Preserving The Pouch
Revision surgery for pelvic pouch failure
By I. Emre Gorgun, M.D., and Feza H. Remzi, M.D.
The Cleveland Clinic Department of Colorectal Surgery

In a majority of individuals, pelvic pouch surgery is the procedure of choice to maintain bowel continuity after removal of diseased colon and rectum for ulcerative colitis or familial adenomatous polyposis. The pouch preserves the normal route of defecation and usually has good functional results.

Pouch failure, though uncommon after this operation, is a condition that merits discussion for our patients. Pouch failure, or pouch loss, is defined as unsuccessful medical or surgical attempts at pouch salvage that lead to the construction of a permanent stoma with or without pouch excision (surgical removal of the pouch).

Frequency of Pouch Failure
In some series in the medical literature, the risk of pouch failure at 10 years has been estimated at 9 percent. However, in a large series from our institution consisting of 1,911 pelvic pouch patients, the rate of pouch failure was 3 percent at six years' follow-up.

Overall, since 1990, the pouch failure rate at the Cleveland Clinic Department of Colorectal Surgery stands at 3 percent in more than 2000 patients with up to 13 years follow-up. The most frequent causes of failure are pelvic infections, severe pouchitis, high stool volume, Crohn's disease, and uncontrollable fecal incontinence.

Studying the Risks Associated with Pouch Failure
We recently conducted a study to show the risk factors associated with pouch failure. We found eight main factors that were related to pouch failure: pathologic diagnosis (Crohn's disease versus non-Crohn's disease), patient's co-morbidities (other chronic illnesses), prior anal diseases, diminished anal sphincter manometry measurements, separation of the pouch connection, outflow stricture, pelvic infection, and perineal fistula (abnormal pas sageway) formation.

Repeat Pouch Surgery
Pouch salvage, or repeat pouch surgery, is usually performed in an attempt to improve pouch function, maintain fecal continence and avoid pouch failure. Repeat pouch surgery is defined as an operation for a malfunctioning pouch using an abdominal approach with complete or partial reconstruction of the pouch.

Repeat surgery can be challenging and has not been popular among surgeons because of concerns about difficulties in re-operation. For this reason, it is important that patients considering pouch revision surgery choose an institution that has experience with this procedure.

Departmental Experience
Our department's experience with repeat pouch surgery has been published and the reported overall pouch salvage success rate was 86 percent. The success rate increased to 96 percent in patients with ulcerative colitis but fell to 60 percent in patients with Crohn's disease.

A high rate of seepage and pad use was observed in the Crohn's patients. However, 90 percent of the patients stated that they would still choose to have surgery again.

The Department of Colorectal Surgery wishes you a wonderful holiday season and a Happy New Year.
Editor’s Note: This information was approved by one of our staff colorectal surgeons. It is intended as a guide only, and does not substitute for medical advice. Please always check with your personal physician or pharmacist about any medication concerns or clarification.

General Medication Tips For The Pelvic Pouch Patient

Often, I receive inquiries about medication absorption and vitamin use. For people that have had their colons removed, it can take about four hours to digest and eliminate food. So pelvic pouch patients should take certain precautions when adding new medications to their regimen.

1) Multivitamins are good for general health and can be taken in a chewable or liquid form, which may enhance absorption. Chewables are available in grocery stores, and liquid vitamins and sublingual sprays are available in many health food stores.

2) Any medicines should be the type absorbed in the upper intestine. Discuss with your pharmacist before taking delayed or time-released medications as they may not be as effective.

3) Be aware that antacids containing magnesium hydroxide combinations (such as Maalox or Mylanta) may have a laxative action and cause diarrhea. Antacids containing calcium carbonate (Tums, Titralac, Calcium Rolaids) or aluminum hydroxide (Altanagel, Amphojel) may not cause diarrhea.

4) Diuretics (water pills) should be used cautiously in pouch patients because they may increase the risk of dehydration when the colon has been removed. You may need to supplement the sodium and potassium in your diet if you are on diuretics, so check with your physician.

5) Do not take large volume laxatives (ex: Golytely, Fleets Phosphosoda), for bowel prep when you have a pouch. Only use a gentle laxative, if needed, for bowel prep for an exam. Bowel prep for pouch patients can often be accomplished with a clear liquid diet the day before the procedure, or a Fleets enema just before an exam.

6) Always clarify bowel prep orders with the ordering physician and remind a new doctor or pharmacist that you have no colon.

Hope this information is helpful, and have a wonderful Holiday Season!

Sincerely,

FROM THE DESK OF

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

Van Hooser Has More Than Guts

New book by former colitis sufferer offers life-changing insights about surviving chronic illness

By John Nocero, Managing Editor

“It Takes More Than Guts,” the second offering from Kentucky native Phillip Van Hooser, recounts in vivid detail a two-year period in his life during which he grappled with ulcerative colitis.

Throughout its 270 pages, Van Hooser’s book provides an invaluable peek into the mind of a sufferer, offering a unique and honest vantage point from which to view the concerns, fears, and expectations of those who struggle daily with uncertainty, pain and physical debilitation due to Inflammatory Bowel Disease (IBD).

This very personal autobiography reveals the unspoken realities of living with IBD with candor, compassion and a healthy dose of humor.

‘I Needed to Write this Book’

A professional speaker and entrepreneurial trainer since 1988, Van Hooser, 47, travels the country helping clients enhance their leadership potential and customer service expertise. So it was a tough ironic that he initially wanted to put the experience of his own proctocolectomy and J-pouch surgery behind him rather than share it.

“For about seven or eight months (following surgery), I had several things I wanted to do to prove to myself I could get back to a normal life,” he says. “I wanted to snow ski. So the winter after my reconnection in 2001, I went to Steamboat Springs, Colorado. Throughout the first day of skiing, my wife, Susan, kept telling me how well I was doing — even if I didn’t have a colon.”

Later that evening, Van Hooser awoke in the middle of the night with his story beginning to form in his head. He immediately got up out of bed and headed for the bathroom — this time not to “go,” but because he had work to do. In less than an hour, he had outlined his book, “It Takes More Than Guts.” Six months later, a rough draft was complete.

For Van Hooser, writing proved much easier than talking about his experience. He tried to reference it during a keynote presentation at a conference in Scottsdale, Arizona. Instead, his efforts seemed to yield nothing but sympathy from audience members. Then, a rugged and rawboned man in his mid-30’s approached him at the conclusion of his presentation.

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The young man proceeded to explain how, as a teen, he accidentally got his foot caught in a grain auger in a farming accident. The damage done to his lower leg was horrific. Though doctors were able to save his leg, the recuperation period took years.

Amazingly, the young man went on to explain that he now viewed the accident as the best thing that had ever happened to him because it taught him how to find his inner strength and to have empathy for others who are really suffering.

“Mr. Van Hooser, you know what I’m talking about,” the young man implored. “You have the communication skills and the public platform to help a lot of people.”

That was the final motivation that Van Hooser needed.

“We hear the facts, but we don’t understand the emotional value that we can share with other folks,” Van Hooser admits. “I think that only someone who has been through it could have answers to the questions that I had. It is a book that I would’ve liked someone to give me.”

What’s Ulcerative Colitis?

Ulcerative colitis was Van Hooser’s first realization of his eventual mortality. In spring 2000, Van Hooser’s episodes of diarrhea had gotten progressively worse before he noticed blood in the toilet for the first time. He consulted with his primary physician, who immediately referred him to a gastrointestinal specialist. A colonoscopy confirmed that Van Hooser was suffering from ulcerative colitis.

“Ulcerative colitis? I’ve never even heard of that. What are you talking about?” Van Hooser writes when being informed of the initial diagnosis. He would soon realize that having no control over his own health would be as troubling psychologically as it was physically.

“I am not a negative person,” Van Hooser muses. “I’ve learned that little good comes from negative thoughts. But I think there were times that I did get a bit negative. I was convinced that I would wear this thing out and everything would be like it was before.

“It was not until my health started failing and I lost 52 pounds and had to start going to the bathroom multiple times a day that I realized I was really sick. Though I tried to stay positive, at some point, your resolve weakens as your body weakens.”

Heading to Cleveland

Though prednisone helped his condition, it was not a panacea, and it became more and more evident the prescribed medical treatments simply weren’t working. A particularly bad flare-up at the National Speakers Convention that year prompted Van Hooser to consult with his gastroenterologist about the prospect of surgery.

Van Hooser was considering surgery because he couldn’t imagine living the way he was if other options were available. After considerable discussion with his physician, Van Hooser was referred to The Cleveland Clinic Department of Colorectal Surgery. Van Hooser had never heard of The Cleveland Clinic, but he trusted his doctor’s recommendation. So he headed north to Cleveland from his home in Orlando for a scouting trip.

Amazed at its size, Van Hooser was impressed by the Clinic’s departmental efficiency. Yet, he still had trepidation because he feared The Cleveland Clinic might be more like a factory than hospital.

Van Hooser met with Dr. Ian Lavery, vice chairman of the Colorectal Department. After the preliminary discussions had concluded regarding the benefits of proctocolectomy surgery, Dr. Lavery asked the question that possibly changed Phil’s life forever: “Phil, how can I help you?”

“That was the real selling point to me,” Van Hooser says. “I told him that I wanted my life back. He told me he thought he could help me. I told him to work out the details and make things happen.”

Dr. Lavery determined that Van Hooser was a suitable candidate for a proctocolectomy and J-pouch ileoanal anastomosis. His pouch surgery happened on November 10, 2000, followed by ileostomy closure three months later.

Fortunate and Happy

Just 16 days after his reconnection in February 2001, he walked onstage at the Opryland Hotel and Convention Center and spoke to more than 700 managers about the importance of personal motivation, commitment and discipline.

Four years later, Van Hooser says he’s glad he swapped his diseased colon for personal independence.

“During the worst flare ups, I couldn’t eat anything and had no confidence,” Van Hooser says. “I did not control my circumstances, they controlled me. Since the surgeries, that has all changed. It is a wonderful new reality.”

Diet-wise, Van Hooser’s regime is almost back to normal, though different from his former dietary staples of cheese puffs and chocolate snack cakes. Initially, he was very careful and stayed away from foods that might cause intestinal distress, such as fried foods and baked beans.

“Today, I occasionally eat fried foods, but I don’t eat as many potato chips as I used to. And I’m careful about spicy foods,” he says. “I’ve learned which foods tend to cause a problem, so I prepare for that and adjust accordingly. I feel very fortunate and happy.”

Strength in Family, Faith

Van Hooser donates 10 percent of all of his profits from the book to the Crohn’s and Colitis Foundation of America, a nonprofit, volunteer-driven organization dedicated to finding the cure for Crohn’s disease and ulcerative colitis.

He feels sorry for people who undergo this surgery alone, without a support system. During his ordeal, Van Hooser unquestionably cites his family, friends and faith as his absolute strength.

He says, “I felt that strength again and again in a very real way through the love and support of my wife, kids, extended family and friends. Now I’m simply trying to offer strength and encouragement to others who are going through what we experienced. I’m just trying to share what I’ve learned.”

Editor’s Note:
Phillip Van Hooser is an accomplished leadership speaker and entrepreneurial trainer. He lives in Princeton, Kentucky. For more information, he can be contacted at 270/365-1536 or via e-mail at phil@vanhooser.com. For more information on “It Takes More Than Guts,” visit www.ittakesmorethanguts.com.
Letter #1:

It was one of the most wonderful moments of my life when I woke up after surgery at The Cleveland Clinic Foundation, and my friend Christiane sat beside me and said, “Antje, be happy. You’ve got an S-pouch.”

This happened after three horrible years and endless discussions with various surgeons and insurance companies.

In July 2000, I was 35 years old and after long years of suffering from colitis, a carcinoma was found and a colectomy was necessary. Then, everything went very fast and a lot of things went completely wrong.

At the University of Giessen, Germany, the construction of an ileoanal pouch-anastomosis failed because the arteria ileocolica was considered to be too short. After surgery, I had renal failure and a lot of other complications. After three months in the hospital, I was completely unhappy.

I tried to cope with the situation by working a lot, but I do not know what I would have done without my psychoanalyst. Finally in December of 2001, the surgeons at Erlangen decided to try again to construct a pouch, but they again failed because of severe adhesions. Several surgeons in Germany said I would have to have an ileostomy for the rest of my life.

One of the doctors had a genius idea and suggested that I go to the United States. While visiting a congress in May 2002, he related my story to Dr. Victor Fazio. An appointment was made, and so was my first trip to the United States to go to The Cleveland Clinic Foundation.

I could hardly believe it when Dr. Fazio told me that he would try to construct an ileal pouch anastomosis or alternatively a continent ileostomy. The following 12 months were full of difficulties. As the treatment in the United States was much more expensive than in Germany, it was hard work to organize everything. Thanks to Marlene Bambrick and the other ladies in the office who assisted me in planning my stay at The Cleveland Clinic Foundation.

Besides two very nice surgeons from Erlangen and Heidelberg, hardly anyone in Germany believed that such a surgery would be successful. They patiently answered all my questions considering surgery and the United States. Finally, I could convince the insurance company to refund at least one-third of the expenses.

When I look back one year later, I can hardly understand why I was so optimistic at that time. I hoped that life would become more comfortable after surgery, but there was also the great danger of complications, like renal problems.

Surgery was planned for September 25 and 26, 2003. Fortunately, my former cello teacher Christiane, who lives in Pennsylvania, stayed with me at the Clinic Guesthouse.

The day before surgery, Dr. Fazio explained very carefully to me what he planned to do, and I was sure that he would try everything to help me. The surgery was rather difficult but finally an S-Pouch, a technique that is not very common in Germany, could be constructed.

In the hospital, where the atmosphere was very different from German hospitals, I recovered very soon. The doctors and nurses, especially the ET nurses, were very friendly. After another week at the Guesthouse, I went back to Germany. I was full of energy and already two months later, the loop ileostomy could be closed.

The pouch function was excellent and I was very happy about my new life. Unfortunately, I spent more than a year trying to wean myself off the steroids before I made the decision to have surgery. I have never regretted that decision.

This past summer was the first summer in three years that I was disease-free, and I realized that I had forgotten how it felt to feel really good. I enjoyed the simple pleasures of taking my dogs for a walk and going to concerts in the park with my husband. I feel incredibly lucky that my disease had a cure. Sometimes, I cannot believe I no longer have ulcerative colitis. I also have been very lucky to experience no complications after surgery.

I am grateful to Dr. Ian Lavery and his staff and to the wonderful nurses on the fifth floor who took such good care of me during my three hospital visits. Thank you for giving me my life back.

Sincerely,

Antje Thiele
Salzburg, Germany

Letter #2:

The first anniversary of the third stage of my pelvic pouch surgery is approaching, and I never thought that I would ever feel this normal. As I filled out the annual Cleveland Clinic Foundation survey, I realized how different my answers are now from my pre-surgery answers.

I suffered from ulcerative colitis for 17 years, since my senior year in high school. In 2001, I experienced a flare up that would not abate and began taking Prednisone for the first time. The disease postponed my plans to start a family and significantly interfered with my life activities. Unfortunately, I spent more than a year trying to wean myself off the steroids before I made the decision to have surgery. I have never regretted that decision.

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Sincerely,

Orly Rumberg
Loveland, Ohio

continued on page 6
Frequently Asked Questions About Sugars and Sugar Alcohols

By Claudia Mueller, R.D., M.S., L.D.
Nutrition Therapy, The Cleveland Clinic

What are Sugars?
Sugars are carbohydrates and a source of energy (calories). Dietary carbohydrates also include the complex carbohydrates starch and dietary fiber. During digestion, all carbohydrates, except fiber, break down into sugars.

Sugars and starches occur naturally in many foods that also supply other nutrients. Some examples of these are fruits, milk, some vegetables, breads, cereals, and grains.

Sugar Value on Food Labels
The sugar value that is listed on food labels includes both naturally occurring and added sugars. Some examples are lactose, which is the naturally occurring sugar in milk, and fructose, glucose and sucrose, which occur in fruit.

Some vegetables, legumes and cereals contain naturally containing sugars. All these foods provide vitamins and minerals for good health. Added sugars are sweeteners added to foods and beverages during processing. Some examples include table sugar and high fructose corn syrup. These foods add calories and little or no nutrients to your daily intake.

Some primary sources of added sugars are soft drinks, doughnuts, cookies, candy, baked goods, and frozen desserts. Some foods with added sugars, like chocolate milk, fruit yogurt and pre-sweetened cereals, also are high in vitamins and minerals.

Added Sugars on Food Labels
A food is likely to be high in sugars if one of the names below appears first or second in the ingredient list, or if several names are listed.

Some names of added sugars appearing on food labels include brown sugar, corn sweetener, corn syrup, dextrose, fructose, fruit juice concentrate, glucose, high fructose corn syrup, honey, invert sugar, lactose, malt syrup, maltose, molasses, raw sugar, sucrose, syrup, and table sugar.

Sugar Alcohols
Sugar alcohols are ingredients used as sweeteners and bulking agents. They occur naturally in foods and come from plant products, such as fruits and berries. As a sugar substitute, they provide fewer calories than regular sugar. But beware! Some of these products may still contain significant amounts of carbohydrates.

Unfortunately, there are some negatives associated with sugar alcohols. The most common side effect is the possibility of diarrhea when sugar alcohols are eaten in excessive amounts. There also is some evidence that sugar alcohols, much like fructose in fruit and fruit juice, can cause a laxative effect.

Some forms of sugar alcohols are mannitol, sorbitol, xylitol, lactitol, isomalt, and maltitol. These sugar alcohols are often found in sugar-free candies and gums.

Will limiting added sugar or sugar alcohols help with diarrhea if I have an ileostomy or a J-pouch?
Yes, limiting these types of sugars or sugar alcohols may help reduce diarrhea. An additional problem with added sugars is that they provide few nutrients besides calories and often replace healthier foods. POG

A Clinical Trial of Amitriptyline in Patients with Irritable Pouch Syndrome

After pouch surgery, patients can develop symptoms of diarrhea, abdominal cramps, bloating, gas, and pelvic discomfort. Irritable pouch syndrome is one of the common causes of these symptoms. To elucidate disease mechanisms and identify effective treatment regimens for irritable pouch syndrome, the IBD Center at The Cleveland Clinic is conducting a federal grant-sponsored trial of amitriptyline and electronic barostat (balloon) testing in patients with irritable pouch syndrome. This is a 12-week, placebo-controlled trial of a total of 64 patients.

Candidates:
1) irritable pouch syndrome diagnosed in the past or 2) current symptoms of diarrhea, abdominal/pelvic pain or discomfort for more than four weeks with normal pouch endoscopy.

Pouch endoscopy with biopsy and balloon test will be performed at the beginning and at the end of the 12-week trial. There will be no cost to the participants. Participants will be financially compensated for their time. Parking will be free.

Contact Kerry Sherman at 216/445-5202, or via e-mail at shermak@ccf.org, or Bo Shen, M.D. at 216/444-9252, or via e-mail at shenb@ccf.org, for further information. POG
Letter #3:
I have been receiving your periodic newsletters for a couple of years, and I wanted to relay to you how impressed I am with your publication.
I did not have my J-pouch surgery at a Cleveland Clinic hospital, but had heard of your cutting-edge department, with surgeons of vast experience, through my research on the Internet. I had my surgery in 1995 in California, and while my surgeon was excellent as far as providing me with information, and my gastrointestinal physician seems to keep quite up to date, your newsletters have some of the best information available.

I am a retired nurse with experience in intensive care and general medicine/surgery and was involved with procedure writing and patient education. I realize the importance of well-written, comprehensive information for patient use. I commend you and your editorial team for excellence in topic selection, well written and fact based articles, and the wealth of information that is provided to the patients.

In our world where complaints seem to prevail, I wanted to let you know that your publication goes far beyond the limits of your patient database and is useful for all J-pouch patients.

The only suggestion I might have is to include wwwj-pouch.org in your list of support groups. It is an excellent alternative for those seeking support and who are not interested in face-to-face support groups.

I have been involved in this online support group for J-pouch patients for more than five years, and your institution is hailed as the “place to go” for the best in colorectal surgery, and surgery for irritable bowel disease and Familial Adenomatous Polyposis, in particular. Members post daily from areas around the world seeking support with J-pouch related issues, and much of the advice I get from the Pouch-O-Gram, I pass on in this forum.

Thanks again for a job very well done! Keep up the good work.

Sincerely,
Jan Dollar, RN, CCRN
(No city and state given)

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

Coming Soon!
The Inaugural Pelvic Pouch Picnic

In the summer of 2005, the Department of Colorectal Surgery plans to invite more than 3,000 pelvic pouch patients as guests of honor at an inaugural Pelvic Pouch Picnic. The pelvic pouch database team has plans to schedule the event at the Cleveland Clinic’s main campus in Cleveland, Ohio. Come enjoy eats and treats (pouch-friendly, of course!) and the fellowship of other CCF pouch patients.

Dr. Feza Remzi would like to find out how many people are interested in attending the event. Please contact Miriam Preen, Pelvic Pouch Database Research Nurse at 216/445-8524 or 800/223-2273, extension 58524 (you may leave a message) or via e-mail at preenm@ccf.org. Please respond by January 30, 2005, if you are interested in attending. A formal invite would be sent out in early 2005. POG