuppressives are used to suppress the immune system, and to help reduce inflammation (CCFA, "Immunomodulator," 2000). In some cases, immunosuppressives help to heal fistulas. They are often prescribed so that patients can limit their intake of steroids or stop taking them all together. Immunosuppressives have side effects, as well, since they interfere with the immune system. They decrease the body's ability to fight infection, and increase the likelihood of infection. Each particular immunosuppressive has its own side effects. The side effects can vary greatly depending on the medication. Some are very mild and some can be life-threatening. For example, Azathioprine and 6-mercaptopurine can interfere with a patient's bone marrow activity, and cause pancreatitis. Some of the mild side effects are loss of appetite, nausea, and vomiting. Methotrexate has similar side effects, except that it may cause scarring of the liver and, in severe cases, *cirrhosis* of the liver (WebMD, "Medication for IBD," 2000).

One of the largest categories of medication prescribed to patients are antibiotics. Examples of commonly used antibiotics are *Metronidazole*, *Ciprofloxacin*, *Ampicillin*, *Cefazolin*, *Gentamicin*, and *Tobramycin*. They are used to treat infections killing bacteria. In Crohn's disease, antibiotics may be the only medication prescribed. Side effects vary between different antibiotics, since each antibiotic treats a specific complication of Crohn's Disease (WebMD, "Medication for IBD," 2000).

The two major antibiotics used to treat Crohn's Disease are Metronidazole and Ciprofloxacin. Metronidazole is prescribed mainly to treat abscesses and fistulas in or near the anus (CCFA, "Antibiotic," 2000). The most common side effects include nausea, loss of appetite, dizziness, headache, drowsiness, confusion, difficulty sleeping, itchy rashes, vaginal discharge, and darkened urine. When taking metronidazole, some people cannot tolerate alcohol. Ciprofloxacin is very effective in treating abscesses around the anus. It can cause difficulty sleeping, vivid dreams, and tendonitis (WebMD, "Medication for IBD," 2000).

The last major category of medication used to threat Crohn's Disease is anti-diarrheal drugs. Examples of this type of drug are *Loperamide*, *Codeine*, and *Diphenoxylate*, which are used to control abdominal discomfort and diarrhea. Anti-diarrheal drugs change muscle activity and retard the functions of the intestines. They can also have side effects, including constipation and bowel obstructions (CCFA, "Antidiarrheal Medications," 2000).

2.22 Surgical Intervention for Crohn's Disease

Surgery as the medical treatment for Crohn's disease is not simply a last resort. Sometimes surgery is the only treatment for a particular condition. Approximately 75 percent of people with Crohn's disease will have surgery at some point in their lives. Surgery becomes an option when massive bleeding or Toxic Megacolon occurs, when medication doesn't work, or when the intestinal lining becomes pre-cancerous or cancerous. It is performed to alleviate the painful symptoms of the disease and improve the quality of life of the patient. Symptoms may go away and medication may be stopped, although the disease may reoccur at any time. Surgery for Crohn's disease may repair damage such as abscesses and fistulas, remove an obstruction or blockage of the bowel, or remove an entire section of diseased tissue (*resection*). Depending on the type and scope of the surgery performed, the patient may later need to rely on alternative means of collecting and removing feces.

The most common surgical procedure for Crohn's disease involves removing an obstruction in the small intestine. Obstructions occur when inflammation causes the wall of the small intestine to thicken. Eventually, the bowel becomes so constricted that food can no longer pass through it. This narrowing is called a *stricture*. A stricture may be corrected either by *strictureplasty* or by resection.

In strictureplasty, the narrowed area of intestine is surgically opened and the intestine is widened. The stricture usually doesn't re-form in the same place. Strictureplasty is a preferred procedure because it does not involve removing a piece of the small intestine.

In a resection, the diseased area of intestine is removed and the remaining sections of healthy tissue are joined together. Surgeons try to avoid procedures that might shorten the ileum whenever possible, because it can lead to *Short-Bowel Syndrome*. The ileum digests and absorbs fat. Short-Bowel Syndrome occurs when there is not enough tissue to absorb the nutrients in food that the body needs. The patient must compensate for the removed or shortened ileum by taking medication and consuming less fat. One symptom of Short-Bowel Syndrome is chronic diarrhea.

The usual procedure for the jejunum is a resection, with the ileum taking over its nutrient-absorbing functions. The duodenum is only several centimeters long, which makes it difficult to do either a resection or strictureplasty. In this case, a *gastrojejunostomy* is performed, is a bypass operation in which the upper jejunum is connected to the stomach.

Surgery for Crohn's disease often only alleviates symptoms for a limited period of time. The recurrence rate for Crohn's disease varies greatly, depending on the affected section of the intestine. The recurrence rate of Crohn's Disease in patients for whom both the small and large intestines are affected is approximately six to eight per cent per year. This rate is slightly less in patients for whom the small bowel was the only section affected. It is even slightly more decreased if the colon was the only section affected. Medical therapy can be used to decrease the recurrence rate of Crohn's Disease (CCFC, "Surgery and IBD," 2000).

2.3 Physical and Emotional Complications Associated with Surgery

Counseling and support is very important after surgery, especially if the patient is coping with the difficulties associated with an ostomy surgery. An *enterostomal therapist* is the person who counsels and teaches patients, both before and after an ostomy surgery. The enerostomal therapist teaches patients how to use and care for any external devices needed after surgery, such as an iliostomy "bag," and counsels patients on how to cope and function with an ostomy on a day-to-day basis.

Surgery may cause changes in digestion. If more than one meter of ileum is removed, there is not enough tissue to absorb nutrients. Some patients will need injections of Vitamin B12 because the body may not be able to absorb Vitamin B12 and bile salts.

When the entire ileum is removed, the liver still produces bile salts but there is less tissue for the body to absorb the bile salts. Bile salts help the intestine digest fat; therefore, fat cannot be absorbed correctly in their absence. This causes the body to absorb more oxalates, which causes kidney stones to form. Patients may have to be put on a low-oxalate diet to alleviate these complications.

Patients who undergo ileostomies release more water than normal. If the patients do not drink enough fluids, they will produce less urine than normal causing uric acid stones to develop. Doctors recommended that these patients drink two to three liters of fluids a day to prevent this complication from developing (CCFC, "Surgery and IBD," 2000).

2.4 Mental Aspects of Inflammatory Bowel Disease

Patients with Inflammatory Bowel Disease suffer from many mental hardships due both to their disease and to the side effects from medications. For all patients, everything starts with the initial diagnosis. Their reaction to the diagnosis may be disbelief, anger, and sometimes confusion (Rood and Stein, 1999). Many patients, when they are first diagnosed, do not even realize how severe their disease can be both physically and mentally. Many patients, until they have a better understanding of Ulcerative Colitis or Crohn's Disease, may feel that this is in some way all their fault (Chipman, 1-30-00).

For most patients, the first few months are the most difficult. This is the time they are bombarded with new information, put on many new medications, and are forced to make many serious changes in their life. This is the time when many patients can become very depressed (Depression, 2000). Their life is suddenly changing for the worse. The most difficult aspect of Inflammatory Bowel Disease for a child is the changes that must occur to his or her social lifestyle (Colitis Foundation, 2000). He or she is no longer able to go out with his or her friends without worrying about having to use the bathroom (Colitis Foundation, 2000). For many children, this adds a lot of mental stress and often causes a reluctance to leave the house (Depression, 2000). IBD causes many physical problems, but often times the mental effects may be more devastating to a child's life. "[C]olitis zaps the motivation right out of you" (http://www.thearea.com/colitis/mylife.html, 2000).

Discussing the disease may be one of the hardest things for a child to do. Not being able to talk with anyone about his or her problems leads to a large build up of anger, depression, and often excess stress, all of which negatively affect a patient's battle against Ulcerative Colitis or Crohn's Disease (Barouta, "Stories," 2000).

Coping with the pain from the disease becomes an extremely large part of a patients life. This often causes a child a great deal of mental pain. Patients often think about the pain constantly. At times this may be the only thing on their mind. Many patients are generally thinking about the pain they are experiencing or the next time they will have to use the bathroom (Barouta, "Tips and Advices," 2000).

Having to cope with the physical changes that occur from the side effects of the disease and the medication is very difficult for many patients. Most patients with Ulcerative Colitis suffer from major weight loss. Patients having to take steroids may also have to deal with weight gain, acne, bloating, and many other side effects which are difficult for a child to deal with.

Being in the hospital, undergoing many procedures, and missing school can change a child's life drastically. "No child ever wants to miss school or be in the hospital for an extended period of time" (Chipman, 1-30-00). Many times a child will experience anxiety caused by all of these factors. Children can become very stressed and scared when they have to stay in the hospital overnight or undergo a medical procedure (Barouta, "Stories," 2000).

There are many ways in which patients with Inflammatory Bowel Disease have been very successful at coping with the mental side-effects of these diseases. Formal and informal support groups are one way to cope with these mental effects. There is also psychiatric help available, along with other means of counseling. The most important issue is that the child feels comfortable throughout this entire process.

Support groups seem to be the best form of coping for a child battling their disease (Demio, 2000). Support groups act as a place where a child can feel extremely comfortable discussing what he or she is going through. A support group may also become a place where a patient no longer feels alone. He or she is in an environment where there are other people with the same problems, which often makes the child no longer feel like they are "the only one."

Support groups are a place where a child and his or her family can receive additional information about Ulcerative Colitis or Crohn's Disease. Many times it is difficult to ask a lot of questions when a patient is in a doctor's office, and a support group can often become the next best place. The first step to attending a support group is wanting to get help from others who share the same problems (Chipman, 1-30-00).

Another way to cope with the mental hardships from Ulcerative Colitis or Crohn's Disease is for a patient to seek help from a psychiatrist. If a patient is in need of psychiatric help it is usually recommended by his or her doctor. A patient may often see a psychiatrist when they become very depressed (Rood and Stein, 1999).

Other forms of coping with the pain and mental hardships involve biofeedback (self-hypnosis), acupuncture, and herbal medicines. These techniques may be helpful for some patients when dealing with the pain associated with their disease (Rood and Stein, 1999).

There are many other ways in which a child can learn to cope with the mental hardships involved with Ulcerative Colitis or Crohn's Disease. Learning to discuss their problems among friends and families is one way. Keeping stress levels low and learning one's physical and mental limits are also very important to the treatment of their disease. "Although it is very difficult for many patients to discuss their disease with others, this is the best way for friends and family of patients to understand the situation and be able to help them" (Chipman, 1-27-00). Many patients find much of their stress relieved when they are able to discuss their problems with their friends and families. Ulcerative Colitis and Crohn's Disease can be very difficult mentally to deal with, but a child needs to learn how not to let the disease win (Barouta, "Stories," 2000). The disease causes many changes in a child's life, but there are always ways to get around these changes. A child and his or her family have many resources available to them, if they are made aware of these resources and choose to utilize them.

Chapter 3 Data Gathering (Small Intestine)

In order to improve patients' quality of life it was first necessary to determine what their specific needs are. The best possible way to do this would have been to speak directly with the patients and inquire as to what they are lacking or would like to see. Unfortunately, the strict policies of hospitals would not permit this course of action. Without gathering data directly from the patients, the project team would have been forced to use more conventional data from research materials such as books, magazines, or web pages. Because this type of data is not as accurate as that gathered directly from patients, however, the team decided that another course of action was necessary. It was decided that a survey would best suit the needs of this project without infringing on the policies of the hospitals.

3.1 Survey Creation

The most important thing that the project team wanted to get out of the survey was an idea of what to design that could improve the quality of life for patients. To do this, it was necessary to determine not only the opinion of the project team, but more importantly the opinion of the patients themselves. The survey was designed so that the questions that asked would give the team a better idea of the patients' needs and wants. When creating the survey, the project team had researched all the facts about Crohn's Disease and Ulcerative Colitis but did not understand what patients' needs were or how to meet these needs.

The survey was designed to get a response from the patients that would allow the project team to understand of what patients wanted. The project team began to design questions based upon an educated opinion about what patients would be interested in. Based on the research that was conducted earlier, the team developed a list of what types of information would be useful to gain from the patients:

- Patients' feelings about their disease
- Extent of their knowledge of the disease
- What types of medication they are on, and how they feel about being on them
- Patients' feelings about surgery
- How they cope with their disease
- How their parents feel

Using this information, the team determined specific questions that would provide the desired information. The team then compiled the questions in a way that would be easy to read and understand for young patients. The final survey with the completed list of questions can be found in Appendix C. Some examples of questions were:

- Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease?
- What medications do you have to take on a regular basis?
- Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Once the initial draft of the survey was completed, the project team realized that this survey was not adequate to get all of the desired information. The problem with a single survey is that objective questions were asked about a social issue, and many of the responses would be emotionally based. In order to gain the most information from the surveys as possible, both objective and emotional, every group involved with the patient's disease and treatment would need to be surveyed. Using the draft of the patients' survey, the project team modified the questions to create a survey for the parents of the patients and another for health care workers who are involved with the patient on a daily basis. The final surveys can be found in Appendix D and E.

Once the initial drafts of the three surveys were completed they were sent to Heather Peach, an employee of MassGeneral Hospital for Children, who oversaw this project within the Hospital. Ms. Peach edited the surveys and then returned them to the group. This continued for many weeks, until both Ms. Peach and the project team were satisfied with the layout and semantics of the surveys.

3.2 Survey Distribution

After the surveys were completed and ready to be handed out, the project team realized that patients would be reluctant to fill out the surveys without understanding why they were doing so. The team decided that a cover letter attached to each survey would be extremely useful. This poignant, concise letter told either the patient, parent, or health care worker who the project team was, a brief explanation of this project, and the goal of the survey. The final cover letters can be found in Appendix F, G, and H.

Once the surveys and cover letter were completed and ready to hand out, they were given to Heather Peach to distribute to IBD patients who came into the hospital. After many weeks, Heather had not given any surveys out due to a lack of patients entering the hospital. The project team members realized that an alternative way to get responses to the surveys was necessary.

One option was to hand out surveys at the GI outpatient clinic at MassGeneral Hospital. Unfortunately time constraints and hospital policies made this option unfeasible, although Paula Curren, the head nurse at the clinic, was extremely helpful. However, the projection team was able to distribute surveys to the outpatient surgical clinic at the Hospital. The team then spoke with Theresa Murphy, the head nurse at the local chapter of CCFA. She said she would be glad to mail out copies of the surveys to all of the families that she had in her database, and also arranged for the project team to distribute surveys at the Symposium that CCFA holds every year to benefit Ulcerative Colitis and Crohn's Disease. Once an adequate number of surveys were returned, the project team was able to analyze the responses.

Chapter 4 Data Analysis and Initial Conclusions (Colon)

Of the 64 surveys distributed, twenty-nine were returned. Seven of these were patient surveys, fifteen were parent surveys, and seven were healthcare worker surveys. The average age of patients responding to the survey was thirteen years old. Of the seven patients surveyed, the average number of flare-ups of their disease per year was two, and almost every patient has had to spend at least one night in the hospital. Most of the patients who have been in the hospital are there once a year and stay for no more than a week. All of the patients take many types of medication, and have been on steroids at one point or another over the course of their treatment.

After reviewing the results of the patients' surveys, the project team noticed a number of similarities in the responses. Many patients feel they are lacking in communication with their friends, and feel that they are having trouble coping with their disease both mentally and physically. Another major concern that became apparent from the responses was that many patients feel they miss too much school.

The responses of the health care workers to their respective survey also proved very informative. The Health care workers indicated that patients have normal feelings associated with a serious illness. They are often scared, depressed, and angry. The health care workers feel that patients often times feel isolated from everyone around them and that they feel that no one else around them understands what they are going through. The health care workers also feel that many times the patients themselves are not educated enough about their own disease.

The information parents' give was very pertinent, but the information can often be skewed by emotional attachments to their child. Nevertheless the value of the information can outweigh this. The parents are the best resource for information next to the patients themselves. Once again, the results from the parents survey contained common ideas. Emotions that the parents saw in their children are anger, fear, and depression. Most children do not understand why they developed either Crohn's Disease or Ulcerative Colitis. The parents indicated that their children are isolated and do not relate to children whom are not afflicted with Crohn's Disease or Ulcerative Colitis very well. Parents feel that their children often times feel embarrassed, and have the fear that other children will not understand what is going on.

4.1 Statement of Issues

After analyzing all of the data from the three surveys, the project team was made aware of two major issues. First, patients have the most difficulty discussing their problems with people other than their parents. There are multiple reasons for this occurrence. Many patients do not feel comfortable talking to their friends about their disease, or may have a fear of rejection from people. Many times the patient is uncomfortable with the idea that he or she has a disease. The patient is aware of his or her situation, but still has not come to terms with it.

The second issue was that most of the patients do not have enough information about Crohn's Disease or Ulcerative Colitis. The project team was aware that most of the patients do not go to support groups. All of the information they have learned has come either from their parents or from their doctors. Also, some of the information that the patients have received has been incorrect.

4.2 Initial Conclusions

In order to remedy the first issue introduced by the results or the surveys, the project group determined that the patients need help to find ways to express their feelings. From the results of the surveys the team understands that while patients are unwilling to discuss their problems with anyone other than their friends, there is a greater chance that they will discuss it with other patients. The second issue can be addressed with relative ease. The reason that patients are lacking in information is not that the information is inexistent, but that the information is not getting to the patients. Utilizing prior research of this project, the project team made this information available to the patients through the design described below.

Through the analysis of the two issues described above, as well as information from prior research, the project group developed a final conclusion. A design needed to be created that will be informative and enjoyable to patients. The three aspects that will be covered are interaction with others, learning, and enjoyment. The interaction can be with the patients' parents, other patients, and even the hospital staff. The learning utilizes information obtained from prior research in a fun and interactive way. This is extremely important for the patient, because it will help to alleviate some of the stress and anxiety of being in the hospital.

4.3 Design Creation

This first design idea discussed by the members of the project team was a computer-generated game or learning device. This idea was rejected because the team members lacked the knowledge necessary to be able to design it and because a computer game would not provide enough interaction with others. The second design idea was to create a book or a manual. Although this would be a great tool for the patients to use to educate themselves about their disease, there would be very little fun involved and there would be no interaction with others. The third idea was to create a video or a skit. This would be a great learning tool and, if done correctly, could be a lot of fun. However, once again there would be no interaction with others.

The fourth and final idea was to create a board game. A board game fits all of the requirements of the design. It would be fun, a great learning tool, and provide interaction with others, which is the most important aspect of the design. After looking at all of the ideas, the project team concluded that a board game would be the best possible way to help the patients with all of their needs and still allow for some fun.

The board game consists of a game board on which is imposed an illustration of the entire GI tract (See Figure 4.1). The GI tract is broken up into sections, which are colored spaces for the players' game pieces to move. On certain spaces there are stars that indicate where the bonus questions are. At the end of the stomach, small intestine, ascending colon, transverse colon, and descending colon there are doors in which the player may exit through. Also, there is a bridge where the small intestine goes under the transverse colon. On the board there are labels pointing to certain parts of the GI tract, describing what they are. At the top of the board there is a mouth, which leads into the esophagus. The path continues to follow the entire GI tract to the anus. The final space is a picture of a toilet, where game finishes. The first player to reach the toilet wins the game.

The game pieces are small pieces of food made from clay. There are trivia questions on cards for players to read to each other, which range from serious to funny. There are two sets of trivia cards, one for the questions and one for the bonus questions. See Appendix L and M for a complete list of the questions. There are also five different sets of pills that each player receives that are colored according to the board. Each players goal is to get rid of these pills throughout the game, since no patient ever wants to have to take pills.

The player proceeds to roll the die, and then moves forward the number of spaces they roll. If the player lands on a space without a star, they are asked a question. If they answer the question correctly they may get rid of a certain number of pills for the section they are currently, in which is indicated on the question card. If they land on a starred space, then they are asked a bonus question. As long as they answer the question correctly they give away a certain number of pills, which is indicated on the card as well. If a player reaches one of the doors and has not gotten rid of all of their pills for that section, they are not allowed to continue on and must go back to the start of that section. When the player gets to the last space on the board game before the toilet they are told to stop, and must have gotten rid of all of his or her pills, or else they must go back to the beginning.

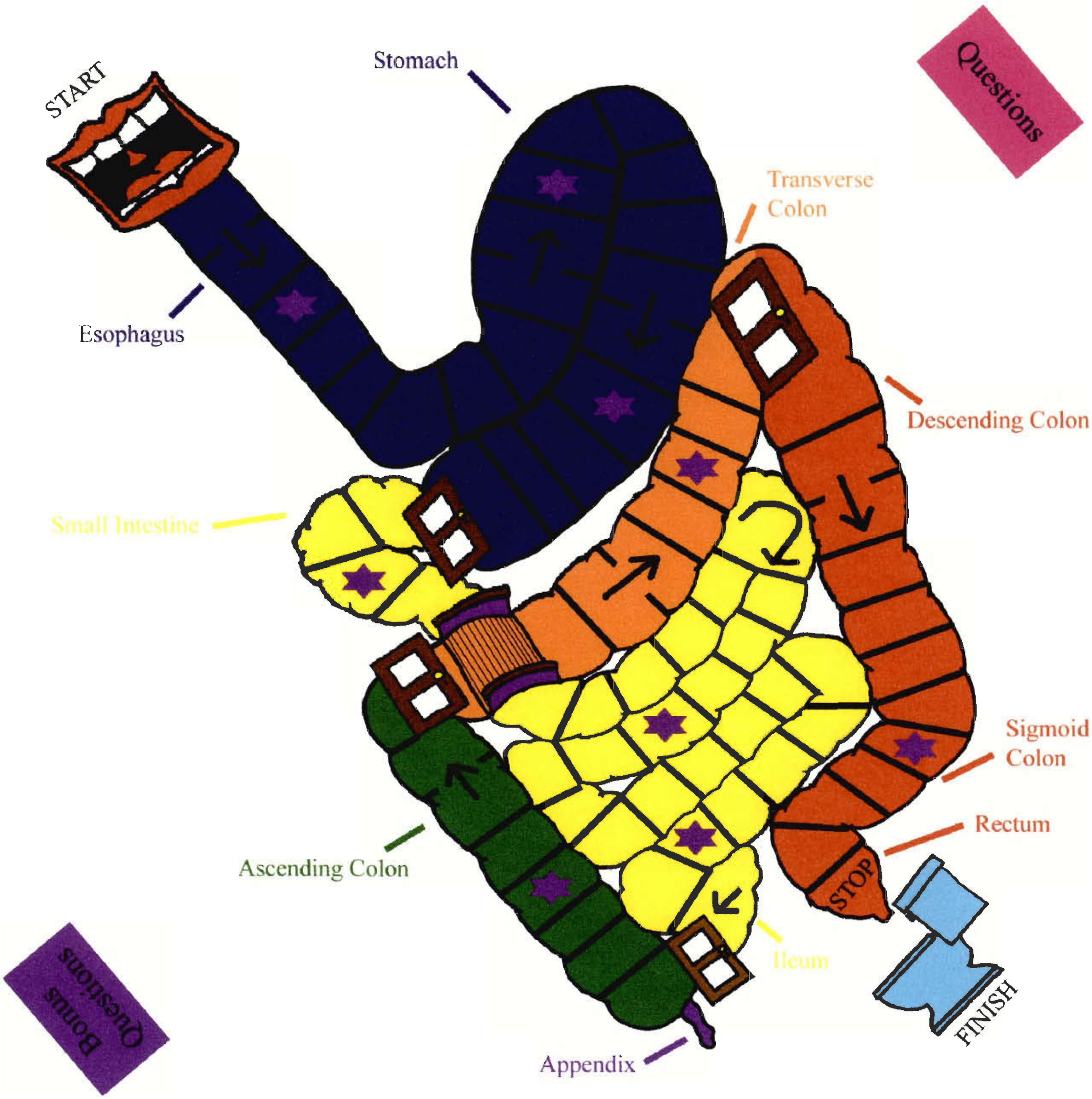


Figure 4.1

This game should be fun for patients to play as well as very informative. The human interaction can be used as a wonderful tool to help take the patient's mind off of his or her problems at the time. The intention of this game was to make the patients' stay in the hospital much easier.

Before building the game board, the first step was to ask patients with Crohn's Disease or Ulcerative Colitis what their opinion on the idea was. The project team wanted to make sure that the game was not found to be offensive to woman in particular, so the team asked four people what they thought. First, the team asked Theresa Murphy who said "I think the idea was unbelievable." The team then asked Rachel Fruchter, a nurse at CCFA, who also thought the idea was wonderful. The third person the team asked was Heather Peach. She felt the idea was very good as long as it was kept completely serious. She just wanted to make sure that the game was not made to be a joke, which it in no way is. The final person that was asked was a student at Worcester Polytechnic Institute who said "[d]efinitely a good idea if it's something you'll really learn from." After speaking with these four individuals, the team felt that the game would not offend anyone and was ready to be built.

4.4 Designing the Board Game

The first step in designing the board game was deciding how to create it. The first idea the project team had was to find pictures of the intestine and copy them onto the board, but this seemed too realistic. The next idea was to take many different pictures of the GI tract and draw what the team thought to be a good depiction of the GI tract on a piece of poster board. After the GI tract, mouth, and toilet were drawn on the poster board in pencil, the project team traced over it in black marker.

The poster board was then cut into four pieces, which were scanned into a computer. After all four pieces were scanned, they were put back together in Adobe Photoshop. Once this was completed, the team members edited out all of the pencil marks and any other marks that may have been on the poster board. Color was put into the organs, spaces were made, and all of the labels were put on the board. Once the board was finished, it was taken to Kinko's Printing where the board game was printed on high gloss paper and attached to the board.

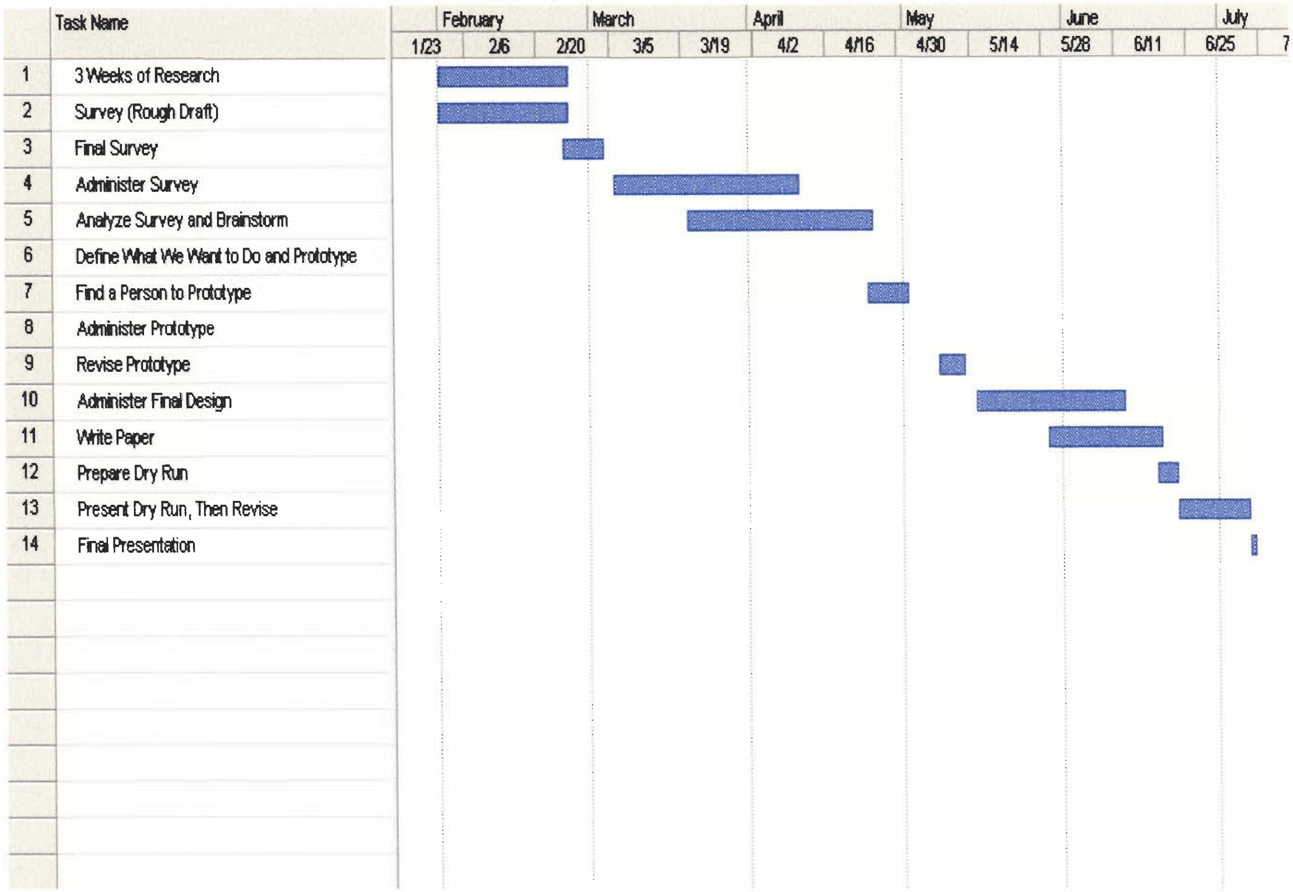
4.5 Additional Project Ideas

The initial idea was to implement the board game and get feedback from patients about the game. However, due to time constraints this was not possible. The board game would have been distributed to patients at the hospital, and after they played the game they would to receive a survey to discuss what they thought was good and bad about the game. After this, the project team would have then made revisions to the board game, based on the patients opinions, and resubmitted it to the hospital. The completion of these steps could serve as an incredible beginning to a future Interactive Qualifying Project at Worcester Polytechnic Institute.

Chapter 5 Final Conclusion (Rectum)

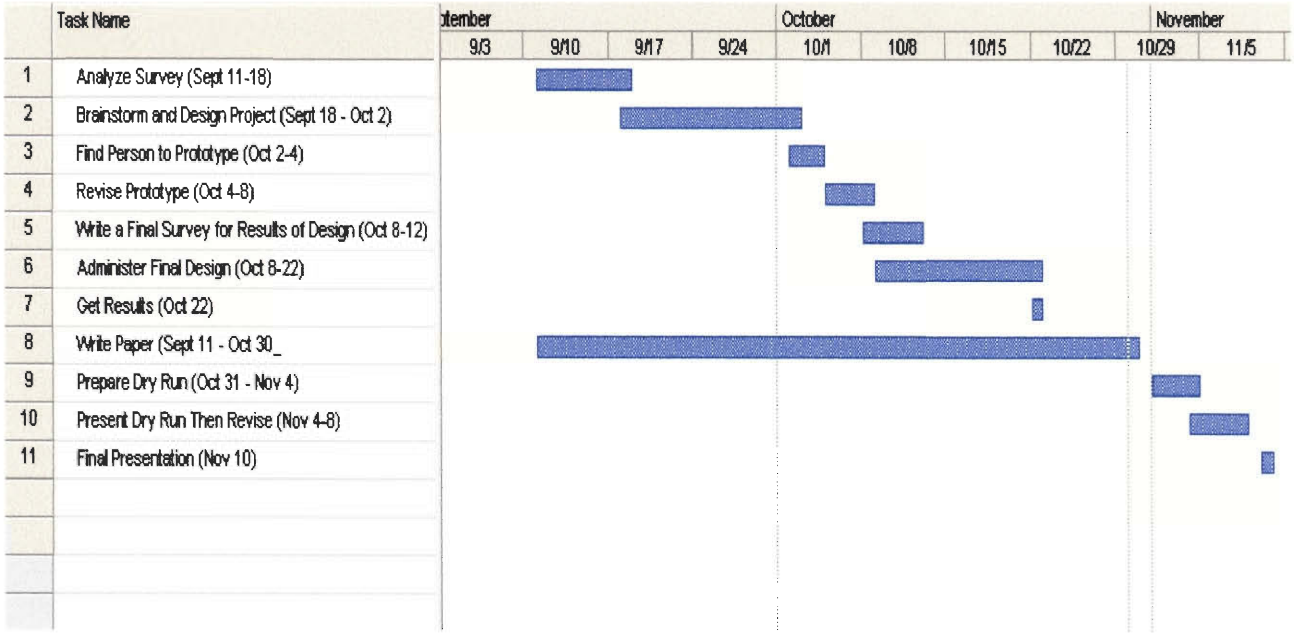
The final outcome of this Interactive Qualifying Project was the application of technology to a social issue accomplished through the design of a board game. The project team was able to research two diseases, Crohn's Disease and Ulcerative Colitis. The team was then able to take the knowledge learned from research and apply this to create surveys to understand the exact needs of the patients. The project team was able to design a board game which will improve the quality of life for the patients. The project team used their engineering skills to design the board game, and set up the means for its implementation. The project was very successful and will help patients to get a better understanding of Crohn's Disease or Ulcerative Colitis, in a fun and interactive way. In turn, this will help the patients to better cope with their disease as well as to improve their quality of life.

APPENDIX A Timeline A



	Task Name
1	3 Weeks of Research
2	Survey (Rough Draft)
3	Final Survey
4	Administer Survey
5	Analyze Survey and Brainstorm
6	Define What We Want to Do and Prototype
7	Find a Person to Prototype
8	Administer Prototype
9	Revise Prototype
10	Administer Final Design
11	Write Paper
12	Prepare Dry Run
13	Present Dry Run, Then Revise
14	Final Presentation

APPENDIX B Timeline B



	Task Name
1	Analyze Survey (Sept 11-18)
2	Brainstorm and Design Project (Sept 18 - Oct 2)
3	Find Person to Prototype (Oct 2-4)
4	Revise Prototype (Oct 4-8)
5	Write a Final Survey for Results of Design (Oct 8-12)
6	Administer Final Design (Oct 8-22)
7	Get Results (Oct 22)
8	Write Paper (Sept 11 - Oct 30_
9	Prepare Dry Run (Oct 31 - Nov 4)
10	Present Dry Run Then Revise (Nov 4-8)
11	Final Presentation (Nov 10)

APPENDIX C **Final Patient Survey**

Are you M ☐ F ☐

How old are you?

What were you diagnosed with? Ulcerative Colitis ☐ Crohn's Disease ☐

How old were you when you were first diagnosed?

How did you first feel about the diagnosis? Angry ☐ Frightened ☐ Sad ☐ Confused/Didn't Understand ☐ Other ☐ ______________________________

Have these feelings changed in any way? How? And Why?

Do you feel you have a better understanding of the illness now?

How did you learn more about Ulcerative Colitis or Crohn's Disease?

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease?

How did your parents first feel about the diagnosis?

How do they feel now?

How many flare-ups per year do you usually have?

How many times a year are you in the hospital overnight?

How long do you usually stay there? Less than a week ☐ 1 Week – 2 Weeks ☐
2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

Are you taking steroids? Yes ☐ No ☐

Are you taking any pain medication while you are at home? Yes ☐ No ☐

Are you taking any pain medication when you are in the hospital? Yes ☐ No ☐

Have you had to have any of these procedures? Colonoscopy ☐ Upper GI ☐
Lower GI ☐ CT Scan ☐

Have you had surgery? Yes ☐ No ☐

If yes, what procedure?

How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☐
Relieved ☐ Other ☐ ______________________________

How do you feel now that you have had the surgery?

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☐ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Do you talk to your friends about your illness? Yes ☐ No ☐

What do you do to cope with your situation? Nothing ☐ Support Group ☐
Talk to Family & Friends ☐ Therapist ☐ Focusing On Other Things ☐

What things? ____
Other ☐ ____

Who helps you to cope and how?

Is there any part of your illness that you feel most uncomfortable talking about?

Do you ever get depressed/anxious because of your illness?

Has Crohn's or Colitis changed your outlook on life? Yes ☐ No ☐ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)?

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☐ No ☐

How do you feel about this?

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

What is the one thing that you would like to do right now that you can't because of your medical condition.

In General, are you under a lot of stress? Yes ☐ No ☐

What is the cause of the stress?

What kind of things do you do to take your mind off of everything?

Is there anything else you would like to tell us?

APPENDIX D Final Parents Survey

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

How have these initial feelings changed over time?

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

Have you taken an active role in your child's emotional and physical treatment process?

How?

Do you think your involvement has helped your child?

☐ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☐ No

How?

Are you completely open and honest with your child about his/her condition?

☐ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child?

Has your child had to take steroids? ☐ Yes ☐ No

Have there been any side effects from the steroids? ☐ Yes ☐ No

Please describe in detail?

Has your child had to have surgery? ☐ Yes ☐ No

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☐ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ________________________

How does your child cope while in the hospital?

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

Is there anything more that could be done to make your child feel better while in the hospital?

Do you have any other thoughts to share?

APPENDIX E Final Health Care Worker Survey

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

How have you seen patients cope with the disease?

☐ Nothing ☐ Support Group ☐ Talk to Family and Friends

☐ Therapist ☐ Focusing on Other Things

If so, what?________________________________

☐ Other ________________________________

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

What difficulties have you observed that patients face as a result of their medications side effects?

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease?

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

Do you have any other thoughts to share?

APPENDIX F Final Patient Survey Cover Letter

The following survey has been written by three students at Worcester Polytechnic Institute, who are trying to make the quality of life for you, the patient, better while at the hospital. If you would care to take 10-15 minutes to fill out this survey, it would be greatly appreciated. Hopefully we will be able to make your stay at MassGeneral Hospital for Children much more comfortable.

Thank You

APPENDIX G Final Parent Survey Cover Letter

We would greatly appreciate it if you would take a few minutes and complete the attached questionnaire. The purpose of it is to help us better understand what your son/daughter's feelings are concerning his/her current health issues. We hope to use your input to design and develop appropriate things that he/she could use to make him/her feel better while in the hospital and when at home.

This is a survey that has been written by three students at Worcester Polytechnic Institute who have the goal of trying to improve the quality of life for you son or daughter.

APPENDIX H Final Health Care Workers Survey Cover Letter

We would greatly appreciate it if you would take a few minutes and complete the attached questionnaire. The purpose of it is to help us better understand what patients, whom you are treating, with Ulcerative Colitis and Crohn's Disease between the ages of 12 to 18, are feeling. We hope to use your input to design and develop appropriate things that patients could use to make themselves feel better while in the hospital or when at home.

This is a survey that has been written by three students at Worcester Polytechnic Institute who have the goal of trying to improve the quality of life for patients with Ulcerative Colitis or Crohn's Disease.

Thank You

APPENDIX I **Completed Patient Surveys**

Are you M ☐ F ☑

How old are you?

15

What were you diagnosed with? Ulcerative Colitis ☐ Crohn's Disease ☑

How old were you when you were first diagnosed?

12

How did you first feel about the diagnosis? Angry ☑ Frightened ☑ Sad ☑ Confused/Didn't Understand ☑ Other ☑ Different from everyone else.

Have these feelings changed in any way? How? And Why?

I am still confused on what the Disease is all about and why I got it. I am not angry, frightened or sad anymore because I have dealt w/ it, become a better person and have become much healthier. I feel as though I dont have the disease anymore.

Do you feel you have a better understanding of the illness now?

I understand a little bit from reading up on it. It's very hard to explain what it is and what it does to other people. Because I honestly dont know exactly.

How did you learn more about Ulcerative Colitis or Crohn's Disease?

My mom is very involved w/ meeting, books and talks to people all the time about it.

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease? What it exactly does to me. Why and how you get it. Describe to ~~tell~~ to children, teenagers. To understand it. I dont understand at all.

How did your parents first feel about the diagnosis?

Sad, but were always there for me and helped me all the way.

How do they feel now?

I never really like talking about it w/ people. When people talk about it I get very mad and always walk away. I don't feel comfortable.

How many flare-ups per year do you usually have?

none

Have you ever had to stay overnight in the hospital? Yes ☑ No ☐

If yes, how many times a year are you in the hospital overnight?

I stayed over twice the year I got the disease

How long do you usually stay there? Less than a week ☑ 1 Week – 2 Weeks ☐

2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

Biaxin - antibiotic

pantanza

I dont take anymore, I stoped

Are you taking steroids? Yes ☐ No ☑

But I did

Are you taking any pain medication while you are at home? Yes ☐ No ☑

Are you taking any pain medication when you are in the hospital? Yes ☑ No ☐

when I was in the hospital when I got the disease

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑

Lower GI ☑ CT Scan ☑

Have you had surgery? Yes ☑ No ☐

If yes, what procedure?

absess and a fissuluer

How did you feel when told about this? Scared ☑ Nervous ☑ Angry ☑

Relieved ☐ Other ☑ confused

How do you feel now that you have had the surgery?

proud of myself. stronger person.

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

yes very much. my mother goes to meetings and is always reading up on the disease. my mother, father and brother are always there when I need them for anything

Do you talk to your friends about your illness? Yes ☐ No ☑

What do you do to cope with your situation? Nothing ☑ Support Group ☐
Talk to Family & Friends ☑ Therapist ☐ Focusing On Other Things ☐

What things? ____
Other ☐ ____

Who helps you to cope and how?
mother by helping me to take my medications, lat night

Is there any part of your illness that you feel most uncomfortable talking about?
Around my rectum

Do you ever get depressed/anxious because of your illness?
yes because thinking back on everything that we went through.

Has Crohn's or Colitis changed your outlook on life? Yes ☑ No ☐ How?
Shown me what so many children go through I don't have it too bad it could be worse.

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)? I'm much slower on doing things and sports. I need to use the bathroom more.

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☑ No ☐

How do you feel about this?
It was very hard for me, we got a tutor.

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?
the doctors should be much more sensitive w/ patients they deal with.

What is the one thing that you would like to do right now that you can't because of your medical condition.

nothing

In General, are you under a lot of stress? Yes ☐ No ☑

What is the cause of the stress?

What kind of things do you do to take your mind off of everything?

listen to musto

Is there anything else you would like to tell us?

Are you M ☑ F ☐

How old are you? 14 yrs.

What were you diagnosed with? Ulcerative Colitis ☐ Crohn's Disease ☑

How old were you when you were first diagnosed? 11

How did you first feel about the diagnosis? Angry ☑ Frightened ☑ Sad ☑ Confused/Didn't Understand ☐ Other ☐ ____________

Have these feelings changed in any way? How? And Why? Never changed

Do you feel you have a better understanding of the illness now? Yes

How did you learn more about Ulcerative Colitis or Crohn's Disease? people, Friends, doctors, books

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease? I want To hear only about cure.

How did your parents first feel about the diagnosis?

very bad

How do they feel now?

same

How many flare-ups per year do you usually have? several

Have you ever had to stay overnight in the hospital? Yes ☑ No ☐

If yes, how many times a year are you in the hospital overnight?

How long do you usually stay there? Less than a week ☑ 1 Week – 2 Weeks ☐
2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

alternative Medicine

Are you taking steroids? Yes ☐ No ☑

Are you taking any pain medication while you are at home? Yes ☐ No ☑

Are you taking any pain medication when you are in the hospital? Yes ☑ No ☐

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑
Lower GI ☑ CT Scan ☑

Have you had surgery? Yes ☐ No ☑

If yes, what procedure?

How did you feel when told about this? Scared ☑ Nervous ☑ Angry ☐
Relieved ☐ Other ☐ ____________________

How do you feel now that you have had the surgery?

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes

Do you talk to your friends about your illness? Yes ☐ No ☑

What do you do to cope with your situation? Nothing ☑ Support Group ☐
Talk to Family & Friends ☐ Therapist ☐ Focusing On Other Things ☑

What things? ______________________________
Other ☑ ______________________________

Who helps you to cope and how?

being with my friends

Is there any part of your illness that you feel most uncomfortable talking about?

I don't like To talk about it.

Do you ever get depressed/anxious because of your illness?

yes

Has Crohn's or Colitis changed your outlook on life? Yes ☑ No ☐ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)?

changed To worse

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☑ No ☐

How do you feel about this?

terrible

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

What is the one thing that you would like to do right now that you can't because of your medical condition.

eating anything I want

In General, are you under a lot of stress? Yes ☑ No ☐

What is the cause of the stress?

Everything

What kind of things do you do to take your mind off of everything?

going Boy's Club

Is there anything else you would like to tell us?

I want To get better.

Are you M ☑ F ☐

How old are you? 13½

What were you diagnosed with? Ulcerative Colitis ☐ Crohn's Disease ☑

How old were you when you were first diagnosed? 10

How did you first feel about the diagnosis? Angry ☐ Frightened ☐ Sad ☐ Confused/Didn't Understand ☐ Other ☑ A little upset but understanding

Have these feelings changed in any way? How? And Why?

Not much, I've just adjusted (even though there wasn't much that I needed to change).

Do you feel you have a better understanding of the illness now?

most definitely

How did you learn more about Ulcerative Colitis or Crohn's Disease?

From my doctor, a video, reading CCFA publications, going to support groups and the CCFA symposium (more my parent + they talk about what was said).

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease? NO

How did your parents first feel about the diagnosis?

Very sad and confused

How do they feel now?

Still sad but more informed

How many flare-ups per year do you usually have? 2-4

Have you ever had to stay overnight in the hospital? Yes ☑ No ☐

If yes, how many times a year are you in the hospital overnight? 0-1

How long do you usually stay there? Less than a week ☑ 1 Week – 2 Weeks ☐
2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

- A sacol
- Prednisone
- Levaquin
- multivitamin
- Viactiv

Are you taking steroids? Yes ☑ No ☐

Are you taking any pain medication while you are at home? Yes ☑ No ☐

Are you taking any pain medication when you are in the hospital? Yes ☑ No ☐

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑
Lower GI ☑ CT Scan ☑

Have you had surgery? Yes ☑ No ☐

If yes, what procedure?

drain created for fistula

How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☑
Relieved ☑ Other ☐ ______________________

How do you feel now that you have had the surgery?

physically better, but I'm still upset because of the restrictions that my doctor gave me

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes

Do you talk to your friends about your illness? Yes ☐ No ☑

What do you do to cope with your situation? Nothing ☐ Support Group ☐
Talk to [✓ Family] & Friends ☑ Therapist ☐ Focusing On Other Things ☑

What things? ~~may~~ reading, sports, school work, friends
Other ☐

Who helps you to cope and how?

My entire family (extended included) have been very considerate and have talked with me and been very caring.

Is there any part of your illness that you feel most uncomfortable talking about?

My fistula

Do you ever get depressed/anxious because of your illness?

Sometimes I feel depressed/upset ~~what~~ when bad things happen

Has Crohn's or Colitis changed your outlook on life? Yes ☐ No ☑ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)? Since my recent fistula + surgery I'm not able to run around and play sports and when I sit I need to use an inflatable ~~[illegible]~~ donut (sometimes)

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☑ No ☐

How do you feel about this?

I'm upset and frustrated because I had a lot of backed-up school work and it was hard to make it all up while being sick + even when I was feeling better.

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

Nothing really – the nurses and doctors were extremely nice and I had plenty to do (TV, video games, read, game room).

What is the one thing that you would like to do right now that you can't because of your medical condition.

play sports

In General, are you under a lot of stress? Yes ☐ No ☑

What is the cause of the stress?

What kind of things do you do to take your mind off of everything?

I read or talk to my family

Is there anything else you would like to tell us?

I'm becoming more actively involved in learning about the disease

Are you M ☐ F ☑

How old are you?
14 yrs

What were you diagnosed with? Ulcerative Colitis ☐ Crohn's Disease ☑

How old were you when you were first diagnosed?
12 yrs

How did you first feel about the diagnosis? Angry ☐ Frightened ☐ Sad ☐ Confused/Didn't Understand ☐ Other ☑ relieved to know what it was

Have these feelings changed in any way? How? And Why?
NO

Do you feel you have a better understanding of the illness now?
Yes

How did you learn more about Ulcerative Colitis or Crohn's Disease?
From doctors and parents

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease? NO

How did your parents first feel about the diagnosis?
Relieved have diagnosis + bit scared/shocked

How do they feel now?
Sometimes sad glad have no flare ups
hope won't get any. worse

How many flare-ups per year do you usually have?
NONE

Have you ever had to stay overnight in the hospital? Yes ☐ No ☑

If yes, how many times a year are you in the hospital overnight?

How long do you usually stay there? Less than a week ☐ 1 Week – 2 Weeks ☐
2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

Azocal, prilosec, lactobifilis

Are you taking steroids? Yes ☐ No ☑

Are you taking any pain medication while you are at home? Yes ☐ No ☑

Are you taking any pain medication when you are in the hospital? Yes ☐ No ☑

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑
Lower GI ☐ CT Scan ☐

Have you had surgery? Yes ☐ No ☑

If yes, what procedure?

How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☐
Relieved ☑ Other ☐ ______________________________

How do you feel now that you have had the surgery?

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes

Do you talk to your friends about your illness? Yes ☑ No ☒

What do you do to cope with your situation? Nothing ☑ Support Group ☐
Talk to Family & Friends ☑ Therapist ☐ Focusing On Other Things ☐

What things? ____________________

Other ☐ ____________________

Who helps you to cope and how?

My Parents they talk with me tell me how it really stinks but I should be glad it isn't anything worse

Is there any part of your illness that you feel most uncomfortable talking about?

No

Do you ever get depressed/anxious because of your illness?

NO

Has Crohn's or Colitis changed your outlook on life? Yes ☐ No ☑ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)? They haven't

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☑ No ☐ I did before it was diagnosed

How do you feel about this?

Glad I don't any more

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

~~I don't stay in~~

What is the one thing that you would like to do right now that you can't because of your medical condition.

NOTHING

In General, are you under a lot of stress? Yes ☐ No ☑

Sometimes

What is the cause of the stress?

homework overload

What kind of things do you do to take your mind off of everything?

I read, listen to music, talk w/ my friends do things with my friends like go to the movies or just hang out

Is there anything else you would like to tell us?

NO

Are you M ☒ F ☐

How old are you?
13

What were you diagnosed with? Ulcerative Colitis ☒ Crohn's Disease ☐

How old were you when you were first diagnosed?
10

How did you first feel about the diagnosis? Angry ☐ Frightened ☐ Sad ☐ Confused/Didn't Understand ☐ Other ☒ "Why me?" "Oh well."

Have these feelings changed in any way? How? And Why?
Not really although I don't think about it much.

Do you feel you have a better understanding of the illness now?
Yes

How did you learn more about Ulcerative Colitis or Crohn's Disease?
My doctor and parents told me,

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease?
No.

How did your parents first feel about the diagnosis?
Worried for me.

How do they feel now?
Concerned when I show symtems,

How many flare-ups per year do you usually have?
1

Have you ever had to stay overnight in the hospital? Yes ☐ No ☒

~~If yes, how many times a year are you in the hospital overnight?~~

~~How long do you usually stay there? Less than a week ☐ 1 Week – 2 Weeks ☐~~
~~2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐~~

~~What medications do you have to take~~ on a regular basis?

Asicall - made me worse

Prednizone - helped a lot

Are you taking steroids? Yes ☒ No ☐

Are you taking any pain medication while you are at home? Yes ☐ No ☒

Are you taking any pain medication when you are in the hospital? Yes ☐ No ☒

Have you had to have any of these procedures? Colonoscopy ☒ Upper GI ☐
Lower GI ☐ CT Scan ☐

Have you had surgery? Yes ☐ No ☒

~~If yes, what procedure?~~

~~How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☐~~
~~Relieved ☐ Other ☐ ______________________~~

~~How do you feel now that you have had the surgery?~~

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☒ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes

Do you talk to your friends about your illness? Yes ☐ No ☒ not usually

What do you do to cope with your situation? Nothing ☒ Support Group ☐ I don't need to do anything
Talk to Family & Friends ☐ Therapist ☐ Focusing On Other Things ☐

What things? ______________________________
Other ☐ ______________________________

Who helps you to cope and how?

Is there any part of your illness that you feel most uncomfortable talking about?

Blood / needles

Do you ever get depressed/anxious because of your illness?

not sure

Has Crohn's or Colitis changed your outlook on life? Yes ☐ No ☒ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)?

no

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☐ No ☒

How do you feel about this?

I like to miss some school, it gives me a break.

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

not sure

What is the one thing that you would like to do right now that you can't because of your medical condition.

eat cashues

In General, are you under a lot of stress? Yes ☒ No ☐ sometimes

What is the cause of the stress?

school

What kind of things do you do to take your mind off of everything?

listen to music, play computer, paint figures

Is there anything else you would like to tell us?

not really

Are you M ☐ F ☑

How old are you? 12

What were you diagnosed with? Ulcerative Colitis ☑ Crohn's Disease ☐

How old were you when you were first diagnosed? 7½

How did you first feel about the diagnosis? Angry ☐ Frightened ☑ Sad
☐ Confused/Didn't Understand ☐ Other ☐ ______________________

Have these feelings changed in any way? How? And Why?

Yes. I have learned that there are ways to controle it.

Do you feel you have a better understanding of the illness now?

Yes

How did you learn more about Ulcerative Colitis or Crohn's Disease?

From My parents and My GI doctor.

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease?

No

How did your parents first feel about the diagnosis?

disappointed

How do they feel now?

Frustrated during Flare-ups

How many flare-ups per year do you usually have?

2-3

Have you ever had to stay overnight in the hospital? Yes ☑ No ☐

If yes, how many times a year are you in the hospital overnight?

I was only in the hospital when I was first diagnosed

How long do you usually stay there? Less than a week ☐ 1 Week – 2 Weeks ☑
2 Weeks – 4 Weeks ☐ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

Asacol, 6-mp

Are you taking steroids? Yes ☐ No ☑

Are you taking any pain medication while you are at home? Yes ☐ No ☑

Are you taking any pain medication when you are in the hospital? Yes ☐ No ☐

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑
Lower GI ☐ CT Scan ☐

Have you had surgery? Yes ☐ No ☑

If yes, what procedure?

How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☐
Relieved ☐ Other ☐ ______________________

How do you feel now that you have had the surgery?

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes

Do you talk to your friends about your illness? Yes ☑ No ☐

What do you do to cope with your situation? Nothing ☐ Support Group ☐
Talk to Family & Friends ☐ Therapist ☐ Focusing On Other Things ☐

What things? ______________________________
Other ☑ I Joke about it

Who helps you to cope and how?

My Mom. She laughs with me

Is there any part of your illness that you feel most uncomfortable talking about?

bleeding, ~~[illegible]~~ mucus in My Stool

Do you ever get depressed/anxious because of your illness?

No

Has Crohn's or Colitis changed your outlook on life? Yes ☐ No ☑ How?

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)? They haven't

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☐ No ☑

How do you feel about this?

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

To get a lot of support

What is the one thing that you would like to do right now that you can't because of your medical condition.

I'm able to do everything

In General, are you under a lot of stress? Yes ☐ No ☑

What is the cause of the stress?

What kind of things do you do to take your mind off of everything?

I fool around

Is there anything else you would like to tell us?

No

[redacted]

Are you M ☐ F ☑

How old are you? 14

What were you diagnosed with? Ulcerative Colitis ☑ Crohn's Disease ☐

How old were you when you were first diagnosed? 12

How did you first feel about the diagnosis? Angry ☑ Frightened ☐ Sad ☐ Confused/Didn't Understand ☐ Other ☐ ______________________

Have these feelings changed in any way? How? And Why?

Yes, but I'm still angry. I [illegible] understand now.

Do you feel you have a better understanding of the illness now?

Yes.

How did you learn more about Ulcerative Colitis or Crohn's Disease? Parents & Books

I learned it was really stinky (in both ways)

Is there anything more you would like to know about Ulcerative Colitis or Crohn's Disease?

No, not really.

How did your parents first feel about the diagnosis?

My sister already had it so they [illegible] already knew.

How do they feel now?

The same.

How many flare-ups per year do you usually have?

I had about 8 last year.

Have you ever had to stay overnight in the hospital? Yes ☑ No ☐

many times

If yes, how many times a year are you in the hospital overnight?

Too ~~Long~~ many - 4 different times

How long do you usually stay there? Less than a week ☐ 1 Week – 2 Weeks ☐

2 Weeks – 4 Weeks ☑ Greater than 4 Weeks ☐

What medications do you have to take on a regular basis?

None right now I already had the operation.

Are you taking steroids? Yes ☐ No ☑

But I was

Are you taking any pain medication while you are at home? Yes ☐ No ☑

But I was

Are you taking any pain medication when you are in the hospital? Yes ☑ No ☒ Epidual

~~But I was.~~

Have you had to have any of these procedures? Colonoscopy ☑ Upper GI ☑

Lower GI ☑ CT Scan ☑

Have you had surgery? Yes ☑ No ☐

If yes, what procedure?

Total colectomy

Not sure But I no longer have a colon.

How did you feel when told about this? Scared ☐ Nervous ☐ Angry ☐

Relieved ☐ Other ☑ grossed out.

How do you feel now that you have had the surgery?

much better.

Do your parents take an active role in your treatment to get better? (i.e. physical support, emotional support, mental support) Yes ☑ No ☐

Very much so.

[redacted]

Are your parents helpful in your coping with Ulcerative Colitis or Crohn's Disease?

Yes very much so. ←

Do you talk to your friends about your illness? Yes ☑ No ☐

Some

What do you do to cope with your situation? Nothing ☐ Support Group ☐
Talk to Family & Friends ☑ Therapist ☑ Focusing On Other Things ☐

What things? ____________________

Other ☐ ____________________

Who helps you to cope and how?

My family.

Is there any part of your illness that you feel most uncomfortable talking about?

The part it does with waste.

Do you ever get depressed/anxious because of your illness?

Yes

Has Crohn's or Colitis changed your outlook on life? Yes ☑ No ☐ How?

life can always get worse.

How have your activities changed since your diagnosis (i.e. School, sports, extra-curricular activities, etc.)?

I have not done as much.

Have you missed a lot of school due to Ulcerative Colitis or Crohn's Disease?
Yes ☑ No ☐

How do you feel about this?

I don't like this.

What would make you more comfortable while you are in the hospital? When you are out of the hospital? Physically, Mentally, and Emotionally?

Being at home.

What is the one thing that you would like to do right now that you can't because of your medical condition.

Not go to the bathroom as much.

In General, are you under a lot of stress? Yes ☑ No ☑

What is the cause of the stress?

? Me

What kind of things do you do to take your mind off of everything?

Read and T.V.

Is there anything else you would like to tell us?

No.

APPENDIX J Completed Parent Surveys

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

frustrated + discouraged

How have these initial feelings changed over time?

since minimal flare-ups, they've improved, however he's still a bit pessimistic and has decreased self esteem, some of which relate to his illness.

Do you notice any changes in your child's emotions since diagnosis?

☒ Yes ☐ No

see last question

What has affected your child the most emotionally as a result of his/her diagnosis?

The fact that he's "not like everyone else'

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

No. He doesn't discuss it with his friends.

Have you taken an active role in your child's emotional and physical treatment process?

Yes.

How?

Do you think your involvement has helped your child?

☒ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☒ Yes ☐ No

How? If we were negative about it, it would only make matters worse.

Are you completely open and honest with your child about his/her condition?

☒ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child? No - he's not interested

Has your child had to take steroids? ☒ Yes ☐ No

Have there been any side effects from the steroids? ☒ Yes ☐ No

Please describe in detail?

Initially, seemed to be delayed growth but now things seem okay

Has your child had to have surgery? ☐ Yes ☒ No

only 2x colonoscopies

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☒ Family ☐ Friends ☐ Support groups ☒ Therapists
☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☐ Yes ☒ No

If yes, how does your child cope while in the hospital?

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

He acts as though he doesn't have it.

Is there anything more that could be done to make your child feel better when in the hospital?

A friend with Crohn's in another state says they have nintendo and a huge video library. They also have kid-friendly food.

Do you have any other thoughts to share?

Dr. Alan Leichtner is awesome!

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? She was 2yrs old & knew nothing.

How have these initial feelings changed over time? (she's 10 now) She resents it sometimes, but we tell her "everyone gets something." (of course, she wants to know what)

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ No [✓ N/A]

What has affected your child the most emotionally as a result of his/her diagnosis?

pain

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? She hasn't had that many problems yet, but I'm careful who I let her visit, I go along on all field trips, etc.

Have you taken an active role in your child's emotional and physical treatment process?

It's difficult to avoid!

How? Parents do it all at this age.

Do you think your involvement has helped your child?

☑ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☑ No

How? Not yet, but I see it coming.

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No but certainly

Have you attended a parent/child support group? How has this helped you and your child? No

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☑ Yes ☐ No

Please describe in detail? Moon face, red face, weight gain

Has your child had to have surgery? ☐ Yes ☑ No

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☑ Family ☑ Friends ☐ Support groups ☐ Therapists

☐ Other: ____________________

Has your child ever had to stay in the hospital overnight? ☑ Yes ☐ No

If yes, how does your child cope while in the hospital?

They put the IV in the hand she used to suck her thumb - that was the worst part ?
She was there because she had chickenpox while on steroids

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Mostly fine

Is there anything more that could be done to make your child feel better when in the hospital? Hasbro (Providence, RI) was great.

Do you have any other thoughts to share?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? Very-very bad, sad. uncontrolable feelings

How have these initial feelings changed over time?

When I started To go Naturopathic Physicians, they gave me more hope.

Do you notice any changes in your child's emotions since diagnosis?

☐ [✓ Yes] ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

depression

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? He is less active

Have you taken an active role in your child's emotional and physical treatment process?

yes

How? alternative medicine

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ [✓ Yes] ☐ No

How?

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No

Have you attended a parent/child support group? How has this helped you and your child? No

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail? Everything. He gain weight, never helped him with his pain, he felt & very tired. no energy, every day headache, etc.

Has your child had to have surgery? ☐ Yes ☐ [✓ No]

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☐ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital?

Good

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

yes

Is there anything more that could be done to make your child feel better when in the hospital?

No

Do you have any other thoughts to share?

No

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? UNSURE OF WHAT IT ALL MENT 7yrs OLD

How have these initial feelings changed over time?

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

Have you taken an active role in your child's emotional and physical treatment process?

How?

Do you think your involvement has helped your child?

☐ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☐ No

How?

Are you completely open and honest with your child about his/her condition?

☐ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child? YES. CCFA SUPPORT GROUPS, HELP US GREATLY TO KNOW OTHER PEOPLE IN SAME POSITION AS US,

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail?

GAINED 15 lbs VERY PUFFY FACE & BELLY, BECAME WEAK, LABORED BREATHING, INCREASE APPETITE.

Has your child had to have surgery? ☐ Yes ☐ [✓ No]

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☐ [✓ Family] ☐ [✓ Friends] ☐ Support groups ☐ Therapists

☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital?

LOVE'S HOSPITAL DOES NOT LIKE NEEDLES/BLOOD DRAW/I.V.'S
LIKE OWN TV. & VCR MAKE FRIENDS EASILY WITH OTHER PATIENTS

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Very well

Is there anything more that could be done to make your child feel better when in the hospital?

Do you have any other thoughts to share?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

Lousy and miserable.

How have these initial feelings changed over time?

He's physically better but the emotional changes are horrific.

Do you notice any changes in your child's emotions since diagnosis?

[✓ Yes] No

What has affected your child the most emotionally as a result of his/her diagnosis?

His dependence on Prednisone. He's an emotional nutcase sometimes.

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

We feel he is less "stable" around others. He seems to have awful moodswings, so we can't predict his behavior

Have you taken an active role in your child's emotional and physical treatment process?

Absolutely.

How?

Present at every single doctor's appt; research every treatment option including some our son doctor isn't used to. We research and read everything we can find on the subject

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ No

absolutely

Do you think your feelings regarding your child's illness affect him/her?

☐ [✓ Yes] ☐ No absolutely

How? My stress level translates into impatience, at times and despair (which makes him even worse) when he flares

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No

As much as we can be with a 7 1/2 year old

Have you attended a parent/child support group? How has this helped you and your child? Yes. Enormously beneficial because we heard similar experiences and got a lot of medical presentations which helped us decide on child's treatment with his physician.

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

On and off (mostly on) for 4 years.

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail?

The usual physical ones (trunk weight gain, moon face, don't know about bone loss yet) but mostly emotional. He is like a totally different human being from 4 years ago when he was diagnosed

Has your child had to have surgery? ☐ Yes ☐ [✓ No]

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☑ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: his pediatrician (not his gastroenterologist) and his school nurse. They are both wonderful.

Has your child ever had to stay in the hospital overnight? ☐ Yes ☑ No

If yes, how does your child cope while in the hospital?

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Well under the circumstances. His biggest anger is ones not being able to have a pet reptile or amphibian due to dangers of salmonella becau he's been on immunosuppressives for 2 years.

Is there anything more that could be done to make your child feel better when in the hospital?

Do you have any other thoughts to share?

Yes - why do little children have to suffer at all?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? Confused and afraid

How have these initial feelings changed over time? As my son's Crohn's got under control, I'd say the above feelings went away. However, more recently he's had to deal with a fistula which has caused frustration, depression, and a lack of motivation

Do you notice any changes in your child's emotions since diagnosis?

☐ [✓ Yes] ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

Having to deal with the fistula.
Also, his pubertal development has been delayed, resulting in him being shorter than his classmates (he's currently 13 1/2 yrs old) which I believe has affected his self-esteem

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

Yes. Inability to play sports at will. Not comfortable around girls due to his height being short.

Have you taken an active role in your child's emotional and physical treatment process?

Yes.

How? Participation in DR. visits
Do lots of reading on the subject
Participate in CCFA walkathon as a family past 2 yrs.
Attend CCFA Symposium past 2 years
Attend support groups

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ [✓ Yes] ☐ No

How? He probably gets sick of me asking him how he feels

Are you completely open and honest with your child about his/her condition?

☐ Yes ☐ [✓ No] Avoided discussions about surgery and topics of that nature

Have you attended a parent/child support group? How has this helped you and your child? Yes. Made me feel like I'm trying to get educated about the illness. Also, makes me feel confident that the DR's are on track for treatment.

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail?

- Delayed growth
- Put on weight
- Puffy face
- Mood swings
- Trouble sleeping

Has your child had to have surgery? ☐ [✓ Yes] ☐ No

What type of surgery did your child have? He had to have an opening enlarged to allow his fistula to better drain properly

How did your child feel before surgery? Frustrated
Depressed
Unmotivated

How did your child feel after surgery? Better, more positive, but still in healing process

What do you think has helped your child cope with his/her illness the most?

☐ [✓ Family] ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ____________________

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital?

OK, because there is always a parent present (mother or father) 90% + of the time

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Generally pretty good, but this recent fistula, which was his first one, has been a challenge to deal with

Is there anything more that could be done to make your child feel better when in the hospital? More interaction with other kids of similar age with same illness

Do you have any other thoughts to share?

A summer camp for kids w/ Crohn and/or U.C. would be a great experiance.

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? scared embarrased

How have these initial feelings changed over time? Somewhat

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ [✓ No]

What has affected your child the most emotionally as a result of his/her diagnosis?

Loss of friends

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? Yes "friends" no [illegible]

Have you taken an active role in your child's emotional and physical treatment process?

Physically - we go to all doctors [illegible]
priescriptions are fill - remind [illegible]

How?

perscriptions.

Emotionally we don't talk about it much
Once she said she wished [illegible] to
and one day she was sick [illegible]

Do you think your involvement has helped your child?

[✓ Yes] ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☐ No Don't know

How?

Are you completely open and honest with your child about his/her condition?

☐ Yes ☐ No Somewhat - we don't tell her the worst - what some people with crohn's and surgery etc.

Have you attended a parent/child support group? How has this helped you and your child? no

Has your child had to take steroids? ☐ Yes ☐ No

Have there been any side effects from the steroids? ☐ Yes ☐ No

Please describe in detail? Wt gain - rather [illegible]
chunky [illegible]

Has your child had to have surgery? ☐ Yes ☐ No

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☐ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ________________________

Has your child ever had to stay in the hospital overnight? ☐ Yes ☐ No

If yes, how does your child cope while in the hospital?

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

Is there anything more that could be done to make your child feel better when in the hospital?

Do you have any other thoughts to share? [illegible]

had a peer [illegible] [illegible]

with [illegible]

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? diagnosed at age 3

terrified - long hospitalizations, multiple surgeries

How have these initial feelings changed over time?

no obvious memory of pre-colectomy life

Do you notice any changes in your child's emotions since diagnosis?

☐ [✓ Yes] ☐ No increasing awareness of body different from others

What has affected your child the most emotionally as a result of his/her diagnosis?

early social isolation due to hospitalizations & steroid treatment; food restrictions, multiple medications

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? socially backward. limited by food restrictions & multiple medication; physically small

Have you taken an active role in your child's emotional and physical treatment process?

yes

How?

father highly involved in medical treatment

mother provides support in academic, social, emotional areas

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ [✓ No]

medical support

Do you think your feelings regarding your child's illness affect him/her?

☐ [✓ Yes] ☐ No

How? anxiety, over-protection

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ [✓ No] about long range prognosis & implications

mostly

Have you attended a parent/child support group? How has this helped you and your child? YES - somewhat, some new information learned

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail? retarded physical growth when on high doses, social isolation

Has your child had to have surgery? ☐ [✓ Yes] ☐ No

What type of surgery did your child have?

~~cole~~ ileostomy
central line insertions
prolapse repair

How did your child feel before surgery? miserable

How did your child feel after surgery? physically better
psychologically traumatized

What do you think has helped your child cope with his/her illness the most?

☐ [✓ Family] ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ____________________

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital? before age 5
psychological trauma
lethargic, withdrawn, "institutionalized" affect

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? OK

Is there anything more that could be done to make your child feel better when in the hospital? more psych. + social work support

Do you have any other thoughts to share?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease? Both of my Children were very young When diagnosed. My daughter is doing great so mainly I am responding to the survey regarding my son.

How have these initial feelings changed over time?

My son has a great attitude but sometimes wishes he wasn't sick.

Do you notice any changes in your child's emotions since diagnosis?

☐ [✓ Yes] ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

Other children commenting on his appearance (has some facial changes) and asking why he has to go to the school nurse for meds. Having to cope with having "accidents" at school.

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

Yes, we feel he isn't able to be away from home overnight.

Have you taken an active role in your child's emotional and physical treatment process?

Yes

How?

Taste his medications before he does to tell him if it's bad or not so bad. Always discuss everything that's going to happen so there's no surprises.

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☐ No

How? I don't think so. We treat his illness with a positive attitude and as his mother - I too have a chronic illness.

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No Absolutely!

Have you attended a parent/child support group? How has this helped you and your child? Yes + Yes. Has been great to compare notes and talk to people who understand what you're going through. my son enjoys meeting other children who "have what he has"

Has your child had to take steroids? ☐ Yes ☐ [✓ No]

Have there been any side effects from the steroids? ☐ Yes ☐ No

Please describe in detail?

Has your child had to have surgery? ☐ [✓ Yes] ☐ No

What type of surgery did your child have?

Biopsies of the mouth

How did your child feel before surgery?

A little afraid

How did your child feel after surgery?

Uncomfortable but great attitude

What do you think has helped your child cope with his/her illness the most?

☐ [✓ Family] ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: Great Doctor

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital?

Very well

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Doesn't let his illness keep him from doing what he wants to do.

Is there anything more that could be done to make your child feel better when in the hospital?

N/A at this point

Do you have any other thoughts to share?

How do you think your child first felt when [✓ he]/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

At first scared, sad and confussed.

How have these initial feelings changed over time?

It seems at this point he is no longer so much scared but that as this disease changes so does his feelings of being sad or confussed!

Do you notice any changes in your child's emotions since diagnosis?

☑ Yes ☐ No

What has affected your child the most emotionally as a result of [✓ his]/her diagnosis?

My son is very ~~[illegible]~~ brave but has become sad as a result of things he cannot ~~[illegible]~~ be involved in any more (or for now!)

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? most recent he is unable to play sports which has had a large effect.

Have you taken an active role in your child's emotional and physical treatment process?

Yes

How?

We as a family talk alot about his illness. My sons doctors are very open and willing to talk. This past 7 months my son has been

Do you think your involvement has helped your child?

☑ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☑ Yes ☐ No

How? We try to be positive. If our son sees there are options & hope threw us he feels less helpless.

Are you completely open and honest with your child about his/her condition?

☑ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child? Yes. We have only attended one to date, but it was a good source of support and ideas. (Salem Parents Group)

Has your child had to take steroids? ☑ Yes ☐ No

Have there been any side effects from the steroids? ☑ Yes ☐ No

Please describe in detail? Growth delay, weight gain

Has your child had to have surgery? ☑ Yes ☐ No

What type of surgery did your child have? Fistula

How did your child feel before surgery?

He was nervous about the diet one and hopeful that it [illegible] would help.

How did your child feel after surgery?

At first he was happy because he felt better but [illegible] ~~then~~ the surgery was not as successful as we planned.

What do you think has helped your child cope with his/her illness the most?

☑ Family ☑ Friends ☑ Support groups ☐ Therapists

☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☑ Yes ☐ No

If yes, how does your child cope while in the hospital?

[illegible] Mom or Dad will stay and a great staff!

How does your child cope while out of the hospital with [✓ his]/her Ulcerative Colitis or Crohn's Disease? We have ups and downs depending on his health

Is there anything more that could be done to make your child feel better when in the hospital? None

Do you have any other thoughts to share?

We feel it is important to come to things such as today.

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

INITIALLY THERE WAS LITTLE EFFECT DUE TO LACK OF KNOWLEDGE ABOUT THE DISEASE.

How have these initial feelings changed over time?

THERE HAVE BEEN MANY UPS AND DOWNS WITH KNOWLEDGE LEARNED ABOUT THE DISEASE. THE CHILD NEEDS CONTSANT REINFORCEMENT TO KEEP THEIR MENTAL STATE ELEVATED

Do you notice any changes in your child's emotions since diagnosis?

☒ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

THE EMOTIONAL CHANGES RESULTING IN THE CHANGING LIFESTYLE. MANY THINGS OTHER CHILDREN CAN DO ARE NOT AVAILABLE FOR THE CHILD WITH UC OR CD

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

ASIDE FROM THE MEDICAL ASPECTS THE SOCIAL CHANGES ARE THE WORST. DUE TO THE ILLNESS THE CHILD HAS DIFICULTY MAINTAING A BOYFRIEND/GIRLFRIEND RELATIONSHIP. CHILDREN MISS MANY EVENTS DUE TO THE DISEASE AND LOSE FRIENDS WHO DON'T UNDERSTAND OR TOLERATE THE DISEASE, ALSO, THE DISEASE HAS AFFECTED THE OPPORTUNITY TO CONTINUE WITH SOME SPORTS

Have you taken an active role in your child's emotional and physical treatment process?

YES!

How?

AS PARENTS WE HAVE MAINTAINED CLOSE INVOLVEMENT IN EVERY ASPECT OF THE DISEASE: VISITS W/ DOCTORS, HOSPITALIZATIONS AND SUPPORT GROUPS. WE HAVE ALSO TRIED TO MAINTAIN POSITIVE REINFORCEMENT TO AVOID POTENTIAL DEPRESSION. WE HAVE ALSO ASSISTED, AS MUCH AS POSSIBLE, IN HELPING WITH ALL EDUCATIONAL NEEDS.

Do you think your involvement has helped your child?

☒ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☑ Yes ☐ No

How?

I BELIEVE THAT THE PARENT MUST MAINTAIN A POSITIVE OUTLOOK WITH THE CHILD, MAKE AN EFFORT TO KEEP SPIRITS HIGH EVEN AS PROBLEM OCCUR.

Are you completely open and honest with your child about his/her condition?

☒ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child?

YES. IT HELPS IN TALKING WITH OTHERS WHO HAVE SIMILAR PROBLEMS AND HOW THEY DEAL WITH THEM. IT IS ALSO A WAY TO LEARN ABOUT OTHER PHYSICIANS AND TREATMENTS.

Has your child had to take steroids? ☒ Yes ☐ No

Have there been any side effects from the steroids? ☒ Yes ☐ No

Please describe in detail?

WEIGHT GAIN, SEVERE ARTHRITIS, OSTEONECROSIS WHICH HAS RESULTED IN BONE GRAFTS AND CARTILEDGE TRANSPLANT TO BOTH KNEES.

Has your child had to have surgery? ☒ Yes ☐ No

What type of surgery did your child have?

ILEO-ANAL PULL THROUGH (POUCH SURGERY)
(SEE ABOVE - OSTEO NECROSIS)

How did your child feel before surgery?

APPREHENSIVE BUT POSITIVE IN HOPES OF CORRECTING HIS U.C. PROBLEM.

How did your child feel after surgery?

PAINED BUT HOPEFUL OF A MORE "NORMAL" LIFE FOR THE FUTURE.

What do you think has helped your child cope with his/her illness the most?

☒ Family ☒ Friends ☐ Support groups ☐ Therapists

☐ Other: PHYSICIANS!

Has your child ever had to stay in the hospital overnight? ☒ Yes ☐ No

If yes, how does your child cope while in the hospital?

HE IS NOT HAPPY TO BE THERE BUT REALIZES IT IS A NECESSITY IN THE BATTLE AGAINST THE DISEASE.

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

HE TRIES TO LEAD A REGULAR ACTIVE LIFESTYLE IN SPITE OF THE DISEASE. HE WILL NOT GIVE IN AT ANY TIME TO THE PROBLEMS FROM THE DISEASE.

Is there anything more that could be done to make your child feel better when in the hospital?

THE CHILD SHOULD HAVE MORE OPPORTUNITIES FOR "FUN" PROJECTS WHILE IN THE HOSPITAL TO KEEP HIS MIND OFF OF THE HOSPITALIZATION

Do you have any other thoughts to share?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

My oldest child: scared

My youngest child: angry

How have these initial feelings changed over time?

They both get upset at times, frustrated also during flare-ups when there are limitations on diets, etc.

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ [✓ No]

What has affected your child the most emotionally as a result of his/her diagnosis?

Embarassment at having to use the toilet so often. Frustration, too!

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

No, for both children. They have very supportive friends.

Have you taken an active role in your child's emotional and physical treatment process?

Yes.

How?

By attending support groups; my younger child continues to see a counselor; by making decisions with her doctor about medications, procedures, etc.

Do you think your involvement has helped your child?

☐ [✓ Yes] ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☐ Yes ☐ [✓ No]

How?

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No

Have you attended a parent/child support group? How has this helped you and your child? Yes, I've learned a lot from guest speakers and other parents.

Has your child had to take steroids? ☐ [✓ Yes] ☐ No

Have there been any side effects from the steroids? ☐ [✓ Yes] ☐ No

Please describe in detail?

Puffiness
Facial Hair
Weight gain
Mood Swings
Increased Appetite

Has your child had to have surgery? ☐ Yes ☐ [✓ No]

What type of surgery did your child have?

How did your child feel before surgery?

How did your child feel after surgery?

What do you think has helped your child cope with his/her illness the most?

☐ [✓ Family] ☐ [✓ Friends] ☐ Support groups ☐ Therapists

☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☐ [✓ Yes] ☐ No

If yes, how does your child cope while in the hospital? My oldest child was hospitalized at age 8 for 8 days. She coped fairly well with visitors, hospital activities & crafts to keep her occupied. My youngest child was recently hospitalized for 17 days. Coping was easier during the first →

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

Is there anything more that could be done to make your child feel better when in the hospital?

Do you have any other thoughts to share?

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

Confused about the possible implications of the disease & unable to understand the concept of Cronic When flare up occurs There was a Combination of Anger & Some embarrasment

How have these initial feelings changed over time?

He is still private about his disease although he now understands That Legal help is available Through the disability office at School That he will Communicate about.
There is a growing anger that this disease almost has a life of its own

Do you notice any changes in your child's emotions since diagnosis?

☐ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways? Actually he has become More active Socially and more Communicative, although not about his illness. I believe this Would have probably occurred anyway because of Age.

Have you taken an active role in your child's emotional and physical treatment process?

yes Tried - Sometimes rebuffed

How? Met with & kept open rapport with all of his doctors although he requests that he deal with Him Directly.
We have tried to set up physcological Support but he was basically not interested

Do you think your involvement has helped your child?

☐ Yes ☐ No Yes & no – We have made sure that He has excellent Medical Support & Treatment & that medicines are taken – He seems to resent our constant involvement

Do you think your feelings regarding your child's illness affect him/her?

☐ [✓ Yes] ☐ No

How? We have handled this illness with the precision of type A personalities – He resents the knowledge & involvement

Are you completely open and honest with your child about his/her condition?

☐ [✓ Yes] ☐ No He Communicates with his own Doctors

Have you attended a parent/child support group? How has this helped you and your child? YES – Excellent Educational experience – particularly in relation to disability programs in College & Medical treatments available.

Has your child had to take steroids? ☒ Yes ☐ No

Have there been any side effects from the steroids? ☒ Yes ☐ No

Please describe in detail?

Sleeping problems, Eating problems, weight fluctuation

Has your child had to have surgery? ☒ Yes ☐ No

What type of surgery did your child have?

Perianal.

How did your child feel before surgery? initially Scared after 2 or 3 occurrences More routine

How did your child feel after surgery?

Anger

What do you think has helped your child cope with his/her illness the most?

☒ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ______________________

Has your child ever had to stay in the hospital overnight? ☒ Yes ☐ No

If yes, how does your child cope while in the hospital?

Very poorly, very abrasive with Hospital personnel

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? Is paying More attention to Control & detail of Medical regiments Has undertaken Aggressive body building Program with significant Success

Is there anything more that could be done to make your child feel better when in the hospital? No - He hates Confinement & attention

Do you have any other thoughts to share?

5/2000

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

That it WAS UNfair / scared

How have these initial feelings changed over time? / less frightened but at times depressed

Attitude has improved as surgery has shown light @ end of tunnel

Do you notice any changes in your child's emotions since diagnosis?

☑ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

When? - She has trouble dealing with the fact she is "normal" no longer

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

conscious

some. Self [illegible] about bag

Always [illegible] friends [illegible] has not [illegible] [illegible]

Have you taken an active role in your child's emotional and physical treatment process?

We have tried

How?

talking & helping her we can

We have had her evaluated at times for depression

She also has been seeing a counselor [illegible] needed basis

Do you think your involvement has helped your child?

☑ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☑ Yes ☐ No

How?

She knows that we are trying to help

Are you completely open and honest with your child about his/her condition?

☑ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child?

yes, helps understanding

Has your child had to take steroids? ☑ Yes ☐ No – There were too many pills she needed to take and she stopped taking them without our knowledge – she wanted surgery.

Have there been any side effects from the steroids? ☑ Yes ☐ No

Please describe in detail?

First phase effects – puffy face – weight gain.

Has your child had to have surgery? ☑ Yes ☐ No

What type of surgery did your child have?

total colectomy w/ resection

Her first operation at Children's in June 20

She has always had a difficult time [redacted]

surgery:
and recovering has been hard-
emotionally more so than physical
It takes alot of courage for her to go to
the hospital and deal with her situation
She is also concerned about the other children
we see and talk to.

It is very hard, for example, for Alexis to allow the
nurses to put a tube down her nose.

How did your child feel before surgery?

Unhappy & Depressed/scared she was going to die.

How did your child feel after surgery?

Much better - happy she woke up and didn't die!

What do you think has helped your child cope with his/her illness the most?

☑ Family ☑ Friends ☐ Support groups ☐ Therapists

☐ Other: girl scout leaders + an adult in our town who has Crohns

Has your child ever had to stay in the hospital overnight? ☑ Yes ☐ No

If yes, how does your child cope while in the hospital?

Not well!

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease?

Not happy but getting better

She is embarrassed by the disease and feels much better in a private room.

Is there anything more that could be done to make your child feel better when in the hospital?

Stay away from UMASS

UMASS doctors and nurses were wonderful but better communication would be helpful between nurses, doctors and main kitchen. Unfortunately for the UMASS [illegible] doctors - my daughter had the worse with taking medication and took her →

Do you have any other thoughts to share?

UMASS Community - very very supportive!

frustrations out on the nurses. I think I, as her Mom, did help Alexis handle her situation with the nurses and the doctors. I support UMASS more than my husband.

Other thoughts:

Thank you for taking time to work on this survey - Good luck.

How do you think your child first felt when he/she was diagnosed with Ulcerative Colitis or Crohn's Disease?

Scared

How have these initial feelings changed over time?

lessened with restoration of relative health

Do you notice any changes in your child's emotions since diagnosis?

☒ Yes ☐ No

What has affected your child the most emotionally as a result of his/her diagnosis?

SEEMS somewhat LESS CONNECTED SOCIALLY (more SUPERFICIAL CONNECTIONS)

Has your child's social life changed at all since being diagnosed with Ulcerative Colitis or Crohn's Disease? In what ways?

WHEN ACTIVELY ILL RESTRICTED - OTHERWISE NOT SO

Have you taken an active role in your child's emotional and physical treatment process? YES

How? EXPLORED AS MANY AVENUES AS POSSIBLE - READING, TALKING TO OTHERS - GENERAL EDUCATION TRIED EASTERN & WESTERN MEDICINE, EMOTIONALLY AVAILABLE & OPEN (PUSH FOR) DISCUSSION

Do you think your involvement has helped your child?

☒ Yes ☐ No

Do you think your feelings regarding your child's illness affect him/her?

☒ Yes ☐ No

How? the thoughts are here & I think is concerned, but he is pretty upbeat

Are you completely open and honest with your child about his/her condition?

☒ Yes ☐ No

Have you attended a parent/child support group? How has this helped you and your child? PARENT only

Has your child had to take steroids? ☐ Yes ☒ No

N/A

Have there been any side effects from the steroids? ☐ Yes ☐ No

Please describe in detail?

Has your child had to have surgery? ☐ Yes ☒ No

What type of surgery did your child have?

How did your child feel before surgery?

N/A

How did your child feel after surgery?

N/A

What do you think has helped your child cope with his/her illness the most?

☒ Family ☐ Friends ☐ Support groups ☐ Therapists

☐ Other: ____________________

Has your child ever had to stay in the hospital overnight? ☒ Yes ☐ No

If yes, how does your child cope while in the hospital?

Very Frightened & over whelmed

How does your child cope while out of the hospital with his/her Ulcerative Colitis or Crohn's Disease? He has been very responsive to Treatment which helps to feel like if he is actively involved in treatment he can have control

Is there anything more that could be done to make your child feel better when in the hospital? PRIVATE Room — or room with another patient that was similarly ill — His Roommate was very sick vomiting lots of through the night Dr. visits... SCARY!

Do you have any other thoughts to share?

APPENDIX K Completed Health Care Worker Surveys

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease? Depressed Isolated Embarrassed

How have you seen patients cope with the disease?

☐ Nothing ☐ Support Group ☑ Talk to Family and Friends

☑ Therapist ☑ Focusing on Other Things

If so, what?________________________

☐ Other ________________________

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

music therapy yoga medication

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face? Interrupted life style, discomfort

What difficulties have you observed that patients face as a result of their medications side effects? Body image issues

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease? Unhappy

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

Do you have any other thoughts to share?

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

Depressed, devestated

How have you seen patients cope with the disease?

☐ Nothing ☑ Support Group ☑ Talk to Family and Friends

☐ Therapist ☐ Focusing on Other Things

If so, what?______________________________

☑ Other Vent about their disease with other pts, staff.

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

① Better communication between nurses, Have staff (interns) attending about plan for their care.

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

Changes in lifestyle, dietary changes.

What difficulties have you observed that patients face as a result of their medications side effects?

① effects of steroids
② concept of having to take medication

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease?

① apprehension
② hopeful

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

① reassurance, ③ good communication
② stable environment

Chip

Do you have any other thoughts to share?

Good luck with your study

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease? Frightened + angry

How have you seen patients cope with the disease?

☐ Nothing ☑ Support Group ☑ Talk to Family and Friends

☐ Therapist ☐ Focusing on Other Things

If so, what?____________________________

☑ Other talking openly + freely c̄ gastro office nurse

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

Inpt → Visits from supportive people from all walks of life → even the office nurse!

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

Need for constant +/or immediate access to bathroom facilities (in all realms!)

What difficulties have you observed that patients face as a result of their medications side effects?

Compliance c̄ actually taking meds, especially when in remission

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease? a last resort!

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

More understanding + knowledgeable adults

Do you have any other thoughts to share?

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

Don't concept fullness or diagnosis - how bad it can △ life or impact things

How have you seen patients cope with the disease?

☐ Nothing ☑ Support Group ☑ Talk to Family and Friends

☑ Therapist ☐ Focusing on Other Things

If so, what?______________________________

☐ Other ______________________________

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

Both areas

Family contact to inform + teach by RN's how serious disease is.

School teaching by CG Foundation for teachers + school Nurses + principals Gym teachers music teachers

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

anxiety
Fear
coping

What difficulties have you observed that patients face as a result of their medications side effects?

Adverse S.E.
coping skills ↓

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease?

Good outlike might improve life for period of time

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

more School teaching by Foundation if School has Student c̄ disease # parent can call to have them come + teach about all factors

Do you have any other thoughts to share?

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

they feel alone, embarrassed c̄ other peers

How have you seen patients cope with the disease?

☐ Nothing ☐ Support Group ☒ Talk to Family and Friends

☐ Therapist ☐ Focusing on Other Things

If so, what?____________________________

☐ Other ____________________________

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

talk with pts who have UC or Chrons

form support groups

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

- tired because of being up all night using Bathroom
- struggling because they want to eat but know eating some foods will put them into a flare

What difficulties have you observed that patients face as a result of their medications side effects?

- weight gain
- striae on body
- irritability

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease?

- hopeful that it will cure the disease

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

- meeting c̄ nutritionist to go over diet requirements
- talking c̄ other children who have disease

Do you have any other thoughts to share?

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

devasted very Sad , confused about the diseases , implications

How have you seen patients cope with the disease?

☐ Nothing ☐ Support Group ☑ Talk to Family and Friends

☐ Therapist ☐ Focusing on Other Things

If so, what?____________________________

☐ Other speak with there Doctor

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

- private room
- trying to get back to a normal routine

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face?

Sleep less

- Body image Δ's from wt loss or gain
- ↓ social life feeling like they can't go far without toilet nearby

What difficulties have you observed that patients face as a result of their medications side effects?

Body image changes

* Mood swings from steroids

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease?

Most patients that require surgery are usually very sick and look to surgery to offer some relief

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

Support group

Do you have any other thoughts to share?

How do you think patients feel when they are first diagnosed with Ulcerative Colitis or Crohn's Disease?

Denial
Sick

How have you seen patients cope with the disease?

☑ Nothing ☑ Support Group ☑ Talk to Family and Friends

☐ Therapist ☑ Focusing on Other Things

If so, what?____________________________

☐ Other ____________________________

What do you think would help patients to better cope with Ulcerative Colitis or Crohn's Disease while in the hospital? While out of the hospital?

family support.
Same age gp support

What difficulties have you observed that patients with Ulcerative Colitis or Crohn's Disease face? socialization
body image

What difficulties have you observed that patients face as a result of their medications side effects? self esteme

How do you think most patients feel, in general, about surgery for Ulcerative Colitis or Crohn's Disease? Don't want it, but are ready for it because they are so sick.

What do you think would help alleviate some of the difficulties that children with Ulcerative Colitis or Crohn's Disease have to deal with.

Support gps
education
family support.

Do you have any other thoughts to share?

ET Nurse f.u. after surgery-

APPENDIX L Trivia Questions

Q: How can Ulcerative Colitis affect a person's spine?

A: Back pain, loss of flexibility, nerve damage

Please give away two pills

Q: How can Ulcerative Colitis affect a person's joints?

A: Joint pain, loss of joint flexibility, permanent joint damage

Please give two pills to another player

Q: What is strictureplasty?

A: Strictureplasty is when a narrowed area of intestine is opened and the intestine is widened

Please discard one pill

Q: What is a resection?

A: In a resection the diseased area is taken out and the remaining portions of healthy tissue are joined

Please discard one pill

Q: In what ways does CCFA provide support to people with Crohn's Disease and Ulcerative Colitis?

A: Organizes support groups, provides educational information, and sets up educational programs and seminars

Please discard two pills

Q: Is an increased appetite a side effect of Prednisone?

A: Yes

Please discard one pill

Q: What is Ulcerative Colitis?

A: Ulcerative Colitis is an inflammation of the colon and rectum, or both

Please give one pill to another player

Q: What is Crohn's Disease?

A: Crohn's Disease is a serious inflammation of predominantly the small intestine and colon, but may effect any part of the GI tract

Please discard two pills

Q: How many people suffer from Crohn's Disease and Ulcerative Colitis in the United States?

A: Approximately two million Americans suffer from Crohn's Disease and Ulcerative Colitis

Please discard two pills

Q: What is the difference between an Upper GI and a Lower GI?

A: In an Upper GI you drink barium, and in a Lower GI they insert barium through the rectum

Please discard one pill

Q: Can emotional stress influence a patient's disease?

A: Yes, since the mind and body are so intertwined, disease can often be triggered by a patients level of stress

Please discard one pill

Q: What is Anemia?

A: Anemia is a low amount of hemoglobin in the red blood cells

Please discard two pills

Q: Does Crohn's Disease run in families?

A: Crohn's Disease may run in families

Please discard one pill

Q: Is good nutrition important in the treatment of IBD?

A: Yes, nutrition is important because the disease takes much of the nutrients, fluids, vitamins, and minerals from the body

Please give two pills to another player

Q: How is Ulcerative Colitis detected?

A: Ulcerative Colitis is detected by a Colonoscopy

Please discard one pill

Q: What is a biopsy?

A: A biopsy is a small piece of tissue taken from a person's body for examination under a microscope

Please discard one pill

Q: What are the names of the two Major League Baseball Teams in New York?

A: The New York Mets and the New York Yankees

Please give away one pill

Q: Is surgery a "last resort" medical treatment for IBD?

A: No, surgery is very much an option for IBD. Sometimes surgery is the only treatment for a specific condition

Please give one pill to another player

Q: What is the percentage of patients with Crohn's Disease that will have to have surgery at some point in their lives?

A: 75%

Please discard one pill

Q: What is the percentage of patients with Ulcerative Colitis that will have to have surgery at some point in their lives?

A: 30%

Please discard one pill

Q: Is it possible for Crohn's Disease to be cured by surgery?

A: No, Crohn's Disease cannot be cured by surgery. However, surgery is done to alleviate painful symptoms

Please discard two pills

Q: Is it possible for Ulcerative Colitis to be cured by surgery?

A: Ulcerative Colitis can be cured when the entire colon and rectum is removed

Please discard one pill

Q: What is meant by a total colectomy or proctocolectomy?

A: A total colectomy or proctocolectomy means the entire colon and rectum are removed

Please give one pill to another player

Q: What is meant by a subtotal colectomy?

A: A subtotal colectomy means removal of the colon, but not the rectum or anus

Please discard two pills

Q: What is an ileostomy?

A: An ileostomy is when the ileum is redirected through the wall of the abdomen to the skins surface. An appliance is then placed over the opening to collect stool

Please discard two pills

Q: What do steroids do to a person's bones?

A: Steroids reduce the amount of calcium that the body absorbs. As a result, bones begin to deteriorate.

Please give one pill to another player

Q: When do Doctors use steroids in the treatment of Crohn's Disease and Ulcerative Colitis?

A: Doctors use steroids when the disease can no longer be controlled by any other medication

Please discard one pill

You just went into remission, discard all pills for any section before the transverse colon and proceed to the beginning of the transverse colon

Q: What is a colostomy?

A: In a colostomy, part of the colon is redirected through the abdomen wall to the skins surface. An appliance is then placed over the opening to collect stool

Please discard one pill

Q: Name one of the two main types of drugs that are prescribed by doctors to reduce inflammation in the affected area of intestine?

A: Steroids and 5-ASA drugs

Please discard one pill

Q: How is Remicade given to patients?

A: Patients receive remicade through an infusion

Please discard one pill

Q: How can Ulcerative Colitis affect a patient's skin?

A: Redness, tender bumps, and sores may occur

Please discard one pill

Q: How can a person receive information from CCFA?

A: They can be reached two ways, one by calling 1-800-932-2423, or on the web at www.ccfa.org

Please give one pill to another player

You got Appendicitis, go to the Appendix

Q: What organs can Crohn's Disease effect?

A: Any or all of the GI tract

Please discard two pills

Q: After a diseased area has been removed in a patient with Crohn's Disease, may disease reoccur?

A: Yes, because Crohn's Disease can never be cured

Please discard one pill

Q: For a patient with Ulcerative Colitis who has had a colectomy, what is pouchitis?

A: Pouchitis is an infection in the patients J or S pouch

Please give away two pills

Q: What is an Enerostomal Theraist (ET Nurse)?

A: An ET Nurse helps patients after they have had a surgery which requires them to have an ostomy

Please give two pills to another player

Q: Is arthritis associated with IBD?

A: Yes, arthritis is often times associated with IBD

Please discard one pill

Q: Is osteoporosis associated with Crohn's Disease or Ulcerative Colitis?

A: No, however it can be caused by the use of steroids for treatment of the disease

Please discard one pill

Q: What is Osteoporosis?

A: Osteoporosis is a disease which results in the destruction of bones causing them to become weak and much more likely to fracture

Please discard two pills

Q: Does Ulcerative Colitis increase a person's risk of getting colon cancer?

A: Yes, that is why a person with Ulcerative Colitis should receive annual cancer examinations

Please discard one pill

Q: What is the cause of Crohn's Disease or Ulcerative Colitis?

A: Currently there is no known cause for Crohn's Disease or Ulcerative Colitis

Please give one pill to another player

Medication is not working, go back to the start

Q: What is IBD?

A: IBD stands for Inflammatory Bowel Disease

Please discard two pills

Q: What organs are affected by Ulcerative Colitis?

A: Ulcerative Colitis may effect the colon or rectum or both

Please discard one pill

Q: What is the name of the first Indiana Jones Movie?

A: Indiana Jones and the Raiders of the Lost Ark

Please give away two pills

Q: What were the Los Angeles Dodgers originally known as?

A: Brooklyn Dodgers

Please give two pills to another player

Q: Who played Indiana Jones in the trilogy?

A: Harrison Ford

Please discard one pill

Q: What is the real name of the music artist "Fresh Prince?"

A: Will Smith

Please discard two pills

Q: What is the golf term for one stroke under par for a hole?

A: birdie

Please give one pill to another player

Q: Where were the 1996 Summer Olympics held?

A: Atlanta, Georgia

Please discard two pills

Q: What music artist sings the songs "Lucky," "Oops, I Did It Again," and "Sometimes?"

A: Britney Spears

Please discard one pill

Q: What is the name of the actor who played Austin Powers?

A: Mike Meyers

Please discard one pill

Q: What is the name of the stadium that the New York Yankees play in?

A: Yankee Stadium

Please discard two pills

Q: Whom is Clark Kent better known as?

A: Superman

Please discard one pill

Q: Name all of the members of the Simpson's household.

A: Homer, Marge, Bart, Lisa, and Maggie

Please give away two pills

Q: When was the last time the Boston Red Sox won the World Series?

A: 1918

Please give two pills to another player

Q: What is Batman's real name?

A: Bruce Wayne

Please discard one pill

Q: Who is the lead singer of Pearl Jam?

A: Eddie Vedder

Please discard one pill

Q: Who is the 42nd President?

A: Bill Clinton

Please discard two pills

Q: Who were the first two men to walk on the moon?

A: Buzz Aldrin and Neil Armstrong

Please discard one pill

Q: Name the original Three Stooges?

A: Moe, Larry, and Shemp

Please give one pill to another player

Q: What is the number of the episode of Star Wars: A New Hope?

A: Four

Please discard two pills

Q: In Star Wars, who was Luke Skywalker's Father?

A: Darth Vader or Anakin Skywalker

Please discard two pills

Q: In the movie Jurassic Park, on what island was the park located?

A: Isla Nublar off the Coast of Costa Rica

Please discard one pill

Q: Who played Superman in the movies?

A: Christopher Reeve

Please give away two pills

Q: Who invented the electric light bulb?

A: Thomas Edison

Please give two pills to another player

Q: Where are the smallest bones in the human body located?

A: Hand

Please discard one pill

Q: Which planet is nearest to the sun?

A: Mercury

Please discard one pill

Q: Where did Mickey Mouse make his first appearance?

A: "Steamboat Willie"

Please discard two pills

Q: In Fahrenheit, at what temperature does water freeze?

A: 32°F

Please discard one pill

Q: What letter does not appear in the name of any of the U.S. states?

A: Q

Please give one pill to another player

Q: How many stomachs does a cow have?

A: 4

Please discard two pills

Q: A perfect tenpin bowling game has how many strikes?

A: 12

Please discard two pills

Q: What states are Disney World and Disney Land located in?

A: Florida and California

Please discard one pill

Q: How many °C is 32°F equal to?

A: 0°C

Please give away two pills

Q: What does a baseball pitcher have to do to walk a batter?

A: Throw four balls

Please give two pills to another player

Q: What is the left field wall at Fenway Park called?

A: The Green Monster

Please discard one pill

Q: How many points is a Football touchdow worth?

A: 6 points

Please discard one pill

Q: What is the real name of the rapper "Eminem?"

A: Marshall Mathers

Please discard two pills

Q: What is the capital of Rhode Island?

A: Providence

Please discard one pill

Q: What is the capital of France?

A: Paris

Please give one pill to another player

Q: Where is the Eiffel Tower located?

A: Paris, France

Please discard two pills

Q: What city and state do the Broncos football team play in?

A: Denver, Colorado

Please discard two pills

Q: What is the name of the Red Hot Chili Peppers bassist?

A: Flea

Please discard one pill

Q: What city do the New England Patriots play in?

A: Foxboro

Please give away two pills

Q: How many feet are in a yard?

A: 3

Please give two pills to another player

Q: What University has the nickname the Fighting Irish?

A: Notre Dame

Please discard one pill

Q: What is Boston College's nickname?

A: Eagles

Please discard one pill

Q: Which fast food restaurant has the golden arches as a trademark?

A: McDonalds

Please discard two pills

Q: What fast food restaurant has a burger called the "Whopper?"

A: Burger King

Please discard one pill

Q: Who is Luke Skywalker's sister?

A: Princess Leia

Please give one pill to another player

Q: Who created Star Wars?

A: George Lucas

Please discard two pills

Q: In what country is the city of Rome located?

A: Italy

Please discard two pills

Q: What was the last Indiana Jones movie called?

A: The Last Crusade

Please discard one pill

Q: How many items are in a dozen?

A: Twelve

Please give away two pills

Q: Where were the first Olympics held?

A: Athens, Greece

Please discard one pill

Q: What organ pumps blood throughout a person's body?

A: The heart

Please discard two pills

Q: Where were the 2000 Summer Olympics held?

A: Sydney, Australia

Please give one pill to another player

Q: What kind of music does Dr. Dre sing?

A: Rap

Please give two pills to another player

Q: How many planets are closer to the sun than Earth?

A: Two

Please discard one pill

Q: What is the major organ involved in helping a person breathe in Oxygen?

A: Lungs

Please discard one pill

Q: What company did Bill Gates create?

A: Microsoft

Please discard two pills

Q: Where are kangaroos found?

A: Australia

Please discard two pills

Q: Who was the first President of the United States?

A: George Washington

Please discard one pill

Q: In what part of the body is the femur located?

A: In the leg

Please give away two pills

Q: If it were removed from the body, how long would the small intestine stretch to?

A: 22 Feet

Please give two pills to another player

Q: How many muscles are needed to frown?

A: 43

Please discard one pill

Q: How many muscles are needed to smile?

A: 17

Please discard one pill

Q: What living things produce oxygen for humans to breathe?

A: Plants

Please discard two pills

Q: Who wrote the children's book The Cat and The Hat?

A: Dr. Seuss

Please discard one pill

Q: When is surgery required for a patient with IBD?

A: Surgery is required when medication no longer is working, or when the doctor and patient both feel that it is more beneficial than continuing on with medication

Please give one pill to another player

Q: What are two groups of people that a patient could talk to, to receive help?

A: Parents, family, teachers, friends, doctors, nurses, and therapists

Please discard two pills

Q: What organization is devoted to providing help and support for people with Crohn's Disease and Ulcerative Colitis?

A: Crohn's and Colitis Foundation of America (CCFA)

Please discard two pills

Q: What are symptoms of Ulcerative Colitis?

A: Abdominal pain, bleeding, diarrhea, and cramps

Please discard one pill

Q: What continent is the Amazon located in?

A: South America

Please give away two pills

Q: What is Mickey Mouse's girlfriend's name?

A: Minnie Mouse

Please give two pills to another player

Q: How many bones are in the human body?

A: 206

Please discard one pill

Q: Who made the first airplane?

A: The Wright Brothers

Please discard one pill

Q: What was the name of the space shuttle that exploded in 1986?

A: The Challenger

Please discard two pills

Q: Who retired from Basketball and then played Baseball?

A: Michael Jordan

Please discard one pill

Q: What team did Michael Jordan play for?

A: The Chicago Bulls

Please give one pill to another player

Q: What team did John Elway play for before he retired?

A: The Denver Broncos

Please discard two pills

Q: What was the name of the original arena that the Boston Celtics played in?

A: The Boston Garden

Please discard two pills

Q: Does England have a President?

A: No

Please discard one pill

Q: What is a Fistula?

A: An abnormal channel occurring between two loops of intestine, or between the intestine and another structure, such as the bladder, vagina, or skin

Please discard two pills

Q: What is an Ileoanal Anastomosis?

A: A procedure done to cure patients of Ulcerative Colitis where an internal reservoir (pouch) is created

Please discard one pill

Q: What is an obstruction of the bowel?

A: An obstruction is a blockage of either the small of large intestine and does not allow normal passing of stool through them

Please give one pill to another player

Q: What is the currency of the Netherlands?

A: Guilder

Please discard one pill

Q: What is the longest river in the Irish Republic?

A: The Shannon River

Please give one pill to another player

Q: What is the highest mountain peak in Europe?

A: Mount Elbrus

Please discard two pills

Q: Other than the Caspian Sea, what is the largest lake in Europe?

A: Lake Lodoga

Please discard two pills

Q: How many countries border France?

A: Eight

Please discard one pill

Q: What three islands make up the Balearic Islands?

A: The Ibiza, Majorca, and the Minorca

Please give two pills to another player

Q: In what country in Europe is the highest waterfall located?

A: France

Please discard two pills

Q: Magyar Koztarsasag is the national name of what country?

A: Hungary

Please discard two pills

Q: Who is the author of the book Animal Farm?

George Orwell

Please discard one pill

Q: Who is the author of the book A Separate Peace?

A: John Knowles

Please give one pill to another player

Q: Who is the author of the book The Stranger?

A: Albert Camus

Please discard two pills

Q: Who wrote the book Little Women?

A: Louisa May Alcott

Please discard two pills

Q: Who shot President William McKinley in 1901?

A: Leon Czolgosz

Please discard two pills

Q: What national landmark opened in Washington D.C. in 1922?

A: Lincoln Memorial

Please give two pills to another player

Q: When it was introduced in 1908, how much did the Ford Model T sell for?

A: $850

Please discard two pills

Q: What medical breakthrough occurred in 1955?

A: The polio vaccine

Please discard two pills

Q: The Star-Spangled Banner was written in 1814 by Francis Scott Key, what year did it become the national anthem?

A: 1931

Please give one pill to another player

Q: Who was the first American woman in space?

A: Sally Ride

Please discard two pills

Q: Who was the first woman elected to Congress?

A: Jeanette Rankin

Please give one pill to another player

Q: Where did Martin Luther King, Jr. give his famous "I have a dream…" speech?

A: The Lincoln Memorial in Washington D.C.

Please discard two pills

Q: What does the 26th Amendment, adopted in 1971, address?

A: The voting age

Please discard two pills

Q: Who was the first woman to win an Academy Award?

A: Janet Gaynor

Please discard one pill

Q: Name two of the major cosmetic manufacturers?

A: Maybelline, Max Factor, Cover Girl, Loreal, Revlon, Neutrogena, Oil of Olay, Coty, and Allmay

Please discard one pill

Q: Name three soap operas on T.V.?

A: Days of Our Lives, Port Charles, General Hospital, Passions, The Bold and the Beautiful, Guiding Light, All My Children, and One Life To Live

Please discard one pill

Q: Who sewed together the first American flag?

A: Betsy Ross

Please discard one pill

Q: “A Civil Action” is a movie concerning toxic waste being dumped into what town’s water?

A: Woburn, MA

Please discard one pill

Q: What is the name of “Beauty” in Disney’s “Beauty and the Beast?”

A: Belle

Please discard one pill

Q: Which U.S. Female rowers won bronze medals in the light weight double sculls competition at the 2000 Olympics?

A: Christine Collins and Sarah Garner

Please give two pills to another player

Q: Who was the star female actress in “My Best Friends Wedding?”

A: Julia Roberts

Please discard one pill

Q: Which company manufactures Barbie Dolls?

A: Mattel

Please discard one pill

Q: Melissa Joan Hart is known for portraying what witch?

A: Sabrina, the Teenage Witch

Please discard one pill

APPENDIX M Bonus Trivia Questions

Bonus Question

Q: Who or what has been your support throughout your illness?

Please discard one pill

Bonus Question

Q: Have you attended any support groups?
If yes, how have they helped?

Please discard one pill

Bonus Question

Q: Has the hospital staff been able to provide you with support?

Please discard one pill

Bonus Question

Q: How have your Doctors been able to support you?

Please discard one pill

Bonus Question

Q: Has there been anything surprising about the support you have received from your peers?

Please discard one pill

Bonus Question

Q: Has it helped you to talk with other children with IBD? If yes, how has it helped?

Please discard one pill

Bonus Question

Q: Do you find it difficult to talk with your friends about IBD and why?

Please discard one pill

Bonus Question

Q: How has your school been supportive of you during absences due to your illness?

Please discard one pill

Bonus Question

Q: How have you dealt with the side effects from your medications?

Please discard one pill

Bonus Question

Q: Do you feel uncomfortable taking your medication? Do you ever skip doses?

Please discard one pill

Bonus Question

Q: If you have had surgery, how do you feel about surgery now?

Please discard one pill

Bonus Question

Q: If you have had surgery, do you feel that the medical staff was supportive before and after surgery?

Please discard one pill

Bonus Question

Q: Have you felt your mood change as a result of your medications?

Please discard one pill

Bonus Question

Q: What feelings did you have when surgery was first discussed as an option?

Please discard one pill

Bonus Question

Q: If you have had surgery, what did you do to prepare yourself emotionally prior to the surgery?

Please discard one pill

Bonus Question

Q: Is there any way that the hospital or medical staff could be more supportive?

Please discard one pill

Bonus Question

Q: If you have had surgery, would it have helped to talk with someone who has had a similar type of surgery prior to surgery?

Please discard one pill

Bonus Question

Q: How have you coped with IBD over time?

Please discard one pill

Bonus Question

Q: What has been most difficult about coping with this illness?

Please discard one pill

Bonus Question

Q: What would you say is the best way to help someone in your position to cope with this illness?

Please discard one pill

Bonus Question

Q: Have you had difficulty finding information about IBD?

Please discard one pill

BONUS QUESTION

Q: How are Crohn's Disease and Ulcerative Colitis different?

Please discard one pill

BONUS QUESTION

Q: How do you cope with your illness?

Please give away two pills

BONUS QUESTION

Q: What do you do when you feel that you might be getting depressed?

Please give two pills to another player

BONUS QUESTIONS

Q: Do you know where the local support groups are near you? If yes, where?

Please discard two pills

BONUS QUESTION

Q: How does your family help you to cope with the disease?

Please discard two pills

BONUS QUESTION

Q: How do you deal with IBD in school?

Please discard two pills

BONUS QUESTION

Q: What are the common side effects of Prednisone?

Please discard two pills

BONUS QUESTION

Q: How do you feel about using public restrooms and how do you go about using them?

Please discard one pill

BONUS QUESTION

Q: What do you do to take your mind off of everything?

Please discard two pills

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