

winter 06-07

From the Department of Colorectal Surgery at Cleveland Clinic to help people deal with issues associated with the pelvic pouch.

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Pouch-o-Gram

Cleveland Clinic Digestive Disease Center Department of Colorectal Surgery

Cleveland Clinic Pelvic Pouch Database and Research Fund Need Your Help

Since 1983, more than 3,000 pelvic pouch surgeries have been performed at Cleveland Clinic, some of which were revision surgeries for patients who had unsuccessful outcomes elsewhere. Cleveland Clinic colorectal surgeons have performed more pelvic pouch surgeries than any other healthcare institution and every patient who undergoes this surgery at Cleveland Clinic is asked to be part of the Pelvic Pouch Database.

This registry is the largest of its kind in the United States, collecting peri-operative, complication and follow-up data in a secured computer database. Patients who consent to inclusion in the registry are given pre-operative and annual follow-up surveys asking them to rate various aspects of their quality of life, health, pouch function and satisfaction with surgery.

Analysis of the information in the database is ongoing. The information is used by the staff when teaching patients what to expect after surgery, and allows them to speak with assurance about long-term success and complication rates. The database also supports numerous academic projects, articles and international presentations, and has proven to be the key component for a

productive research program. With nearly 250 pelvic pouch cases entered per year, the database is home to an incredible amount of information that can be used to determine a variety of patterns and eventually improve patient care.

As part of a not-for-profit organization, Cleveland Clinic physicians are charged with securing funding for projects such as the Pelvic Pouch Database. Although millions of dollars a year are granted to investigators from organizations such as the National Institutes of Health, these grants are usually "rewards" as compared to "awards." In other words, investigators must show a sufficient amount of progress with their project before large granting organizations will consider them for funding. This, coupled with decreasing reimbursements from insurance companies, forces researchers to depend on outside sources to help pay for research personnel, hardware and software, and patient education materials.

Thanks to the generosity of Edward and Josephine Story of Center Point, TX, a fund has been established to launch a philanthropic opportunity, the Pelvic Pouch Research Fund. Mrs. Story, a patient of Feza Remzi, M.D., was

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treated at Cleveland Clinic after several unsuccessful pouch surgery attempts. Mr. and Mrs. Story wanted to express their gratitude and Dr. Remzi suggested that supporting the Pelvic Pouch Database would make the biggest impact.

“Dr. Remzi gave me my life back. I would do anything to show my appreciation,” Mrs. Story says.

The Pelvic Pouch Research Fund is supporting personnel dedicated to the Pelvic Pouch Database. Financial support is imperative for this very important research to continue and we are asking all past patients and their families to consider making a tax-deductible donation to the fund. Together, we can improve the quality of life for patients undergoing pelvic pouch surgery.

To discuss ways in which you can support the Pelvic Pouch Research Fund, please contact:

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Snapshot

Snapshot of the Pelvic Pouch Database:

- Total Number of Patients Enrolled: 3156 (1983-2006)
- 1st time pouches: 3057
- Re-do pouches: 95
- Demographics: 1750 Male, 1381 Female, Median Age: 47.5 years
- Mucosal Ulcerative Colitis: 1815
- Indeterminate Colitis: 435
- FAP: 189
- Crohn's Disease: 119
- Cancer: 18

Ongoing Studies

Bo Shen, M.D., is conducting the following studies:

- “A Randomized, Double-blind, Placebo-controlled Clinical Trial of Rifaximin in the Treatment of Patients with Antibiotic-Dependent Pouchitis.” This is a 36-week study.
- A clinical trial of amitriptyline (Elavil) and electronic barostat (balloon) test in patients with irritable pouch syndrome. This is a 12-week, placebo-controlled trial.

Candidates for irritable pouch syndrome: irritable pouch syndrome diagnosis and currently having symptoms of diarrhea, abdominal/pelvic pain or discomfort for more than 4 weeks with normal pouch endoscopy.

To learn more, call Kerry at 800.223.2273 ext. 55202 or 216.445.5202.

Soothing Irritated Perianal Skin

The skin is the body’s outermost organ, offering protection, temperature regulation and sensation. The perianal skin is very sensitive. It can easily become irritated from excessive moisture, aggressive cleaning with or without use of perfumed soaps and detergents, tight-fitting clothing, heat and bacterial overgrowth. In addition, drinking certain beverages such as beer, milk, citrus fruit juices or drinks containing caffeine such as tea, coffee or cola or eating foods like chocolate, citrus fruits, tomatoes, nuts and popcorn can aggravate this condition.

The most common complaint from people who suffer from perianal skin irritation is an itchy bottom accompanied by a strong urge to scratch. The damaged skin is less resistant to friction, therefore vigorous wiping or giving in to the urge to scratch can result in skin tearing. Irritated perianal skin is common among patients who have had an ileo-anal pouch procedure, particularly immediately after the closure of the

ileostomy, when they experience loose, frequent stools and the need to wipe more than usual.

People with ileo-anal pouches may experience seepage of liquid through the anus between stooling, which keeps the skin wet. As the perianal skin remains exposed to moisture and aggressive, repetitive wiping, the symptoms of itching and mild burning advance to fiery pain. It is common to see bloodstains on the toilet paper when the skin is irritated. The blood is coming from tears in the skin.

Perianal skin care is problematic due to the anatomical location. Most of the time, the patient needs a second set of eyes and hands to do the care properly, regardless of how tall or short they are.

The best treatment of perianal skin irritation is prevention. Be gentle to your bottom – it is a sensitive area.

Handling Perianal Skin Irritations

| CONDITION | WHAT TO DO | WHEN TO CALL YOUR COLORECTAL PHYSICIAN |
|--------------------------------------|--|---|
| Excess moisture | <ul style="list-style-type: none"> - Take showers instead of baths - Pat skin dry with a soft towel or use a hair dryer set at cool to dry the skin - Wear loose-fitting clothing - Keep absorbent cotton ball or gauze between skin folds | If the condition does not improve or becomes worse |
| Friction | <ul style="list-style-type: none"> - Avoid toilet paper - Use baby wipes or alcohol-free adult wipes - Do not “polish” your perianal skin with excess wiping - Never rub the skin - Avoid scratching | If the condition does not improve or becomes worse |
| Fungal or bacterial infection | <ul style="list-style-type: none"> - Avoid excess moisture | Your physician will prescribe specific treatment |
| Loose stools | <ul style="list-style-type: none"> - Thicken your stools by using Metamucil or Citrucel - Use Imodium to decrease the frequency of the stools - Use protective skin care products to avoid contact with stool, i.e. Desitin or zinc oxide (both available over the counter in the baby section) | <p>If you have not been told how to use Metamucil, Citrucel or Imodium</p> <p>Your physician will discuss other specific skin care products and their use</p> |

Team Bios



Feza Remzi, M.D.
Staff Surgeon
Department of Colorectal Surgery
Principal Investigator

Dr. Feza Remzi is a graduate of Hacettepe University School of Medicine in Ankara, Turkey. He joined Cleveland Clinic in 1990, and completed his internship, residency, fellowship and other advanced training here. Dr. Remzi became a staff surgeon in the Department of Colorectal Surgery in 1997 and has become a leader in the field of performing the pelvic pouch, or ileal-anal anastomosis. This procedure has helped improve the lives of many people suffering from ulcerative colitis and other inflammatory bowel diseases.

Dr. Remzi has worked countless hours to help establish one of the largest registries involving the pelvic pouch procedure. His specialty interests also deal with complex anal and rectal problems, intestinal stomas, continent ileostomy (k-pouch), sphincter-saving operations, surgery for carcinoma of the colon and rectum and laparoscopic procedures. Besides dealing with complicated issues of the bowel, Dr. Remzi is an active leader in educating the future leaders of colorectal surgery while promoting research to help lead the way in expertise and world-class care.

Since the mid 1980s, the Department of Colorectal Surgery has been an international referral center for patients with conditions such as inflammatory bowel disease or Inherited Colorectal Cancers such as FAP (familial adenomatous polyposis) requiring surgical intervention.



Aggie Medrick, R.N., B.S.N., O.C.N.
Clinical Research Nurse
Department of Colorectal Surgery
Study Coordinator

Aggie Medrick has joined in Dr. Remzi's quest to make the pelvic pouch database stronger and better. Aggie joined the colorectal surgery team in 2004 and started working

on the database in January 2006. Her role as work leader and coordinator of the database involves recording important data regarding patients who have had the pelvic pouch procedure at Cleveland Clinic.

Aggie started working at Cleveland Clinic in 1976 on a gynecology/urology floor. She then worked with a surgical gynecology/oncologist as his nurse clinician for 11 years. Cleveland Clinic Florida was also her home base for 8 years as a nurse clinician to a urologic surgical oncologist. She came

back to Cleveland Clinic's Main Campus in 1996 and worked in the Taussig Cancer Center until joining the Colorectal Surgery Research Department.

Patient care delivery and outcomes are a very important part of caring for patients. Quality-of-life scores and long-term follow-up are important criteria to evaluate. Obtaining this information and maintaining our databases helps the Colorectal Surgery Research Department pursue new research ventures. This feedback will also help the staff educate patients on what to expect after surgery and how best to assure the long-term success of the pelvic pouch procedure. As Aggie stated, "We are all in this together. If we can do or find one new concept to help these folks get through this process quicker and without complication, we could not ask for more."



Margaret O'Malley, B.S.
Clinical Research Assistant
Department of Colorectal Surgery
Study Coordinator

Margaret O'Malley is a graduate of The University of Toledo College of Pharmacy, where she received her bachelor of science degree in pharmaceutical science. Since joining Cleveland Clinic in 1997, Margaret has held various roles in the Inpatient Pharmacy. She joined the Department of Colorectal Surgery in 2005 and has worked on several studies ranging from databases to sponsored trials.

Patient Letters

Mother after Surgery: 'I Am So Glad I Did It'

When I was asked to write about my experience this year with all my body has gone through, I was very excited to have the opportunity to help others. I am 36 and had ulcerative colitis (UC) for seven years.

With this disease, I was in constant flairs and constantly taking steroids. Every time my gastroenterologists suggested surgery, I was so terrified that I changed doctors so they would continue to treat me with steroids and not push surgery. They all eventually told me surgery was inevitable.

Over the seven years, I had five colonoscopies and was hospitalized six times. At the first of the six hospitalizations, my GI doctor said I would not have lived three more days if I had not gone into the hospital. I was down to 100 pounds and having 20 bloody bowel movements each day. My blood pressure was dangerously low. Luckily the steroids through the IV helped and I went home in 10 days.

I did not get much better over the years. It was like having the stomach flu every morning. I had to map out my days by where bathrooms were because the urgency was so bad. Many mornings, I was not able to make it home after driving my daughter to school and had to run into the school bathroom, which was very embarrassing to her and me. This continued for so many years that I was absolutely worn out from fighting the UC and looking horrible from the steroids.

Finally, the last GI doctor I went to said he had never had a patient on steroids for 7 years and I had to have surgery. He sent me to Ian Lavery, M.D., at Cleveland Clinic. I was beginning to become more mentally prepared for what lay ahead. After I met Dr. Lavery, I felt confident he was the man who would cure me and give me my life back. I was getting too tired to fight the UC anymore and the steroids were becoming less effective.

The mental preparation for the surgery was a challenge in itself – a combination

of fear and excitement. I was scared of what my body would look like afterward and also what life would be like with an ileostomy for 3 months, but I was also excited to get on with life without severe abdominal pain and medicines. My family was such a huge support and I was able to focus on the positive. When driving my daughter to school one day, I was explaining all that I would be going through with the surgery and that it would probably be a good 4 months of total recovery. She was very happy that I had a way to get rid of the UC, and she said “Mom, you would have just spent those months sick with flair ups. You may as well be spending them getting better.” I knew then there was no looking back.

Dr. Lavery and the nurses made me feel so comfortable that it was easy to remain positive and focused on the end result. I had told him my biggest concern, which was the fact that my husband and I had been trying to conceive for 3 years. We had gone through fertility treatments, but were having no success. We figured it was because I was so sick for so long and on so many medications. Having this surgery was our only hope to make our dream of conceiving another child come true. Dr. Lavery assured me there would be no reason that I couldn't conceive after the surgery, and it should be easier because there would be no more disease and no more medications. This was something I could focus on to make it all worth it.

The surgery (March 16, 2006) went very well and I was released from the hospital in 6 days. Dr. Lavery removed my large intestine and rectum. The nurse was so helpful in teaching me how to care for the ileostomy that I felt confident doing it myself. Although the recovery was certainly not easy, I managed to get through it with the help of my family. It was about 8 weeks until I was better at staying hydrated and didn't feel light-headed every time I got up, but then I started feeling good. I was so happy that I could eat foods that had made me sick before. I was losing all the weight I gained on the steroids – about 30 pounds. Dr. Lavery said I would go back to my

“pre-sickness weight” and he was right. I returned to the exact weight that I was before I was diagnosed with the UC. It was so nice to not be in pain when I ate. Having the ileostomy (although there were some challenges to it) was a nice break. I was eating so many types of food. I wasn't even done with my surgeries and I already felt as if I had my life back.

The second surgery, my reversal, which was 3½ months later (July 6, 2006), went very well. It was so much easier than step one. I was in the hospital 2 days, and the stoma site totally closed up within 3 to 4 weeks. It was so nice to be able to sleep on my stomach again. It takes a while for your body to adjust to its new J-Pouch, but going to the bathroom every few hours during the day is nothing when there is absolutely no abdominal pain and no urgency. I can hold it if needed. I notice it slows with each passing month.

Having this surgery saved my life. I wish I had not been so scared and would have done it years ago. I recovered quickly after the reversal and the next month was blessed with the best news, confirmation that I was healed: I was pregnant! My husband and I were so amazed. It was as if God said to me “good job on staying strong and positive and getting through that trying time, here is your reward.” Everything looks great with the pregnancy. I feel it never would have happened if I still had the UC. Now I am healthy and not on any medications. Going through every day in no pain and eating what I want is such a great feeling. Dr. Lavery gave me my life back and through that enabled me to give life to another.

Thanks to Dr. Lavery and all the staff at Cleveland Clinic for saving and improving my life. Also, thanks to all the wonderful, caring people I met on the United Ostomy Association of America website who provided me with so much support, understanding, education, encouragement and friendship.

Sincerely,
Gina Callahan
Stow, Ohio



Pouch-o-Gram
 The Cleveland Clinic Foundation
 9500 Euclid Avenue / W14
 Cleveland, OH 44195

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 ONE OF
 AMERICA'S
 TOP 3
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Cleveland Clinic is ranked third in the nation in *U.S. News & World Report's* 2006 Best Hospitals Survey. **The Digestive Disease Center is ranked second.**

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CLEVELAND CLINIC DIGESTIVE DISEASE CENTER DEPARTMENT OF COLORECTAL SURGERY

Patient Letters
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Thankful to be Climbing Mountains

My name is Benjamin Klein. I am 25 years old and live in Longmont, CO. I had a pouch surgery at Cleveland Clinic in summer 2003 and a reconnect that fall.

My surgery was not easy; in fact, it was probably the hardest thing I have ever been through in my life. In addition to the surgery, I had complications including, but not limited to, infections in the abdomen, blood clots in my liver and a urinary tract infection. These complications kept me in the hospital for an extra month after my surgery.

But the purpose of this letter is not to go on about how hard that time in my life was. The purpose is to let you know that going through all of that was worth it. People have often asked me, "Are you glad you had that surgery?" I never know how to answer them. I see my surgery as something that was necessary, not a choice. I am sure glad of the results, but I wouldn't say I was glad to have the surgery, especially at the time.

In the three years since my surgery, I have done many things that I wouldn't have thought possible before my surgery. Before my surgery, I was a climber. I would climb mountains or cliff faces or frozen waterfalls. I am still a climber, but much more expanded now. I have climbed 11

mountains over 14,000 feet and numerous rock and ice climbs. I can be out all day on the side of a cliff and feel confident that I won't have to run to a bathroom that does not exist. My energy level is much higher, allowing me to train harder and therefore do harder climbing routes and mountains. I am currently planning my next 4,000 foot mountain and I will climb Mt. Rainier this fall.

In closing, I would just like to say thanks to all the nurses and doctors at Cleveland Clinic who helped me get where I am today. I once told a man whom I was standing next to at 14,129 feet that I had no colon. He couldn't believe it. I thought of all the hard work the people at Cleveland Clinic had put into me in that moment and I just wanted to say it is a job well done!

Sincerely and thankfully,
 Benjamin Klein
Eighth-grade science teacher
 Longmont, CO
 Formerly of Garfield Heights, Ohio