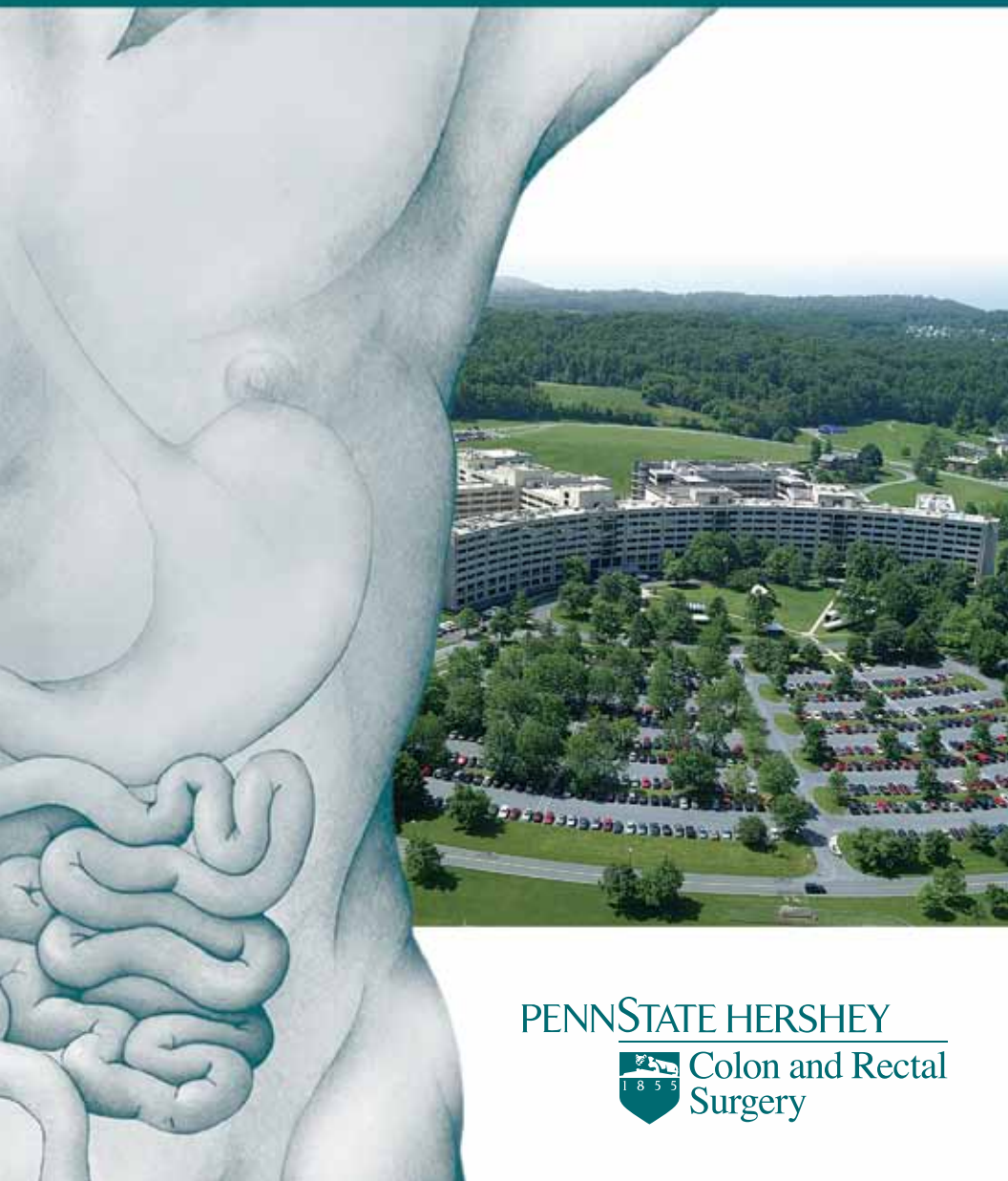


The Ileal Pouch Anal Anastomosis

A Patient Guide



PENNSTATE HERSEY



Colon and Rectal
Surgery

Penn State Hershey Colon and Rectal Surgery

Leading the Way in Treating Complicated Colorectal Disease

The ileal pouch anal anastomosis (IPAA) is a one- to three-stage operation that is indicated for patients with ulcerative colitis or familial adenomatous polyposis.

In this operation, the colon and rectum are removed, but the anal sphincters are preserved. An internal pouch-like reservoir is created from the remaining small intestine for storing fecal material and allowing “normal” elimination of stool. Although the procedure involves a temporary stoma, it eliminates the need for a permanent stoma.

The IPAA is also known by the following terms:

- ileal pull-through
- Park’s procedure
- pull-through operation
- modified Park’s procedure
- J-pouch

Before IPAA

After IPAA



Table of Contents

Introduction	2
Your Health Care Team	3
Normal Function of the Gastrointestinal Tract	4
Important structures and functions.....	5
Overview of the IPAA	6
Who is and is not a candidate for the IPAA?.....	6
Surgery.....	8
Expected outcomes.....	10
Success Rate.....	10
Sexual Activity, Reproduction, and Related Issues.....	12
What to Expect During Your Hospitalization	13
Two-Stage IPAA: The First Surgery—Removal of the colon and creation of the pouch and temporary ileostomy.....	14
Two-Stage IPAA: The Second Surgery—Ileostomy closure.....	19
Ostomy Care	22
Long-term IPAA Management	25
Diet.....	25
Management of bowel habits.....	26
Medications.....	27
Perianal skin care.....	28
Follow-up care with your surgeon.....	28
Resources—Who to Contact	29
Glossary	30
Research	31

Introduction

To our patients and families:

This booklet was written for you by members of your health care team to educate you about the planned surgical procedure, the ileal pouch anal anastomosis (IPAA).

We know that surgery is a stressful event, and we believe that an understanding of the process can help reduce these fears. We encourage you to share this information with your families and significant others.

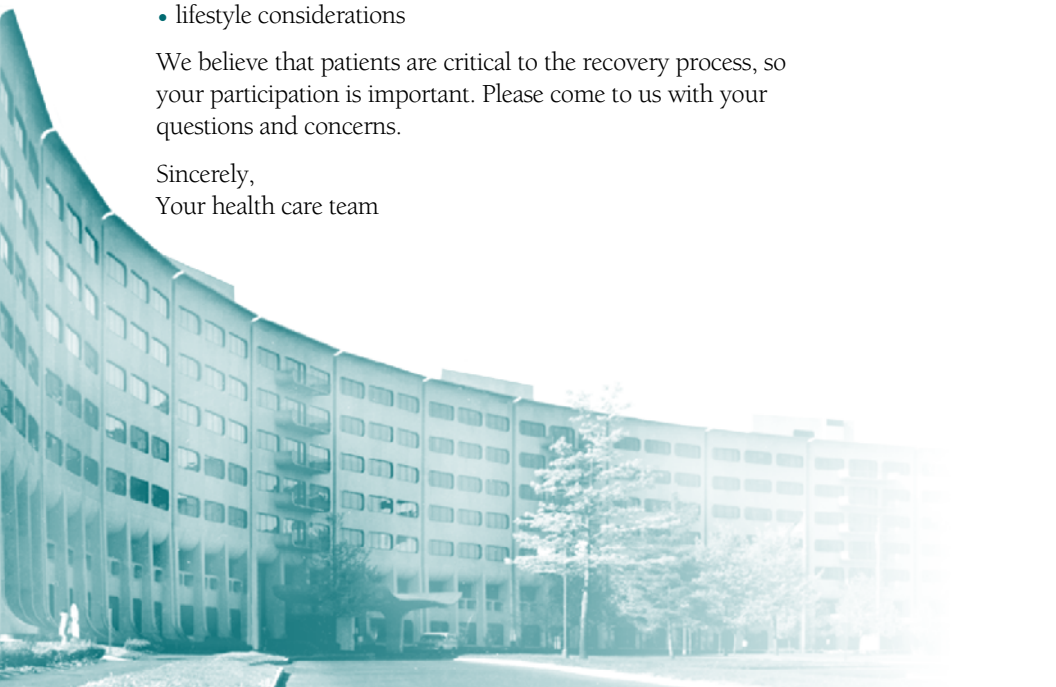
Although the IPAA may be a one-, two-, or three-stage operation, this booklet focuses on the two-stage procedure, because it is the one most commonly performed at Penn State Milton S. Hershey Medical Center.

This booklet describes the following:

- normal anatomy and function of the colon
- diseases treated by the IPAA
- surgical procedures involved
- pre- and post-operative care
- home care
- stoma care
- short- and long-term dietary needs
- lifestyle considerations

We believe that patients are critical to the recovery process, so your participation is important. Please come to us with your questions and concerns.

Sincerely,
Your health care team



Your health care team

The team from Penn State Hershey Colon & Rectal Surgery includes board-certified surgeons and highly-skilled specialists offering the most advanced and effective medical care available. They provide hope for a full, rewarding life after treatment.

Walter Koltun, M.D., F.A.C.S., F.A.S.C.R.S.

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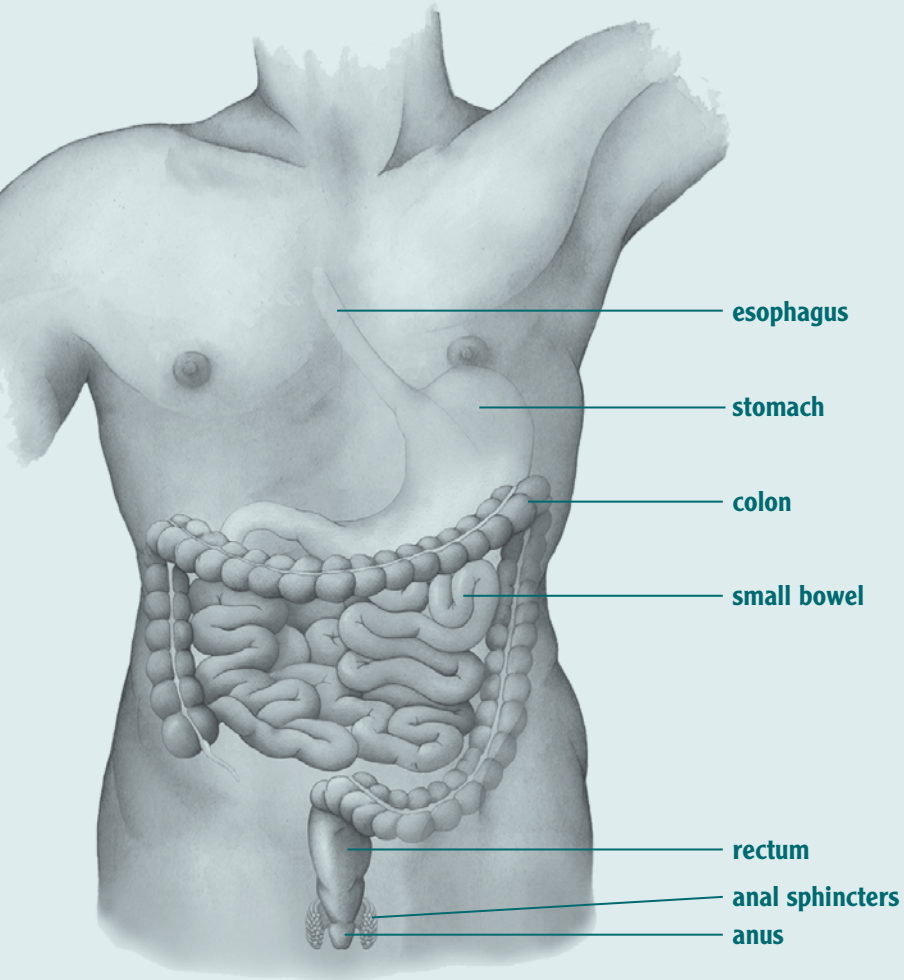


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Normal Function of the Gastrointestinal Tract

The gastrointestinal (GI) system begins at the mouth and ends at the anus. The GI tract digests and stores food, absorbs vitamins and nutrients, and eliminates stool.

Six segments make up the GI tract: the esophagus, stomach, small bowel, large bowel (also known as the colon), rectum, and anus.



Important Structures and Functions

Esophagus

The esophagus is a tube that is approximately ten inches long; the passageway in which food moves from the mouth to the stomach.

Stomach

The stomach is a stretchable sack where stomach acids and enzymes breakdown eaten food by making it into a paste-like liquid. The liquid then passes into the small bowel.

Small Bowel

The small bowel is the major site for digestion and absorption of vitamins and nutrients.

In the small bowel, fluid is secreted to further break down and digest the liquid food. Absorbed nutrients are carried into the bloodstream to provide fuel for the body. The last part of the small bowel is called the terminal ileum.

An adult's small bowel is approximately ten feet long.

Large Bowel or Colon

The large bowel has two major functions—absorption of water and storage of stool.

As water is absorbed from the paste-like liquid, the material that remains becomes semi-solid stool. The stool is stored in the large bowel until it is passed (defecated) through the anus.

An adult's colon is approximately five to six feet long.

Rectum

The rectum is the last part of the colon and extends seven to nine inches from the anus. When your rectum becomes filled with stool, you feel an urge to defecate. As the anal sphincters relax, the rectum squeezes and expels the stool.

Anal Sphincters

The anal sphincters are ring-like muscular structures that control bowel movements. They close and open, providing the muscular control needed to hold back stool or let it pass.

Overview of the Ileal Pouch Anal Anastomosis (IPAA)

Who Is a candidate for the IPAA?

The IPAA is performed on people whose disease is limited to their colon—it is essential that the GI tract is free of disease from the mouth to the terminal ileum (end of small bowel). People with ulcerative colitis and familial adenomatous polyposis are potential candidates for the IPAA, because these illnesses only affect the colon.

Ulcerative Colitis (UC) UC is a form of inflammatory bowel disease (IBD) and can be acute or chronic in nature. In this disease, the innermost layer of the colon is inflamed. As a result, people with UC can have frequent and debilitating bouts of diarrhea and bleeding. UC increases the risk of colon cancer.

The disease usually begins at the rectum and extends a variable distance up into the large bowel. It can, but does not necessarily, affect the entire colon. When the colon is removed, so is the disease.

Familial Adenomatous Polyposis (FAP) FAP is a genetic disorder that results in many polyps in the colon. This disease will result in cancer of the colon at an early age unless the colon is removed.

People with FAP can be cured of the disease in their colon with an IPAA; however, they continue to require careful post-operative follow-up care, because FAP has the potential to affect other parts of the GI tract and body.

Who Is not a candidate for the IPAA?

Crohn's disease is another form of IBD. In Crohn's disease, the entire GI tract can be affected, including the small bowel. People with Crohn's disease are not candidates for IPAA surgery, because the inflammation of Crohn's disease continues after an IPAA and can affect the internal pouch.

Surgery

The IPAA can be done in one, two, or three stages, as shown on the following pages. The number of stages (operations) is determined by the severity of the disease, the dosage and duration of medication(s) being taken, and other patient considerations.

Most patients require the two-stage surgery. Patients who are very healthy and not taking steroids or other immuno-suppressive medications might be candidates for a one-stage procedure. Patients who are severely ill and taking high-dose steroids may require three stages. The differences in these procedures can be discussed with your surgeon.

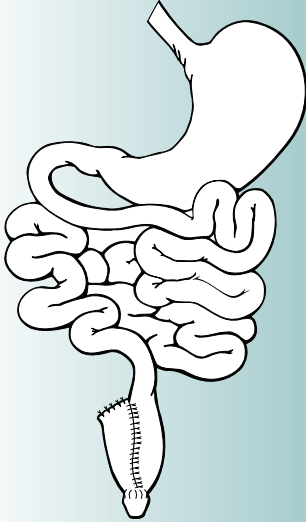
Because most patients have their IPAA done in two stages, this booklet focuses on the two-stage technique.

Mark Trump, a Penn State alumnus, was “back in his game” just one year following surgery for ulcerative colitis.



The Three Surgical Techniques

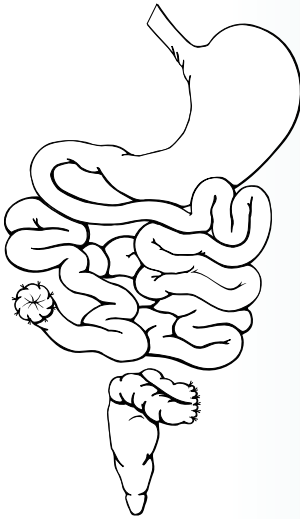
One-stage Technique



One-stage technique

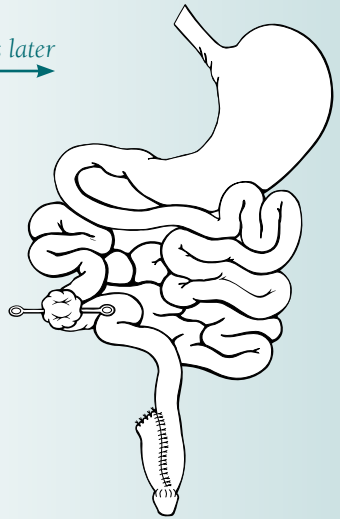
The colon is removed, an internal reservoir is created; no stoma is needed.

Three-stage Technique



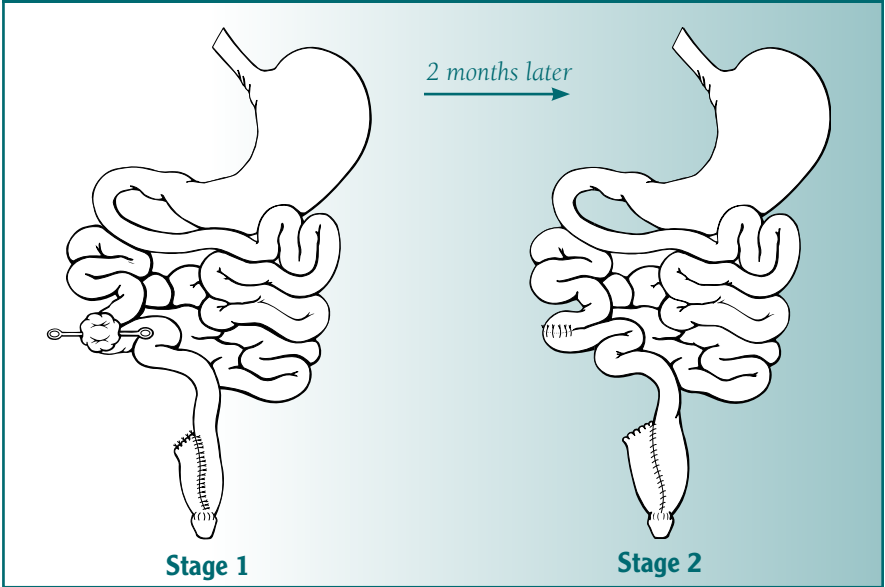
Stage 1

6 months later
→



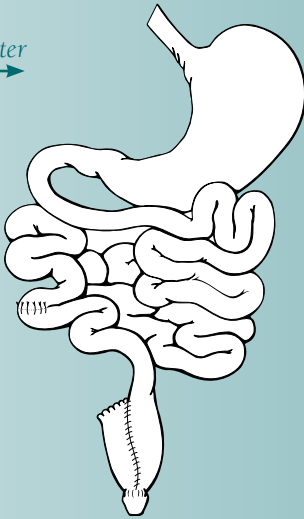
Stage 2

Two-stage Technique



Two-stage technique The colon is removed, an internal reservoir and a temporary loop ileostomy is created. Two months later, the ileostomy is closed.

2 months later



Stage 3

Three-stage technique

The colon is removed. Six months later, an internal reservoir and a temporary loop ileostomy is created. Two months later, the ileostomy is closed.

Success Rate

The overall success rate for the operation is 90-95 percent.

The 5-10 percent failure rate can be due to difficulty with continence, infection, or recurrent inflammation in the new pouch (“pouchitis”). Approximately 5 percent of patients will need to have the pouch removed and a permanent ileostomy created. Anyone undergoing the IPAA needs to understand that a permanent stoma may result if complications arise. Another 1-5 percent of patients will keep the pouch, although it will not function perfectly. Overall, approximately 90 percent of patients are very happy with the IPAA and would do it again if necessary.

Number of bowel movements Patients usually have about ten to twelve bowel movements a day immediately after the ileostomy is closed. This number decreases rapidly, so that by six months after surgery, patients average five to six bowel movements per day. The frequency continues to decrease over months to years, but usually at a slow rate.

Expected Outcomes

Outcome of Surgery

Success 90-95 percent

Failure 5-10 percent

Continence

Perfect control for 80 percent of patients

Occasional nighttime spotting for
15-20 percent of patients

Bowel Movements

Initially after surgery, ten to twelve a day

Six months after surgery, five to six a day

Pouchitis

Occurs in 5-35 percent of patients

Rarely leads to removal of pouch

Consistency of stool During the first few days to weeks after the ileostomy is closed, the consistency of the stool is loose. With time and with dietary changes (and sometimes with medicines), stools become much firmer; however, they will always have a thick, pasty consistency.

Control of elimination More than 80 percent of patients have perfect control of their elimination after the ileostomy is closed. About 15-20 percent of patients have occasional spotting during periods of sleep. Usually the spotting leaves such a small amount of staining that a patient may or may not choose to wear a disposable pad at night.

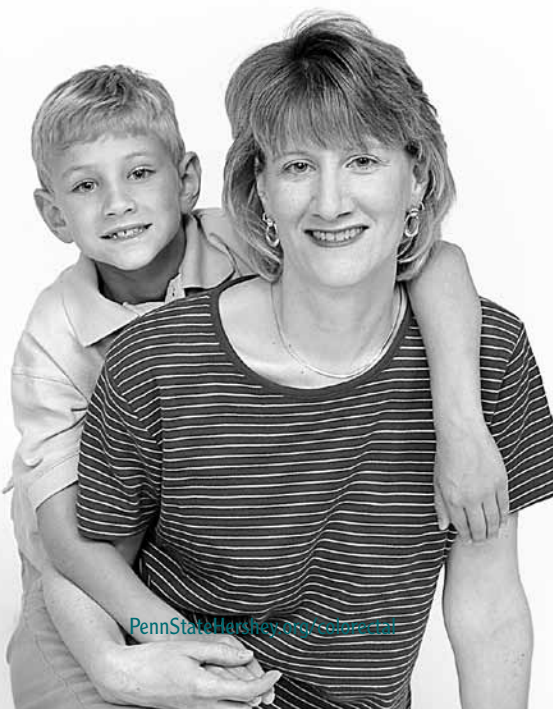
Pouchitis

A complication of this operation is recurrent inflammation in the newly created internal reservoir. This is called “pouchitis.” Pouchitis occurs in 5-35 percent of patients who have had an IPAA.

Pouchitis symptoms are similar to those of ulcerative colitis and may include an increased number of bowel movements, fever, and a feeling of weakness. Sometimes blood may be present in the bowel movements.

The cause of pouchitis is not known. Fortunately, it is treated effectively with an oral antibiotic, and symptoms usually resolve in a few days. Sometimes pouchitis can be severe and respond poorly to medications. On rare occasions, pouchitis is so severe that the pouch must be removed.

Lisa Custer, shown here with her son Zach, experienced a normal pregnancy following her advanced IPAA surgery.



Sexual activity, reproduction, and related issues

Normal sexual activity is possible while you have a temporary stoma. Special undergarments are made for people with ostomies. These garments are attractive and conceal the ostomy appliance for intimacy. The enterostomal therapy nurses can give you more information about these products.

Just as with a stoma, normal sexual activity can be expected after the stoma is closed, after the discomfort of the abdominal incision has subsided.

Information for women

Pregnancy after the IPAA is possible and common, although, as with any abdominal surgery, there is a small increased risk of infertility from adhesions.

You may be advised to wait about six months after the surgery before becoming pregnant. If you become pregnant, your obstetrician or surgeon will need to discuss delivery options with you. Some women choose to deliver by Cesarean section to avoid the risks of incontinence that may be associated with an episiotomy done for a vaginal delivery.

Information for men

Sexual or urinary difficulties can occur because the surgery takes place near the bladder, prostate gland, certain nerves, and other structures. Such complications are unusual (occurring in 1-3 percent of patients) and usually resolve with time.

It is rare that the IPAA results in problems with erection. The most common sexual dysfunction as a result of the IPAA is a difficulty with ejaculation. When affected, ejaculation is sensed by the man, however, it is retrograde (flows back) into the bladder. Therefore, any male who has an IPAA has a chance of becoming infertile. When this is a concern, a preoperative sample can be supplied to a sperm bank and should be discussed with your surgeon.

What to Expect During Your Hospitalization

The following pages describe the course of events for the usual two-stage IPAA. The IPAA is usually done as a “same day admission”—that is, patients are admitted to the Medical Center on the morning of surgery.



Surgeries are performed in our advanced surgery suite featuring the most sophisticated operating room technology.

Two-stage IPAA

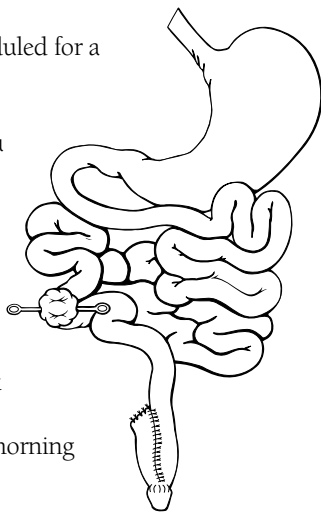
The First Surgery

Removal of the colon and creation of the pouch and temporary ileostomy

The preoperative visit

After you have decided to have the IPAA, you are scheduled for a preoperative visit to prepare for surgery. You are given prescriptions and instructions to follow the day before surgery, including “bowel prep” instructions. Ask if you should take your usual medications on the morning of surgery. Blood is drawn for laboratory tests; you may also have a chest X-ray and an EKG.

You may also be seen by a nurse who specializes in caring for ostomy patients. This nurse teaches patients about ileostomies, answers questions, and marks the location on your abdomen where she recommends that the surgeon place the ileostomy. If this marking is not done during the preoperative visit, it will be done the morning of surgery.



The Day Before Surgery

The day before surgery, you will be contacted with day of admission instructions. If surgery is scheduled for Monday, you will be contacted on Friday.

Bowel prep Before surgery, it is essential that the bowel be as clean as possible to prevent infection. To do this, you will follow a standard “bowel prep.” You are instructed to drink a solution that has a strong laxative effect (such as CoLyte, GoLyteLy, NuLyteLy), to take some antibiotics, and to follow a liquid diet. Do not eat solid foods. The antibiotics decrease the amount of bacteria in the bowel to decrease the risk of infection.

You should not eat or drink anything after midnight.

Day of surgery

Usual medications If you have been told to take any medications at home before surgery, take them with small sips of water.

You will be admitted to Penn State Hershey Medical Center the day of the operation. Patients are usually hospitalized for four to six days after the surgery.

The surgery takes two to four hours. With preparation before surgery and time in the recovery room, it will be approximately six hours before you are admitted to your room.

Family members may wait in the surgical waiting area. The surgeon will either call or visit with family members after the surgery, so they should sign in and out with the attendant if they leave the waiting area.

Hospitalization after surgery

Recovery room After surgery, you are taken to the Post-Anesthesia Care Unit (recovery room), where you are monitored closely until you awaken fully from the anesthesia. No visitors are allowed in the recovery room. You are then admitted to an inpatient unit.

Intravenous line(s) You will have at least one intravenous (IV) line. An IV is a long, flexible tubing connected to a small catheter that is inserted into the top of a hand or an arm. It is used to give fluids and medications. The IV will be used until you are taking enough fluid by mouth to prevent dehydration, usually about five days.

Drainage tubes While you are asleep in the operating room, the following tubes and drains are placed:

- The nasogastric (NG) is a tube placed through the nose into the stomach to drain fluids. Usually this tube is removed in the recovery room, and patients do not remember it. Sometimes this tube is left in place to be removed later.
- A soft, flat, piece of rubber tubing is left in the anus to drain the fluid that collects in the pouch. A dressing is placed over this tubing to collect drainage; it is changed as needed. This drain is painlessly removed three days after surgery.
- A urinary catheter is placed in the bladder to collect urine. It is painlessly removed four or five days after the surgery.
- Two soft pieces of tubing are left in the abdomen, coming out the side next to the incision. These collect fluid and are removed three to five days after surgery.

The First Surgery *(continued)*

Pain control

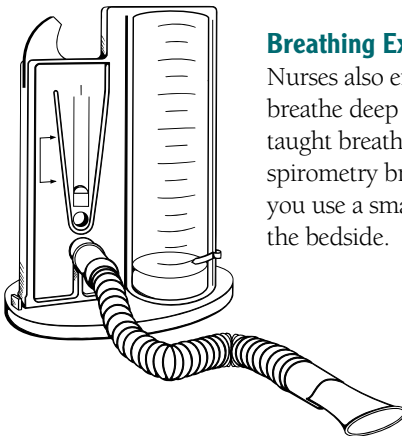
Before surgery, talk with the surgeon and anesthesiologist about pain control. The three of you decide which method of pain control is the best choice. Two of the possible methods that can be used after an IPAA are epidural analgesia or patient controlled analgesia (PCA):

- Epidural analgesia consists of placing a small, thin catheter into the patient's back, outside the spinal cord. The epidural catheter is inserted while the patient is in the operating room. When medications are given through this catheter, a patient feels numb in the general area of the abdominal surgery. This catheter is left in for three to four days after the surgery to control pain.
- The PCA is a small pump attached to the IV line by a hand-held control button. The patient receives medication to control pain by pushing this button at will.

Pain scale Nurses will frequently ask you to rate your pain on a scale of zero to ten, with ten being the worst pain you have ever felt. If you have significant pain, tell a nurse so that your medications can be modified. You may not be totally pain free, but your pain should be at a tolerable level that will allow you to breathe deeply, get out of bed, and walk.

Activity

It is essential to begin moving as soon as possible after surgery to prevent complications from bed rest. These complications include blood clots in leg veins and respiratory infections. On the day of surgery, you will get out of bed and sit in a chair at least once with the assistance of a nurse. The first day after surgery, a nurse will help you get up and walk.



Breathing Exercises

Nurses also encourage you to cough and breathe deep to prevent pneumonia. You are taught breathing exercises called incentive spirometry breathing (ISB). For these exercises, you use a small, hand-held machine kept at the bedside.

Diet

You will not have anything to eat or drink until there is evidence of bowel function (fecal material coming from the stoma into the ileostomy bag). As normal bowel function returns, your diet is advanced in steps.

Clear liquids You will begin with small sips of clear liquids (water, fruit juices)—one medicine cup full of liquid per hour. When you tolerate this without nausea, vomiting, or increased pain, you may have as many clear liquids as you like. You will get a tray of liquids at meal time (juices, tea, broth, Jell-O). You may not have carbonated liquids.

Full liquids When you tolerate clear liquids without any difficulty, your diet is advanced to full liquids. This diet includes clear liquids as well as creamy soups, milk, egg nog, ice cream, and cream of wheat. If you have lactose intolerance, please tell the surgeon before being placed on full liquids.

Low-fiber diet After you are able to tolerate full liquids, you are advanced to a low-fiber diet that you should follow for approximately six to eight weeks. The low-fiber diet helps avoid difficulties with stool passing out of the ileostomy.

While hospitalized, a nutritionist will teach you about low fiber diets and provide some reference material for home. You are given a phone number to call after discharge, in case you have any questions about the diet.

See page 25 for more information about diets.

Managing Your Stoma

For three to four weeks after surgery, the drainage from an ileostomy is watery. The consistency becomes a thicker liquid or semi-solid as the small bowel begins to take over the process of absorbing water.

Learning to care for an ileostomy may seem overwhelming and time-consuming at first, but most patients soon find themselves caring for it with ease. The certified ostomy nurses teach you how to change the appliance covering your ostomy, how to empty and rinse it, and how to purchase supplies for ostomy care. These nurses also tell you how to get assistance if you have any problems with your ostomy after discharge.

You may need help with changing your ostomy appliance at home. A family member may help with this; we can arrange for a visiting nurse to help with this, as well. You may also meet with the certified ostomy nurse when you have a follow-up clinic appointment with the surgeon, if you are having any ostomy issues.

See page 22 for specific information about ostomy care.

The First Surgery *(continued)*

Discharge

Patients who have an IPAA are usually discharged four to six days after surgery. Discharge instructions include information about caring for the incision, activity guidelines, signs and problems to watch for, and how to reach a physician if you need advice at home.

At the time of discharge, you should be able to walk independently, tolerate at least a full-liquid diet without difficulty, pass stool through the ileostomy, and be able to urinate without any difficulty.

Follow-up care

Before discharge, a clinic appointment is scheduled with the clinical nurse practitioner about ten days after surgery (usually one to four weeks after discharge). A follow-up visit with your surgeon can be scheduled to discuss ostomy reversal.

Staple removal Staples at the incision site are usually removed before discharge. Because steroids can slow the healing process, the staples stay in place longer for patients who are taking steroids. If you have been taking steroids, you may be discharged with the staples left in and asked to come to the office a few days after discharge for their removal.

Patients who take steroids for a long time before surgery are given a schedule for decreasing the dose and then discontinuing the steroids. This usually takes place during a two to four week period.

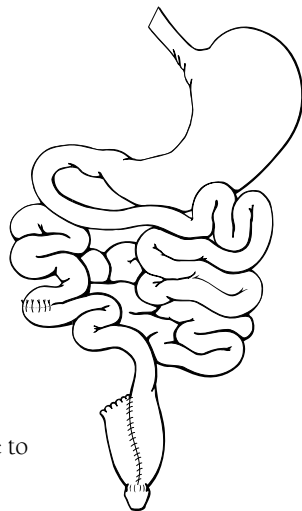
Brian Swenson was a third-year medical student at Penn State College of Medicine when he underwent successful IPAA surgery. He now enjoys a career in surgery.



The Second Surgery

Ileostomy Closure

Before the stoma is closed, you will undergo an X-ray of the pouch to ensure that it has healed properly. If the X-ray is normal, the stoma closure is scheduled, and you will have a preoperative visit similar to that of the first surgery.



The Day Before Surgery

The day before surgery you will receive a phone call to tell you what time to come to the Medical Center and where to go for admission.

Bowel prep The bowel prep for the ileostomy closure is slightly different from that of the first surgery. It is again very important for the small bowel to be as clean as possible to decrease risks of infection. You may receive prescriptions for antibiotics and directions for drinking a laxative, Magnesium Citrate.

Foods Once the bowel prep is begun, do not eat any solid foods; diet should consist of only clear liquids. After midnight, do not eat or drink anything.

Day of surgery

You will be admitted on the day of surgery. Patients are usually hospitalized for two or three days after this surgery.

The ileostomy closure usually takes less than an hour. The incision is made as a circle around the stoma, and the stoma is closed restoring elimination through the anus. The incision is then partially closed. A midline abdominal incision is rarely needed.

Hospitalization after surgery

Recovery room After surgery, you are taken to the Post-Anesthesia Care Unit for close monitoring. When you recover from anesthesia, you are admitted to an inpatient unit.

Intravenous lines An IV line is used to infuse fluids and medications. When you are able to take enough liquids by mouth to prevent dehydration and to take medications by mouth, the IV line is discontinued.

Urination Urinary catheters are usually not inserted for the ileostomy reversal; therefore, you will be getting up to use the bathroom. Initially, you will need assistance from a nurse. Nurses measure and record your urine output, so do not empty the containers used to collect urine.

The Second Surgery *(continued)*

Pain control Pain after the ileostomy closure is much less than after the first surgery and can usually be controlled with medication given through an IV line. When you feel you need medication for pain relief, ask a nurse—these medications are not given automatically. Your pain should be at a tolerable level, which allows you to get out of bed, walk, and do deep breathing exercises. If necessary, a PCA pump is ordered.

Activity and breathing exercises As before, it is essential to move as soon as possible after surgery to prevent the complications of bed rest. You will again be expected to do ISB exercises, and to cough and breathe deep to expel secretions and prevent pneumonia.

Diet The day after surgery, you start on sips of clear liquids every hour. When you have passed stool, you may have as many clear liquids as you like. If you tolerate this clear liquid diet, you are advanced to a full-liquid diet.

You may be sent home following a full-liquid diet with instructions for advancing to a low-fiber diet at home. You will follow a low-fiber diet for approximately two weeks. If you need a review of the low-fiber diet, the nutritionist can do this. Many patients tell us that three small meals a day with snacks in between helps to establish control of bowel movements.

Bowel movements Patients usually begin having bowel movements on the first or second day after surgery. Initially, you may have urgency, which means that you will have little time to get to a bathroom when you sense the need to move your bowels. It is also common to have nighttime soilage. Both the urgency and the nighttime soilage lessen with time.

You can expect to have five or six bowel movements a day after the ileostomy reversal; patients sometimes have more in the immediate postoperative period.

Skin care Apply Desitin ointment to the skin around your anus after every bowel movement for the first two weeks after ileostomy closure. The stool from the pouch contains secretions that are very irritating to skin and may cause breakdown. Desitin will provide a protective barrier. When the bowel movements have thickened and the frequency is decreased, you may not need the Desitin.

Desitin is ordered for you to use while you are in the hospital, and the tube is given to you to take home. If you need more, you can buy it in any drug or grocery store.

For more information about skin care, see page 28.

Wound care You may have an open wound where the ileostomy was removed. The open area will be approximately three inches in length and one inch in depth. One suture in the middle brings the edges of the wound together. This site is left open and heals from the inside out to the skin. Leaving this open avoids the development of infection.

Packing the wound The open wound needs to be packed three times a day while in the hospital and two times a day at home. At first, most people require visiting nurses to assist with this at home. If you have a family member who is willing to learn the dressing change, or if you are able to learn yourself, you will be taught.

Showering You may shower at home. Try to coordinate showering with dressing changes. Remove the packing, shower, and then the packing can be replaced.

Discharge

Patients are usually discharged two or three days after surgery. At the time of discharge, you should be able to tolerate at least a full-liquid diet and have bowel movements without difficulty.

You will receive instructions for caring for the wound, guidelines for activity, advice about problems you should watch for, and how to reach a physician if you need assistance. If you need follow-up care by a visiting nurse, this is arranged before discharge, and you are given the name and phone number of the agency.

Follow-up care

Before you leave the hospital, an outpatient appointment is made for follow-up. This appointment is usually two to four weeks after discharge. If you are discharged on a weekend or holiday, a representative from Central Scheduling will call early the following week.

Ostomy Care

What is an ileostomy?

An ileostomy stoma is a piece of small bowel (ileum) that has been brought to the surface of the abdomen and then stitched in place. Stomas are round or oval, red, moist, feel soft to the touch, and may be raised above the skin slightly. A stoma is not painful when touched. When stool passes out of a stoma, it does not hurt. As a stoma heals, it may become a little smaller.

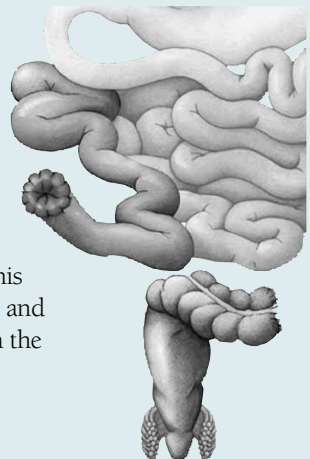
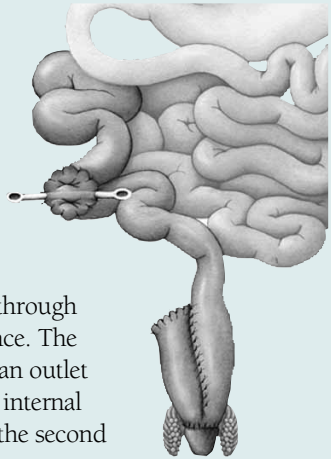
There are two types of ileostomy stomas: a loop stoma and an end stoma. Care for these stomas is basically the same.

Loop ileostomy A “loop ileostomy” is created when the IPAA is done in two stages. In this procedure, a loop of ileum (i.e., a piece of the small bowel) is brought to the surface of the abdomen. This loop of bowel is supported by a small, white plastic bar. The white bar may be removed before discharge or at the first clinic visit. The bar slides out painlessly when it is removed.

A loop ileostomy has two openings. Stool passes through one opening and empties into the ostomy appliance. The second opening, which may be difficult to see, is an outlet for the mucus that comes from the newly created internal reservoir. It is normal for mucus to pass through the second opening and drain into the ostomy appliance.

Occasionally the internal pouch produces a pinkish or brownish-colored mucus. It is also normal to pass mucus from the anus following this surgery. You may even pass some bloody mucus from the anus.

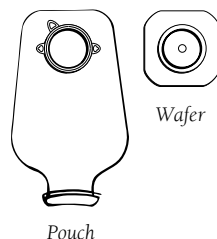
End ileostomy When an IPAA is done in three stages, an “end ileostomy” is created during the first surgery. In this procedure, the end of the small bowel is brought up to the abdomen and sutured to the marked location on the abdomen. This stoma only has one opening for the passage of stool and does not require the white plastic bar that is used in the loop ileostomy.



Commonly asked Questions about Ostomy Care

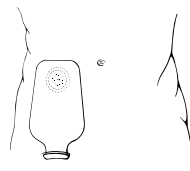
What do I put over my stoma to collect the stool and protect my skin?

The manufacturers of ostomy supplies have developed ostomy appliances (wafers and pouches) that are odor-proof and easy to apply. These appliances all have a sticky skin barrier on the back that can be custom-cut to fit around the stoma. This sticky skin barrier is very gentle on the skin and protects the skin surrounding the stoma from stool. Ostomy appliances are designed to be secure enough that you can shower or bathe while wearing them.



The drainage from an ileostomy can make the skin surrounding the stoma very sore. The key to protecting your skin is cutting the protective barrier to the right size; the opening you cut should be about 1/8 inch larger than your stoma.

Ostomy appliances come in one- and two-piece types. While you are hospitalized, the certified ostomy nurses show you the different types. Select the one that will work best for you. As the stoma heals, these nurses may recommend a change in your system of ostomy care.



Other ostomy products may be needed to provide a secure appliance system. Some of these products are adhesive pastes, skin barriers, skin sealants, and ostomy belts. Again, the enterostomal therapy nurses help you with these special products and recommend them when needed. The goal is to keep your appliance changes as easy and inexpensive as possible.

For patients having a three-stage procedure If your surgery will be done in three stages, you will have an end ileostomy after the first surgery and a loop ileostomy after the second surgery. This means your stoma changes in size and shape, so you may need to switch the size and type of appliance you use. Your enterostomal nurse helps you with the necessary changes.

When do I need to empty my ostomy appliance?

Your ostomy appliance needs to be emptied when it is half-full. If the appliance becomes too full, **it will leak.**

Immediately after surgery, the drainage from your ostomy will be greenish and very watery. Your appliance needs to be emptied more often at first. It is important for you to know how to empty your appliance before you are discharged from the hospital so that you can empty it before it becomes too full.

About two months after the ostomy surgery, most patients empty their appliance four to six times in a twenty-four hour period.

Ostomy Care *(continued)*

When do I need to change the ostomy appliance?

Appliances are usually changed every three to seven days. Patients have reported that it is helpful to set a routine time to change the appliance—for example, every fifth day, immediately after getting up in the morning. Establishing a routine can help when you plan other activities.

The appliance must be changed if leakage of stool is seen at the edge of the skin barrier. It does not do any good to merely tape the edge of the appliance if it leaks. The appliance must be changed or the skin surrounding the stoma will become very sore.

Appliances must also be changed when there is itching or burning under the skin barrier.

What can I do if I have ostomy appliance leakage problems?

Occasional leakage is normal. Prepare for this by having an extra appliance system with you in the car, at work, etc.

If leakage is an ongoing problem, contact an enterostomal therapy nurse. A minor change in the appliance system can make a big difference in controlling leakage.

What should I do if I have diarrhea?

If the output from your stoma is more than one to two quarts in a twenty-four hour period, then you may become dehydrated. This can occur if you have contracted a virus that affects the bowel, such as gastroenteritis.

Symptoms of dehydration include watery output from your stoma, dry mouth, cramping or tingling feeling in your hands or legs, fatigue, and faintness, especially when standing.

If you think you are dehydrated, drink salt-containing fluids such as Gatorade, salty soups, or bouillon. Drink at least eight to ten glasses of fluid daily. Each glass should contain eight fluid ounces.

If the watery output from your stoma occurs for more than twenty-four hours or occurs with vomiting or stomach pain, contact the Medical Center immediately. If you have these symptoms, you need to speak with one of the physicians to determine if you have a more serious problem.

See page 29 for information about contacting Penn State Hershey Medical Center.

Long-term IPAA Management

Diet

One of the most frequently asked questions after an IPAA is, “What can I eat?” Follow the low-fiber diet for two weeks after the ileostomy closure, as directed by the nutritional therapist. When you feel up to adding foods to your diet, we suggest the following guidelines:

- Add only one food at a time.
- Have small quantities of new foods to see how your body reacts.
- Chew all food thoroughly.

Foods that may decrease the number of bowel movements and control diarrhea

If you experience diarrhea, the following foods may help.

Dairy	cheese, low-fat cottage cheese
Fruit	bananas
Other	boiled white rice, tapioca, creamy peanut butter

Foods that may change the color of stool

Beets Gatorade Red gelatin Tomato sauce

Many patients tell us that three small meals a day with snacks in between helps to establish control of bowel movements.

Some foods may cause short-term problems. For example, some patients have reported that apple juice results in cramping and increased stools. Therefore, apple juice is one liquid you may want to eliminate from your diet for awhile after surgery.



Long-term IPAA Management

(continued)

Diet *(continued)*

Remember that everyone is different, and there may be foods that cause problems for one person and not for another. Many patients report that after six months, they can eat anything!

Foods That May Cause Problems

Foods that may produce gas	
Dairy	milk, eggs, cheese
Fruits	melons
Liquids	carbonated
Vegetables	dried beans and peas, sweet potatoes, asparagus, onions, and vegetables of the cabbage family (broccoli, Brussels sprouts, cabbage, cauliflower)
Other	nuts, sugar

Foods that may increase reservoir output or cause diarrhea	
Liquids	beer, caffeinated drinks
Vegetables	green leafy vegetables, broccoli
Fruits	raw fruit
Other	highly seasoned or spicy foods, beans, chocolate

Foods that may cause anal irritation	
Vegetables	raw vegetables, salad greens, celery, coleslaw, tomato seeds
Other	foods with seeds, hard to digest kernels or cellulose nuts, coconut, popcorn, corn, oriental vegetables
Spicy	highly seasoned or spicy foods

Management of bowel habits

After six months of having the internal pouch, most patients have approximately five or six bowel movements per day. With time, the number of bowel movements may decrease further.

Signs and symptoms of pouchitis The signs and symptoms of pouchitis are similar to those of ulcerative colitis or gastroenteritis: increased number of bowel movements, fever, feeling of weakness, blood in bowel movements, and urgency of bowel movements.

For more information about pouchitis, please see page 11.

Inflammation of residual ano-rectal tissue It is not uncommon for a small amount of colonic tissue to be left near the anus after an IPAA. This tissue may become inflamed and irritated and result in blood on toilet paper, burning, and pain at the anus. These symptoms are similar to hemorrhoids and are treated effectively with hemorrhoidal medications, such as steroid suppositories.

It is important to remember that the presence of any residual colonic tissue has a very small increased risk of cancer. This is another reason that you should continue to see your surgeon at least annually for a physical examination.

Stricture Sometimes the connection between the pouch and anus becomes tight; this tightness is called a “stricture.” A stricture is treated very effectively by digital rectal examination, which dilates the stricture. With time, as stools become more firm, the passage of the formed fecal material itself will treat most stricture formation.

Long-term IPAA Management

(continued)

Medications

Approximately 35 percent of patients need some sort of medication after the operation because of looseness of stools or frequency of bowel movements.

Agents that slow the number of bowel movements or increase the solid nature of the stool may include fiber products like Citrucel, Konsyl, and Metamucil, or bowel-inhibiting agents like Imodium and Lomotil. Sometimes an antibacterial medication, such as Flagyl (Metronidazole), is prescribed.

If you have questions about stool frequency or the need for any of these agents, please speak with the surgeon.

Perianal skin care after ostomy closure

The perianal area should be kept as clean and dry as possible.

Tips for preventing sore perianal skin

- Use soft toilet tissue after each bowel movement. Gently pat the area dry; do not wipe vigorously.
- Disposable baby wipes with aloe are helpful in cleaning this area. Do not use any products that contain alcohol. Alcohol is drying and will sting.
- Warm tub baths or a gentle shower spray may be soothing after a bowel movement.
- After drying the perianal skin, apply a protective ointment such as Desitin, A&D Ointment, or Bag Balm.
- Some patients find it helpful to wear a soft disposable panty liner to absorb any seepage and to keep moisture from collecting in this area.
- If your skin still becomes sore following these guidelines, call the colorectal surgery office.

Follow-up care with your surgeon

After the IPAA, you should visit the surgeon every three to six months for the first year, and at least annually thereafter. These visits usually include a rectal examination.

Resources

Your health care team is available to respond to your questions and concerns. If you would like, your surgeon can refer you to another patient who has already had the IPAA and is willing to provide support and information from a patient perspective.

Penn State Milton S. Hershey Medical Center

- Medical questions or concerns, or referral to another patient (weekdays)
Penn State Hershey Colon and Rectal Surgery
717-531-5164
- Medical questions or concerns (nights, weekends, holidays)
Page Service (Ask for the colorectal surgical resident on-call.)
717-531-8521
- Ostomy care or nutrition questions or concerns (weekdays)
Certified Ostomy Nurses
717-531-5427

Other resources available for information and support

The companies that manufacture ostomy supplies (Hollister, Convatec, Coloplast, etc.) provide free literature on ostomy care. They may also provide free samples of their appliances. Contact them directly.

Inflammatory bowel disease (IBD) support group

This group provides education and emotional support for those with IBD. Call 717-531-5164 for further information.

The Crohn's and Colitis Foundation of America (CCFA)

A national organization dedicated to finding the cause and cure for inflammatory bowel disease. There are excellent books on IBD available through the CCFA. They also have free brochures on selected topics related to IBD. Call 800-343-3637 for more information or visit their website at CCFA.org.

The United Ostomy Association (UOA)

A self-help organization composed of people who have had ostomy surgery. There are hundreds of chapters in the United States. For more information, call the UOA at 800-826-0826.

Glossary

Anal Sphincters — Ring-like muscular structures that surround the anus and control bowel movements.

Anus — The opening at the end of the rectum that allows stool to pass out of the body.

Clinical Case Manager — A registered nurse who assists in coordinating your care during the hospitalization(s) and helps arrange home-care services.

Colon (large bowel or large intestine) — The portion of the GI tract extending from the ileum (end of the small intestine) to the anus that stores stool.

Crohn's Disease — A form of inflammatory bowel disease that can affect the entire gastrointestinal tract.

Enterostomal Therapy Nurse — A registered nurse who specializes in ostomy care.

Epidural Analgesia — A form of pain control delivered through a catheter that is placed in the lower back.

Familial Adenomatous Polyposis (FAP) — A genetic disorder that results in formation of many polyps in the colon and eventually leads to colon cancer.

Gastrointestinal System (GI Tract) — The group of structures from the mouth to the anus that are responsible for the ingestion (taking in), digestion, and absorption of nutrients, as well as the storage and elimination of fecal waste.

Inflammatory Bowel Disease (IBD) — A term used to refer to ulcerative colitis and Crohn's disease, which are diseases that result in inflammation of all or a portion of the GI tract.

Ileal Pouch Anal Anastomosis (IPAA) — A surgical procedure in which an internal reservoir is made to collect stool and is then connected to the anus to allow "normal" elimination.

Ileostomy — The end of the small bowel is extended through the abdominal wall. This allows stool to be eliminated into a bag that is adhered to the skin.

Ileum — The last part of the small bowel.

IV (Intravenous) Line — A long, flexible tubing that is connected to a small catheter inserted in a vein used for giving fluids.

Patient-Controlled Analgesia (PCA) — A form of pain control, delivered through an IV, in which the patient uses a small pump to control the timing and amount of medication received. The maximum amount of medication that can be delivered is programmed into the pump, so the patient receives a safe and effective dose.

Pouch — See "reservoir."

Pouchitis — An inflammation in the surgically-created internal reservoir.

Rectum — The last portion of the colon that connects to the anus.

Reservoir (pouch) — An internal pouch-like sack created surgically from the small bowel to store stool.

Small Bowel (small intestine) — Major organ for digestion and absorption of nutrients.

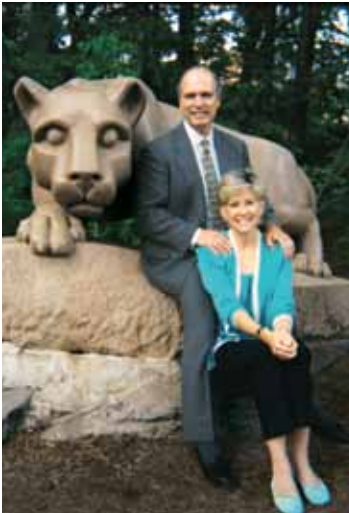
Stoma (ostomy) — An opening created in the intestine and brought to the abdominal wall surface during a surgical procedure. An ileostomy, or colostomy, are two types of stoma.

Ulcerative Colitis — A form of inflammatory bowel disease that affects only the colon.

Searching For A Cure

Inflammatory Bowel Disease (IBD) affects more than two million men, women, and children in the United States. Ulcerative colitis and Crohn's disease are the two conditions that comprise IBD and their cause remains unknown. Ongoing research at Penn State Milton S. Hershey Medical Center paves the way to determine the cause of, and cure for, these serious illnesses.

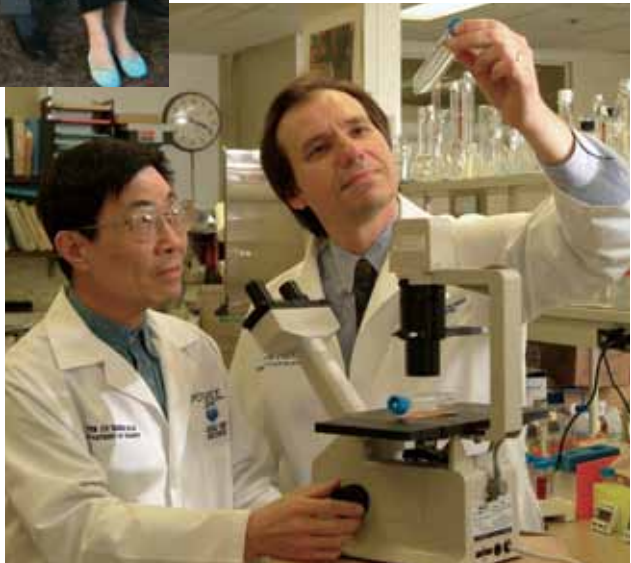
Generous support from donors, such as Peter and Marshia Carlino, provides the foundation to continue these efforts. The creation of a professorship to underwrite investigation into IBD research is one of the most notable accomplishments.



For more information on how to make a donation to fund research at Penn State Hershey, contact the Office of Colon and Rectal Surgery at 717-531-5164.

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