If you are reading this booklet, you or a loved one are considering an ileal-pouch anal anastomosis (IPAA), an operation to restore the passage of stool through the anus after removal of the colon and rectum. The combination of these two surgeries is the treatment of choice for ulcerative colitis or familial polyposis.

We believe that patients undergoing the IPAA have better results when they are cared for by a multidisciplinary team of professionals with experience in this procedure, and when the patient and family have a clear understanding of the unique features of the IPAA.

This booklet will assist in your decision, prepare you for surgery, and serve as a basis for questions and concerns you might have. It is important that you fully understand your choices before you start your road to recovery – a recovery that includes your mind and feelings, your family and your lifestyle, as well as your body.

# **About the Procedure**

The IPAA is designed to allow bowel movements through the anus after removing the entire large bowel and most of the rectum. A straight connection of the small bowel to the anus is undesirable because it results in a high frequency of bowel movements. By creating a pouch with the end of the small bowel (ileum), the frequency of bowel movements is reduced to a more acceptable level, about six to 10 per day. Other names for the procedure include: ileo-anal procedure, ileo-anal anastomosis, ileo-anal pull-through, pull-through procedure, Soave procedure, "J", "s" or "w" pouch.

# **Ulcerative Colitis**

Nine out of ten patients have this operation to treat ulcerative colitis (UC), which is a chronic inflammation of the inner layer of the colon or large bowel producing painful and bloody diarrhea. The mechanism underlying this inflammatory process is an overreaction of the immune system to the usual intestinal bacteria. Immune reactions designed to attack microorganisms turn against one's self and destroy the cells lining the colon. The medicines used to treat patients with ulcerative colitis are corticosteroids (Prednisone), sulfasalazine (Azulfidine<sup>™</sup>), derivatives of 6-aminosalicylic acid (e.g., Pentasa<sup>™</sup>, Rowasa<sup>™</sup>) and drugs that suppresses the immune system (6-Mercaptopurine, Azathioprine, Cyclosporin).

Patients with ulcerative colitis are referred to surgery when one of four situations arises:

- When medicines are not able to control the symptoms of ulcerative colitis
- When medications produce serious side effects
- In some patients, the inflammation progresses to produce a sudden enlargement of the colon (toxic mega colon), massive bleeding, or a perforation and peritonitis. These are all emergency situations where surgery cannot be delayed.
- Dysplasia and colon cancer multiple episodes of ulcerations and healing can turn the lining of the colon cancerous. For that reason, patients with UC undergo "surveillance" colonoscopy and biopsies. If the cells lining the colon start losing their normal structure, called dysplasia, we can anticipate the development of cancer and perform a preventive surgery. If cancer has already developed, then surgery is performed as a cure along with chemotherapy.



# **Crohn's Disease**

Another inflammatory condition of the colon is called Crohn's disease. IPAA is not a good option for these patients because the inflammation can extend into the ileal pouch and create fistulas.

#### **Indeterminate Colitis**

This condition is neither typical for ulcerative colitis nor for Crohn's disease. When the symptoms of indeterminate colitis are more consistent with ulcerative colitis than with Crohn's disease, then IPAA is good option and patients generally have the same results as if they had ulcerative colitis.

#### **Familial Polyposis**

Familial polyposis is a rare hereditary condition where an error in the gene code produces many polyps in the colon. Over time, these polyps can also develop into cancer. Individuals with familial polyposis are usually brought to the doctor in their teen years, by their parents, without having any symptoms or discomfort.

# **About the Colon**

The colon, also known as the large intestine or large bowel, is a horseshoe-shaped tube that connects to the small bowel where most digestion and absorption takes place, and travels up (ascends) from the lower right side, crosses (traverses) the abdomen, then descends the left side and connects to the rectum in the pelvis, framing the small intestine on three sides. The diameter of the colon varies along its course but, on average, is twice as big as the small intestine/small bowel.

The colon has three layers of tissue mounted on top of each other:

- Mucosa the inner layer (lining) that contains the epithelial cells that absorb water and salts
- Middle layer the muscle that contracts to propel stool into the anus
- Serosa the outer layer

At the anus, the muscle fibers of the rectum become rearranged to form the internal anal sphincter. The anal sphincter, which has another muscle called the external anal sphincter, is responsible for keeping the anal canal closed at all times and open only to produce a bowel movement.

The colon is normally filled with bacteria that constitute the colonic flora. These bacteria are capable of fermenting part of the vegetable fiber that escapes digestion in the small bowel. The bacteria extract energy from fiber without causing any harm to the host.

Some of the energy products generated by the bacteria are used by the colon and help in the absorption of water and salts.

# What Surgical Options Are Available?

First, it's important to understand the terminology regarding the different surgical options:

- Colectomy when the colon is entirely removed through the abdomen
- Proctectomy removal of the rectum

The two procedures combined are called proctocolectomy. In a restorative proctocolectomy, the anus is preserved and the small bowel is connected to the anus.

When the anus is excised along with the rectum in an operation known as an abdominoperineal resection (APR) or Miles procedure, then the options are:

#### lleostomy

The ileum is projected through the abdominal wall muscles, usually in the lower abdomen, and folded over above the skin level. Liquid stool flows through this ileostomy into an external plastic pouch. This plastic external pouch, the "appliance", is attached to the skin with a special adhesive material, called a flange, and is worn constantly.

#### Kock pouch or continent ileostomy

Instead of constantly wearing an external appliance, liquid stool is collected inside the abdomen within a pouch created with the ileum. In order to prevent the constant flow of liquid stool outside of the body, a nipple valve is created at the very end of the bowel that allows passage of stool out of the pouch only when a tube is placed through it.

Patients have to place the tube four to six times a day, usually at the same time as urination. This operation eliminates the need for an external appliance and allows for more control of the stool output. Initially, this operation had a high degree of failure, mostly at the nipple valve, and patients required multiple operations for revisions. When the IPAA was introduced, the technique for creating a Kock pouch was improved to almost eliminate the need for revisions. Although the Kock pouch is clearly a second choice compared to the IPAA, many patients enjoy very productive lives with this type of surgery.

#### IPAA

The IPAA consists of the creation of an ileal pouch, similar to the Kock pouch, and a connection of the pouch to the anus. The entire operation, including the colectomy and the IPAA, can be done at one time or it can be staged in different operations depending on the severity of the colitis and the certainty of the diagnosis of ulcerative colitis at the initial surgery. If the colitis is very severe, the patient is receiving potent immunosuppressive medications, or there is doubt that the colitis could be due to Crohn's disease or the patient may have invasive cancer, the initial operation may be limited to the removal of the colon and creation of an ileostomy.

Then, in a second stage, the IPAA is created when all those conditions are dealt with. If necessary, a temporary ileostomy is created in the second stage, which will then require a third operation for its reversal known as the third stage.

The addition of a temporary ileostomy to an IPAA is to prevent damage to the pouch if a leak occurs in the IPAA connection. The ileostomy prevents the passage of stool through the IPAA and although this itself does not help with healing, it does make the leakage less of a problem if it were to happen.

Therefore, the temporary ileostomy is added in patients who are at risk of leakage. These include patients receiving a high dose of steroids, anti-TNF drugs (e.g., Remicade<sup>™</sup>), or cyclosporin, and those who are very weak and sick. Another factor determining the need for an ileostomy is the technical difficulty at surgery.

If the mobilization of the pouch is too difficult, as in heavyset men, and the IPAA seems at risk, the ileostomy is created. Unfortunately, obesity also creates a difficulty in bringing through the ileostomy and can even be counterproductive for healing. Therefore, this decision is made at the time of surgery considering all these variables. In a second operation, usually eight to 12 weeks later, the ileostomy is closed and stool is allowed to flow through the anus.

# Ten Steps for a Successful Surgery

From the time a patient is referred to us for surgery until the patient returns to a normal level of activities, there are ten steps. Each of these steps is equally important to arrive at a successful outcome.

- 1. Initial visit
- 2. Preadmission testing
- 3. Enterostomal therapist visit
- 4. Pre-operative bowel preparation
- 5. Admission to the hospital
- 6. Surgery
- 7. Immediate post-operative period
- 8. Discharge process
- 9. Follow-up visits
- 10. Convalescence (and second surgery, if needed)

# **Initial Visit**

By the time you are reading this booklet, you may have already gone through the initial visit. Occasionally, this booklet is mailed to patients prior to their visit to the hospital.

It is important for us to have as much information about your illness as possible. If you have any medical reports (colonoscopy and biopsies) or X-rays at home (CDs), please mail them to us or bring them with you to your initial visit. Usually we receive these materials directly from your doctor's office, but occasionally they do not arrive before you come.

Please bring a list of any medications you have taken in the past and what you are presently taking, including over-the-counter drugs and supplements.

During the initial visit, we will get a full medical history from you and perform a physical exam. The surgeon will also perform a rectal exam on you. We are aware that the rectum and anus may be sore in most patients, but we still need to confirm that the strength of the anal sphincter is sufficient to carry out the IPAA to success.

Please write down any questions you may have and feel free to ask them at either the initial visit, anytime between the initial visit and the day of surgery, or even the day of surgery.

One issue that you may want to discuss with your surgeon is the need for blood for the operation. We like to have two units of blood available to use only in case of serious bleeding.

- You may choose to let us find blood suitable for you in the blood bank. Nowadays, the risks of transmissible infections associated with transfusions of banked blood are extremely low.
- Some patients prefer to designate a donor who may be a relative or a friend. This is always an option, but be aware that just because another person has the same blood type as you does not mean that it is compatible with yours.
- Bank your own blood (autologous blood). While this may seem the preferred way we don't encourage to it for several reasons. First, many patients with ulcerative colitis have anemia due to rectal bleeding so they cannot donate blood. Second, time is needed to bank the blood (72 hours) and to allow the body to replace some of the red cells (seven days). More importantly, patient can even have reactions to their own blood so we try not to give any blood to any

patient, even if we have autologous blood in the bank. Your blood will serve you better in your body than in the blood bank.

# **Preadmission Testing**

Before your admission to the hospital we need to be sure that you are healthy enough to undergo surgery.

- We will schedule an appointment to have your blood tested for cell counts, and chemistries.
- We usually ask for a urine sample to be sure that your bladder is sterile.
- Depending on the age of the patient we will also ask for a chest X-ray and electrocardiogram.

# **Enterostomal Therapist Visit**

We will try to schedule this visit either the same day as the initial visit with your surgeon or with the preadmission testing. An enterostomal therapist (ET) is a nurse specialized in any kind of opening of the gastrointestinal tract to the skin such as ileostomies and colostomies. The ET's role in the IPAA is crucial and involves:

- Informing the patient pre-operatively about ileostomies
- Selecting the appropriate site in the abdominal wall to create an ileostomy if needed
- Assisting the patient in the post-operative period with the management of an ileostomy and the protection of the perianal skin

The ideal site for an ileostomy varies from person to person depending on the shape of the body, clothing style and dexterity. During the pre-operative visit, the ET will determine the best site by having the patient take various positions while trying an appliance. Once the site has been agreed upon, the ET will mark that site with a special ink and sometimes cover it with a transparent dressing.

# **Pre-operative Bowel Preparation**

In the past, patients were admitted to the hospital for bowel preparation. Now, insurance coverage does not approve hospitalization for bowel preparation, so we rely on patients and families being very meticulous about this important step prior to surgery.

Many patients undergoing an IPAA have already experienced some form of bowel preparation for colonoscopy, which usually involves drinking a polyethylene glycol solution (GoLYTELY<sup>™</sup>). Before surgery, the bowel preparation is essential to minimize the chances of post-operative infections. Bowel preparation consists of three parts: diet, laxatives and antibiotics.

# Two days before surgery:

- 1. No solid foods may be eaten.
- 2. Drink only a clear liquid diet starting at breakfast. Clear liquids include water, tea, and coffee with no added milk or cream, broth, carbonated beverages.
- 3. Do not eat milk products, solids, or gelatin.
- 4. Take four biscacodyl tablets (i.e. Dulcolax) at bedtime.

# The day before surgery:

- 1. 1.Continue drinking a clear liquid diet all day, stop at 9:00am and resume after drinking GoLYTELY; do not eat solid food.
- 2. Drink the gallon of GoLYTELY (polyethylene glycol & electrolytes) at 12:00 Noon.
  - a) You should fast for three hours prior to ingestion of the solution; clear liquids are allowed after ingestion of the solution.
  - b) Take any other needed medications at least one hour before you start the solution.
  - c) Take 240 ml every 10 minutes up to four liters or until your fecal discharge is clear and free of solid matter (don't worry if after having seen the fecal discharge clear you have some particles in the stool, even if it is on the morning of surgery).
  - d) We recommend that you drink the solution rapidly rather than drinking small amounts continuously.
  - e) It usually starts to work in 30 to 60 minutes.
- 3. Take 500 mg of Flagyl and 1 gm of Neomycin by mouth at 7:00pm and 11:00pm
- 4. Shower carefully with a strong soap the night before surgery.
- 5. Ensure that your umbilical area (belly button) is clean; one way is by using a Q-tip.
- 6. Take nothing by mouth after midnight prior to your surgery. No candy, no mints, no chewing gum, and no water. This is essential to undergo general anesthesia. The anesthesiologist will not proceed with anesthesia if the stomach has not been absolutely empty for eight to 12 hours.
- 7. Follow special instructions for your medications.

We strongly recommend going to bed early the night before surgery. If you have trouble falling asleep, you are welcome to take a sleeping pill.

# Admission to the Hospital

You will be asked to come to the surgical access unit two hours prior to the start of your surgery.

- You will be admitted to the hospital. This process takes about 30 minutes. You will need to show your ID and insurance card.
- You will then be escorted in to the holding area. You will encounter many new people asking you many of the same questions over and over again. This is a safety mechanism to make sure you do not have any drug allergies, and that we have recorded as much information about you as possible.
- You will change into a gown, which can be a body warmer.
- An intravenous will be started in your arm.
- You will see your surgeon and/or other members of the team who will answer any last minute questions you may have.
- If you had not signed consent at your initial visit, you will be asked to do so now. Even if you did, it will be updated.
- You will meet the anesthesiologist and you will be offered a sedative to make you feel comfortable.
- You will then be taken to the operating room.
- If your family members are waiting they will go to the family waiting room. Your surgeon will come and speak to them when your surgery is finished. If they prefer to wait at home, the surgeon will phone them.

# Surgery

You will meet with your anesthesiologist prior to your surgery. You will then have an opportunity to discuss the general anesthesia you will receive.

You may be offered to have an epidural catheter placed prior to the induction of general anesthesia. This catheter, which lies in a space surrounding the spinal cord, is used to deliver effective analgesia in the post-operative period without the side effects and drowsiness of analgesics delivered into the blood stream. Or, you may have a patient-controlled analgesia (PCA) pump that delivers pain medication into your blood stream at the push of a button, Both methods are equally effective so that pain is not really a major issue after surgery.

Everyone working in the operating room will have a face mask. There are usually two nurses assigned to each operating room who will come to greet you and assist you to the operating room table. The anesthesiologist will place you under general anesthesia. From the time you fall asleep until we start the surgery there is an additional hour that we need to pad and position your legs, examine and irrigate the rectum, scrub the abdomen and anal area, and finally cover the rest of the body.

The operation will take between four and six hours depending on many factors.

- Gender: in females the operating time is shorter because it is easier to expose the rectum in the pelvis
- Body size: in heavyset patients the operation is more difficult
- Severity of the colitis

# **Immediate Post-Operative Period**

After surgery, you will spend approximately two hours in the recovery room and then you will go to your room. You will not remember much of what happened the day of your surgery. You will wake up the following day realizing that there are a number of devices attached to your body:

- Intravenous tube in your arm and perhaps another intravenous tube in one of your neck veins.
- A catheter in your bladder and possibly one in your new rectum.
- If you have a PCA pump, there will be a control button that you push to receive analgesics as needed.
- The most important device of all is your call button for your nurse.
- On a rare occasion we may leave a nasogastric tube draining gastric juice

The day after surgery you will be assisted to get out of bed and sit up in a chair. Being out of bed helps to aerate your lungs and gives you a sense of well-being.

By the second post-operative day we start removing devices such as the nasogastric tube and catheter. We will then encourage you to walk in the room and possibly in the hallways.

Usually by the third post-operative day we start detecting signs of your bowel recovering from surgery. Signs of bowel activity start with sounds that we can hear with a stethoscope of your passing gas and stool, either through the rectum or the ileostomy if we created one. Once we document bowel activity, we will start you on a clear liquid diet, which is the same as the pre-operative liquid diet. After 24 hours of tolerating liquids, we will add solid food. At this point, we are interested in knowing how much stool you output. Initially it will be high and, over a few days, will decrease. We need to be sure that you are drinking plenty of fluids to compensate for the fluid losses.

We will use a cream (Calmoseptine<sup>™</sup>) to protect the skin around the anus. You will also use this cream when you leave the hospital.

# **Discharge Process**

You will be ready to go home once you are eating, the intravenous fluids are stopped and you are tolerating medications by mouth.

If we created an ileostomy, we will give you enough supplies to take home with you and will make arrangements for a visiting nurse to go to your house and assist you with the first exchanges.

Your discharge instructions will include:

- Avoid lifting any object heavier than 10 pounds (four weeks)
- Avoid baths in the tub (four weeks)
- Avoid driving until you stop taking analgesics
- You should be careful with your diet, avoiding spices or any food item that can cause diarrhea.
- You will be encouraged to walk as much as you can. There is no problem going up stairs.
- Avoid sudden changes in temperature or exposure to people with colds since developing a cough or sneezing will be painful in your incision as well as being potentially dangerous.

# **Follow-Up Visits and Convalescence**

You will return to see your surgeon in approximately two weeks from the time of discharge. At this point, there may be a very superficial exam of your anus. Patients who had an ileostomy created will have an X-ray taken of the pouch (pouchogram) before having the ileostomy closed.