Ileal pouch-anal anastomosis (IPAA) is the surgical treatment of choice for patients with medically refractory ulcerative colitis (UC), UC with cancerous/precancerous (dysplasia) conditions, or Familial Adenomatous Polyposis.

This surgery has greatly improved health-related quality of life in UC patients who require surgery. However, problems such as pouchitis, cuffitis (inflammation of the rectal cuff or anal transitional zone), or Crohn’s disease of the pouch, can develop after surgery. Disease conditions of the pouch can be classified as mechanical (such as a stricture), inflammatory (such as pouchitis), and functional (such as irritable pouch syndrome). Stricture may occur in up to 13 percent of pouch patients, thus merits discussion here.

Defining A Stricture
A stricture is a condition where the lumen (passageway) of the gut becomes narrowed. Two areas of the pouch that are more prone to develop a stricture in some patients are the pouch-anal anastomosis (pouch outlet) and the pouch inlet (also called the afferent limb).

Causes of stricture include Crohn’s disease, cuffitis, ischemia (impaired blood flow), abscess (infection), and non-steroidal anti-inflammatory drug (NSAID) use, such as ibuprofen (Motrin) and naproxen (Aleve).

Patients with pouch stricture may present with non-specific symptoms such as diarrhea, abdominal pain, urgency, blood in stools, difficult evacuation, bloating, nausea, and vomiting. Some patients with stricture may have minimal symptoms.

Pouch stricture may or may not co-exist with inflammatory conditions such as pouchitis, Crohn’s disease, and cuffitis. Crohn’s disease may cause a stricture at any part of the pouch. Cuffitis may lead to pouch outlet strictures.

Diagnosis and Treatment
Pouch strictures can be diagnosed by digital examination, pouch endoscopy and retrograde barium X-ray (pouchography). Once a pouch stricture is diagnosed, all possible causal factors should be removed. Patients are encouraged to avoid NSAIDs, since these agents may contribute to pouchitis and pouch strictures.

If patients with pouch stricture also have inflammatory conditions of the pouch, these diseases should be treated medically. The vast majority of pouch strictures can be treated conservatively (avoiding surgical intervention), especially in patients with short strictures. Outlet strictures can be treated with digital dilation, bougie dilation and endoscopic balloon dilation.

Strictures in the mid pouch or pouch inlet can be treated with endoscopic balloon dilation. These procedures are typically done in an outpatient setting and often require no sedation. Patients with high-grade strictures or recurrent strictures may require several sessions of dilation with injections of local, long-acting corticosteroids to prevent re-closing of the strictures.

A recent study done here has shown that endoscopic balloon dilation in combination with medical therapy is safe and effective in maintaining pouch patency, relieving symptoms and improving patients’ quality of life in the majority of patients.

For patients with pouch stricture who fail bougie or endoscopic balloon dilations, surgery, such as stricturoplasty, may be necessary.

Endoscopic balloon dilation in combination with medical therapy is safe and effective in relieving symptoms and improving quality of life in the majority of patients.

Pouch Picnic Cancelled

The Department of Colorectal Surgery’s Inaugural Pelvic Pouch Picnic, scheduled for Saturday, July 30, 2005, has been cancelled. Tentative plans are in the works to reschedule the picnic sometime in the summer of 2006. If you have questions, please contact Miriam Preen, Pelvic Pouch Database Research Nurse, at 216/445-8524 or 800/223-2273, ext. 58524 (you may leave a message), or via e-mail at preenm@ccf.org. Thank you to all who expressed an interest in attending. We apologize for any inconvenience this may have caused, and we do hope to go forward with the picnic in 2006.
In this issue, we are highlighting those pelvic pouch patients that have had their pouches for up to 20 years! Here are some general stats of our pelvic pouch population, based on our returned Quality of Life surveys:

We have a group of 375 patients that had surgery in the years 1985 through 1989. 74% of these have been followed up for 11-20 years, through the end of 2004. 128 of these patients have been followed for 15-19 years.

Of the patients that have been followed 11-20 years (278 patients), as a group they rate themselves in the following categories on a scale of 0-10:

- Quality of Life: 8.5
- Quality of Health: 8.3
- Quality of Energy: 7.6
- Happiness with results of surgery: 9.2

Average bowel movements per day: 5.5
Average bowel movements at night: 1.7
Total average bowel movements/24 hours: 7

83% rarely or never have incontinence.
70% rarely or never have urgency.
75% never have seepage during the day.
60% never have seepage at night.
75% never wear pads or protection during the day.
65% never wear pads at night.
50% of those that wear pads wear them for peace of mind only, rather than necessity.
97% of this group of patients state they would choose to have this surgery again.

This data indicates that our pouch patients continue to experience satisfactory function up to 20 years after surgery. Please remember that this information reflects group data, so individual results may vary. THANKS SO MUCH to all of you who continue to fill out our surveys.

Sincerely,

FROM THE DESK OF

Miriam M. Preen, B.S.N., R.N.

Q and A with Richard Profancik, Pelvic pouch patient since 1989

Recently, the Pouch-O-Gram sat down with Richard Profancik to reflect on his life since his pelvic pouch surgery.

Profancik had his surgery with Dr. Victor Fazio in 1989, after struggling with mucosal ulcerative colitis for several years.

**Pouch-O-Gram:** Looking back on the last 15 years, what has surprised you most about how you feel since your surgery?

**Richard Profancik:** I feel like I’ve got my life back. Even before I had my stoma closure, my energy level increased tenfold, to where I could go and mow the grass if I wanted. It was a significant difference. Before, I could hardly walk to the mailbox without getting tired. I would come home from work and be totally exhausted. I would spend 14 hours a day in bed. I would wake up in the morning and have felt like I didn’t sleep. Now, it’s almost like a bad dream that you are so glad you woke up from, one that you totally forget about. A couple of my friends that I talk to, who have had the surgery, we have shared our experiences about being off the medication and not having to go to the doctor as much. It is so much of an improvement. It is a new lease on life.

**POG:** Dietary-wise, do you have any restrictions now? Has your diet changed to a more normal diet? Is there anything that you specifically try to avoid?

**RP:** My diet is pretty much back to normal now. I love popcorn and sometimes if I have it two or three times a week, it could be trouble, but really, there is nothing that I say I avoid.

**POG:** Do you have any physical limitations? Is there anything you weren’t able to do at first that you can do now?

**RP:** I have no physical limitations.

**POG:** If you could tell something to any of our pelvic pouch patients, either those considering having the surgery, or maybe someone struggling in their first year, what would it be?

**RP:** I think that you don’t even need a year to feel better. It would probably be around three months that you will realize the benefits of having the surgery. I adapted very well. You will just be overcome by a feeling of having a new lease on life. You can go places, do things and not have to look for a bathroom every time you turn around. I felt like a prisoner in my own home. It is so hard to explain how I feel now, that I have that freedom. A chronic illness is not something you or anyone else would want to live with.

POG

Gene Study in Inflammatory Bowel Disease

Researchers are studying the genes that cause Crohn’s Disease and ulcerative colitis. You may be eligible to participate if you:

- Have Crohn’s Disease or ulcerative colitis
- Are willing to donate two tubes of blood
- Are willing to answer a brief questionnaire
- Have a spouse/significant other also willing to donate blood and answer a brief questionnaire

All lab work is covered at no cost. This is a one-time blood draw. No additional visits to the clinic are required.

For information about this study, please contact:
Debbie Vogel
Research Assistant
216/445-1229 or 800/223-2273, ext. 51229
Happy Anniversary!
Pouch Patient Linda Conway celebrates 20 years with her pelvic pouch

By John R. Nocero, BA
Managing Editor

Linda Conway, the 45-year-old native of Voorheesville, New York, is one of the earliest pelvic pouch patients at The Cleveland Clinic Foundation. In 2005, she celebrates her 20th anniversary with her pelvic pouch. To celebrate her anniversary, Conway hopes to reconnect with other patients who had surgery in the 1980s to compare experiences.

“I want to be able to talk to other people to see what they are doing, what works for them, to see if they get up at night, or what they can eat and can’t eat,” Conway says. “I don’t know a single soul who had the surgery when I did and I would love to be able to communicate with them to find out what works for them and what doesn’t.”

Conway was diagnosed with ulcerative colitis in 1979 and lived with the condition for approximately six years before Dr. Victor Fazio performed surgery here in 1985. Though she says the details from 20 years ago are a bit sketchy due to the lapsed years, Conway doubts she would be able to live a normal life without having the operation.

Though she has chronic pouchitis and irritable pouch, Conway says living with ulcerative colitis compared to living with the pouch is like night and day.

“I wouldn’t have been able to have a life if I continued to be sick (with ulcerative colitis),” she says. “My (quality of life) wouldn’t have been good if I still had ulcerative colitis and had to take all of the medicines that go along with it. I don’t know if I would’ve been able to do things normally. I am so very happy with the pouch. I exercise and travel and there are so many things I can do now that I couldn’t do before.”

Her baby girl

Conway is one of a group of women to have a baby after her pouch surgery, delivering a seven-and-a-half pound baby girl in October 1993, which she named Michaela. Just listening to her talk about her surgery and pregnancy shows how her priorities have changed.

“I was 25 when I went to The Cleveland Clinic Foundation, and the day before checking in to have my surgery, one of the Fellows told me that this surgery could affect my fertility,” Conway says. “I was 25 and single and wanted to have the surgery because at that point, I was not concerned with being able to have a child. I was not thinking of kids because I was just so sick for a long time and was focused on getting better.”

“I was 30 when I got married,” she continues, “and I used a fertility treatment to try to get pregnant…I did have some trouble. It took me three-and-a-half years. But I had a pretty normal pregnancy. I wouldn’t discourage anyone who was thinking of having the surgery, if they knew beforehand they were able to conceive.”

Gradual changes

Right after her original surgery, Conway’s post-op course was hampered by a small bowel obstruction and infection that was treated by her local physician. Four years after her original surgery, she had four additional small bowel obstructions within six months, necessitating a laparotomy in 1989. These were found to be due to adhesions.

“Since I had my adhesions removed, I have had no problems,” she says.

Conway’s pouch function has undergone very gradual changes over time. Compared to 15 years ago, she has more gassiness or the feeling of having to empty her pouch at night, but she has no problems with leakage or control. The biggest change she makes to avoid unnecessary problems is her diet.

“Fifteen years ago, I could eat whatever I wanted but I am not able to do that so much now,” Conway says. “There are some foods that I cannot include in my diet now, so I have had to make some changes in the last 10 years. Of course, I can eat many more foods than I was able to when I had ulcerative colitis, but certain foods bother me now, so I stay away from spicy foods and red Italian sauces, and I eat fewer fruits and vegetables. I just can’t eat a lot of them without consequences.”

Completely worthwhile

Though 20 years have passed since her surgery, Conway emphatically says she would tell anyone to go through with the surgery if it could empower that person to improve his or her quality of life as it has hers. Conway lives an extremely active lifestyle. She is an avid skier, roller blader, lifts weights, and competes in local 5K races.

“It is not an easy thing to go through but I have never regretted it,” she says. “I lived through it and the piece of mind that I have now compared to when I was living with ulcerative colitis is amazing. Before, when I would be out running, I would have to find a bathroom or look where the bathroom was. “Now, I have total control,” she continues. “I hike in the Adirondacks and travel wherever I want to go. I would tell every woman that I talk to that the surgery is completely worth it.”

“The piece of mind that I have now is amazing. I would tell (everyone) that the surgery is completely worth it” — L. Conway
Dear Dr. Fazio,

My name is Patty Hurrell, and I am a former patient of yours from 1983-1985. I am writing to you at this time, as January marked the 20th anniversary of the closure of my loop ileostomy and the full functioning of my J-Pouch.

The road traveled up to the point of the J-Pouch construction was a scary ride. I became suddenly ill in July 1983 with proctitis and by the end of August was hospitalized for dehydration and fatigue. It was discovered at that time, that the disease had progressed rapidly and was now full-blown ulcerative colitis. The gastroenterologist that I was seeing at Fairview Hospital here in Cleveland tried everything to get me back on my feet, to no avail.

That fall, October 1984, you performed the first of a two-part J-Pouch construction with the closure coming in January 1985.

I am writing to thank you for taking such great care of me. I thank God almost daily for you and your expertise. I’m sure there are more institutions that perform this surgery now, but at the time, I know it was still a relatively new procedure. I’m sure had I lived elsewhere in the country, I would have had difficulty receiving the same care. I think the thing that amazes me the most is that I have never had any problems in this 20-year span with the pouch. Not even the most minor things that could go wrong. I do not need fiber therapy, medication or even pads (at night-time). I eat anything I want without concern. The most wonderful part is that I no longer consider myself different from most other people because I don’t have a colon. I don’t spend my days counting bowel movements or wondering “where is the nearest bathroom?” I just don’t think about it.

When I became sick, I was 24 years old and married only two years to my husband, Bob. The illness put a big strain on the marriage but we made it through and now have two terrific teenage daughters, Danielle, 17, and Megan, 13. (By the way, Danielle and I are pictured on the cover on the booklet that colorectal surgery published in 1988, which describes the pouch surgery. Danielle was 6-months-old at the time.) I created my own business 10 years ago designing, fabricating and installing custom window treatments. To be the wife, mother and business owner that I am I need all the energy I can get. Thankfully, I don’t have ongoing problems with my digestive system that could possibly drag me down.

I have, over the years, shared my experiences with many patients who were either contemplating pouch surgery or had already undergone the procedure. Many who have undergone the procedure call me looking for guidance on coping with some of the problems they have experienced. Unfortunately, I can’t be of much help because my experiences have been nothing short of, dare I say, miraculous!

Thank you for your untiring dedication to those of us who suffer and have suffered from digestive disorders and diseases. I am aware of the advances the Departments of Colorectal Surgery and Gastroenterology have contributed to the medical community in the United States and the world.

Patty Hurrell
Avon Lake, OH
20 years after pouch surgery

Once in awhile I need to be reminded how lucky I am, and this afternoon, while filling out the questionnaire, I again realized that. Dr. Turnbull performed my first surgery in 1967 and Dr. Church performed three surgeries on me in 1990, one surgery on my daughter also in 1990, and my two sons in 1991 and 1992, I believe.

Today we are all doing fine and have few, if any, side effects. The downside is NOT much; knowing what our limitations are and knowing the location of a restroom isn’t too much considering the “Big Picture.” In 1990, all I asked God for was the opportunity to see my children graduate from high school and to be able to walk my oldest daughter down the aisle; that has come to pass and much more.

The three oldest children have gotten married, and I have six beautiful grandchildren. What more could I have asked for?

I do hope this questionnaire helps those that follow, and please pass along my best regards to Dr. Church and Ellen McGannon. I wanted to thank all the doctors and staff for all that has been done for me and my family.

Michael (M.G.) Tighe
Bucyrus, Ohio
15 years after pouch surgery

Editors Note: We would like to highlight more letters in upcoming issues, from those who have had their pouches 15-20 years. Please send us your stories so we can include them in the summer or fall editions. POG

Note: We reserve the right to edit submitted letters prior to publication for length, clarity or grammar.