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**Jacksonville
 Contact Information:**

Patti Langenbach
 (800) 741-0110
 (904) 733-8500

patti@ostomymcp.com

Support group meets the 3rd Sunday of each month 3 p.m.
 4836 Victor Street
 Next Meeting: **Sept 15th**

**Gainesville Support Group
 Contact info:**

JoAnne Bell at 352-284-4214
 Meets the 1st Sunday of each month (except Holidays)
 at Hope Lodge 2121 SW 16th St
 Gainesville, FL
 Next meeting: **Sept 1st**

Ocala Support Contact info:

Lynn Parsons 252 337-5097
www.ostomyocala.com

Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview.
 Next Meeting: **Sept 8th**

Citrus County Support Group

Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building **Sept 15th**

**Amelia Island Area
 Ostomy Support Group**

(904) 310-9054

Meets second Monday of each month at 6:30pm UF North Campus UF Health North 15255 Max Leggett Parkway Jacksonville, FL 32218 (Meeting Room 3-4)
 Free parking
 Next Meeting: **Sept 9th**

The Villages Ostomy Support

Group We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August)
 Saddlebrook Recreation Center
 3010 Saddlebrook Lane
 The Villages, Florida
 Linda Manson
tvostomy@gmail.com
 865-335-6330
 Next Meeting: **Sept 10th**

“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”



Perusing the Spring 2019 US Phoenix ostomy mag, Gutsy saw this article and bravely emailed Bill Van Clief at: horses@execpc.com...here was his response:

Hi Linda,

I enjoyed reading your email requesting permission to print my article in your newsletter. Although I have no objection and would welcome the opportunity for others to read it, I have emailed the Publisher of The Phoenix about your request as a professional courtesy. I will email you his response.

As you undoubtedly gathered from my article, I am well involved in disseminating information about continent ostomies, primarily the K pouch and the BCIR. Although these procedures have been available for many years, they have generally been replaced by the J pouch as the primary alternative to a conventional ileostomy. The K pouch and BCIR are now performed primarily for those with failed or problematic ileostomies and J pouches. The key appeal of these procedures is that they do not require an external bag.

There are several websites that contain information, articles and videos are:

QOA website: www.qla-ostomy.com

Palms of Pasadena website: www.bcir.com

Olympia Medical Center: www.ileostomy-surgery.com

J- Pouch Group (K pouch korner forum) www.j-pouch.org

I am sure that the readers of your newsletter will find these websites to be interesting and informative.

My first article in The Phoenix entitled “Researching my Options” has been re-printed in the Quality Life Association’s webpage (www.qla-ostomy.org) under the News tab. Anyone can access that web site and read the article. While on that website, they can look through lots of information about continent ileostomies and the QLA organization itself. Each year, QLA has an annual conference attended by over 100 people, many of whom have a BCIR or K pouch or a spouse with one. You do not have to be a QLA member or have an internal pouch to attend. There are some excellent presentations and the opportunity to meet and socialize with others. The program and registration form are on the QLA website. Perhaps this would be of interest to some members of your group. This year’s conference is in Knoxville, TN on August 22-24. My wife and I will be there. If any of your members might have interest in the BCIR procedure, the surgeons who do them will be present and available to answer any questions.”...

The following is reprinted with permission from The Phoenix magazine, www.phoenixuoaa.org, 800-750-9311, the official publication of the United Ostomy Associations of America.

Two years ago, I stood in front of an audience at the annual Quality Life Association convention in St Petersburg, Florida. I gave a presentation entitled, “Health, Happiness and the Internet.” The mission of the Quality Life Association, www.qla-ostomy.org, is to support continent ileostomy procedures and those who have them. I first had interest in making this presentation shortly after getting my Barnett Continent Intestinal Reservoir (BCIR) in 2013. I realized how limited the information about continent ileostomies is and that there are few surgeons who perform them. I am not a professional speaker, but I felt that my experiences would make giving this presentation easier. Once I ascended the stage, I felt perfectly at ease with an audience that could personally relate to what I said. Everyone either had one of these procedures or was familiar with them.

My Medical Journey

My long medical journey began in 1981 when I attended a hospital financial management seminar. During the morning break, I went to use the restroom and a significant amount of blood flowed into the toilet bowl. I had no prior indications of medical problems and was frightened by this occurrence. A gastroenterologist at the hospital where I was Vice President of Finance performed a colonoscopy and found hundreds of polyps and referred me to a surgeon to get an ileostomy.

With years of experience in the medical field, I knew what an ileostomy was and did not want to end up having an external bag with its associated issues. This was a personal opinion on my part and I realized that others might not feel the same way. I also did not want to avoid surgery, since to do so would mean a death sentence. My diagnosis was familial adenomatous polyposis (FAP), a genetic disorder that has a 100% chance of developing into colon cancer unless treated on a timely basis. No other family members had this condition, and fortunately neither of my daughters inherited it from me. My father, who had connections at the Mayo Clinic, found out that they had recently started performing a couple of surgical procedures that did not require having an external bag. I had a comprehensive examination at Mayo that confirmed the original diagnosis. My surgeon there explained three options that were available for me: a conventional ileostomy, a Koch pouch and an ileoanal anastomosis (IPPA). He suggested that I get the third option since K pouches at that time had a significant rate of valve failure (which has since been corrected). I was one of the first to have this procedure at the Mayo Clinic and I participated in a study to measure its effectiveness. The results of this study were published in a medical journal. My IPPA was later converted to a J pouch when the bathroom use frequency did not reduce to a tolerable level. My first experience in using the internet for medical research was during the period of 2000-2005 when my late wife had advanced cervical cancer. Internet searches provided me with a wealth of information about her condition and eventually enabled me to locate and have her participate in eight clinical trial studies that some doctors felt extended her life and provided a better quality of life. Through the internet, I also made contact with a number of cancer researchers and their staffs in the U.S. and abroad. Shortly after her death, my gastroenterologist found high grade dysplasia and a malignant polyp in my anal canal during my annual scope exam. The polyp was successfully removed by a surgeon, but apparently the function of the internal sphincter was compromised by the procedure. Five years later, recurrent high-grade dysplasia was again discovered in the same location and removal of the pouch was recommended. I returned to Mayo where the diagnosis and recommendation of my GI was confirmed. The surgeon's only recommendation was an end ileostomy, which I still did not want. He wished me well when I mentioned my interest in a K pouch, but did not provide any information about it.

Researching My Options

After returning home, I went online to further research the K pouch option. My efforts led me to a modification of the K pouch called the BCIR, which utilizes a "living collar" of small intestine to better stabilize the valve and a different suture pattern to reduce the occurrence of fistulas.

Preparing My List of Questions

My online research provided me with a wealth of information about the two options I was interested in pursuing: the K pouch and the BCIR. To assist with my decision, I prepared a list of questions and concerns relating to the evaluation of the options available to me. This list will be different for everyone preparing it due to variations in lifestyle, personal beliefs and individual experiences. Here are a few questions your list could contain: What body image concerns impact my decision? • Will I be able to continue with physical activities, sports and social activities in a way that is satisfactory to me? • Will my insurance cover my desired procedure? • How do I feel about the possibility of potential complications of this procedure and am I willing to accept them? • Will the ongoing supply and other maintenance costs relating to this procedure be a significant financial burden for me? • Do I have concerns that physical intimacy will be a problem for me? • Will this procedure eliminate the possibility of disease recurrence? • How many separate operations are needed for this procedure? • Will I be able to continue performing my current job and favorite activities? • Will the routine maintenance needed for this procedure be acceptable for me? • How far am I willing to travel to get this procedure?

Stay tuned for the rest of the article in the October MailBag!

Genetic-testing scam targets seniors and rips off Medicare.

This article was taken from NBCNEWS.com (thanks to one of our own for the tip! – his Medicare was billed \$9,000 for the same test!) This is happening locally (here in Jacksonville).

By Melissa Bailey, Kaiser Health News

The 86-year-old woman in rural Utah doesn't usually answer solicitations from strangers, she said, but the young couple who knocked on her front door seemed so nice. Before long, she had handed over her Medicare and Social Security numbers — and allowed them to swab her cheek to collect her DNA.

She is among scores of older Americans who have been targeted in a scam that uses DNA tests to defraud Medicare or steal personal information. Fraudsters find their victims across the country through cold calls, door knocking, email, Facebook ads and Craigslist. They also troll low-income housing complexes, senior centers, health fairs and antique shops. Sometimes they offer ice cream, pizza or \$100 gift cards. Some callers claim to work for Medicare, according to a fraud alert by the Federal Trade Commission.

The woman in Utah said she didn't know the purpose of the DNA test she submitted to this month — “I'm too old to remember” — but the visit troubled her for several nights, she said. “I'd lie awake thinking about it, saying, ‘You fool, you shouldn't have done that.’” (She spoke on the condition of anonymity for fear of being targeted by other scams.) In interviews with Kaiser Health News, seniors around the country reported feeling betrayed, exposed and confused.

Capitalizing on the growing popularity of genetic testing — and fears of terminal illness — scammers are persuading seniors to take two types of genetic screenings that are covered by Medicare Part B, according to experts familiar with the schemes. The tests aim to detect their risk for cancer or medication side effects. The scammers bill Medicare for the tests. The patients, who might never receive any results, typically pay nothing. But they risk compromising personal information and family medical history. And taxpayers foot the bill for tests that may be unnecessary or inappropriate.

Scammers can really cash in: Medicare pays an average of \$6,000 to \$9,000 for these tests, and sometimes as much as \$25,000, according to the Office of Inspector General at the Department of Health and Human Services. DNA test scams appear to be ramping up: Complaints to the inspector general fraud hotline have poured in at rates as high as 50 per week, according to Sheila Davis, an OIG spokeswoman. That's compared with one or two complaints a week at the same time last year, she said.

The inspector general issued a fraud alert in June, urging seniors to refuse unsolicited requests for their Medicare numbers and take DNA tests only with the approval of a doctor they know and trust. By Medicare rules, DNA tests must be medically necessary and approved by a physician who is treating the patient.

In cases that have gone to court, scammers were accused of breaking those rules by paying kickbacks to doctors who agreed to order DNA tests for patients without ever treating them. The front-line recruiters who solicit the tests might work directly for a lab, or as independent contractors who divide revenue with a laboratory in exchange for bringing in extra business. Some solicitors try to scare seniors into cooperating, said Shimon Richmond, an assistant inspector general for investigations. They warn seniors that they could be vulnerable to heart attacks, stroke, cancer or even suicide if they do not take the DNA tests.

“That's a pretty egregious form of patient manipulation and emotional abuse,” Richmond said.

Richmond said the two tests involved in the scams are: CGx, which tests for genetic predisposition to cancer, and PGx, a pharmacogenomic test for genetic mutations that affect how the body handles certain medications. They're part of a new frontier of preventive genetic health. In New Jersey, three people were sent to federal prison in May for a scheme that used a purported nonprofit called Good Samaritans of America to persuade hundreds of seniors to take DNA tests. The co-conspirators raked in \$100,000 in commissions from labs that ran the tests, according to the government.

“This is a gold-rush area for folks. It's leading to a big response by the government,” said Assistant U.S. Attorney Bernard Cooney, a prosecutor in the case. This month, a Florida doctor was charged in federal court for his role in an alleged fraud scheme to order DNA tests for patients in Oklahoma, Arizona, Tennessee and Mississippi. Patients were recruited through Facebook ads offering \$100 gift cards, according to court records. The doctor allegedly confessed that he was being paid \$5,000 per month to approve these tests, even though he never spoke to any of the patients involved.

Some labs accused of billing Medicare for unnecessary genetic tests — including [Companion DX Reference Lab](#) — agreed to repay the government but declared bankruptcy before doing so, leaving taxpayers on the hook.

Meanwhile, older Americans are encountering sales pitches that leave them feeling deceived. In Weslaco, Texas, Will Dickey, a 71-year-old retired police detective, submitted to a DNA test at a health fair in February.

“I have a bunch of cancer in my family,” he recalled thinking, so “it'd help if I had an idea of what genes I had in me.” Three weeks later, he saw the same salesperson rounding up business at his RV park, where his wife and several neighbors got their

cheeks swabbed. Dickey, who spent 10 years working with DNA tests in a police crime lab, said he was surprised at the cost: A lab in Mississippi charged Medicare \$10,410 for his tests. He didn't get results until he requested them by phone. The report, which listed results as "uncertain," was "a bunch of gobbledygook that makes no sense to anybody who's not in the medical field," he said. He reported the case to authorities as possible fraud.

As in Dickey's case, scammers often gain access to places that seniors trust by persuading gatekeepers to let them make presentations. Bev Beatty allowed a genetic testing company to run a booth at a senior health fair she organized in Oak Forest, Ill., last year. At least 10 seniors took the tests. Afterward, she was irate to discover they had been roped into a scam. Test-takers told her they never received their DNA results, even though Medicare paid thousands of dollars.

"If somebody's going to be fraudulent and bill Medicare, it kind of riles me up," she said. "I would like to see them hanged."

In Paducah, Ky., Donald McNeill, a 72-year-old Vietnam War veteran, was persuaded at an event at his senior center in December to submit a cheek swab for a DNA cancer screening. The company never sent results, he said. But it billed \$32,212.86 to his Medicare supplement insurance plan. He's worried his personal information will be misused. "I've lost my identity to these people," he said. "They got my DNA and they got my information through this scam. I'm extremely upset."

Others may face consequences for merely engaging with scammers. In Idaho, a woman in her late 60s said she responded to an online ad for free genetic testing and got a callback 20 seconds later. She received a cheek swab kit in the mail but, suspecting a scam, never sent it in. Now, she said, she finds her phone suddenly plagued by robocalls.

In California, 1 in 4 cases reported to the state's Senior Medicare Patrol this year for potential fraud have been related to genetic tests, according to Sandy Morales, statewide volunteer coordinator. Sherry Swan of Roseville, Calif., is one of many who have filed complaints. She said she was home one Sunday afternoon in early June when a man named Caleb knocked on her door, and said, "I'm here to do your DNA testing."

"What are you talking about?" she recalled asking him. She said he failed to produce an ID when asked. "It was just a scam from the minute he opened his mouth." Swan said she spent five minutes arguing with the man, then called the police when he left.

"I'm aggressive. I work with homeless in the county," said Swan, who is 64. But she said she worried about the more passive and trusting neighbors in her senior living complex. She later discovered that many had been persuaded to take the tests and divulge their family medical histories. A man named Freddy, who answered a number on a flyer that Caleb had left at Swan's door, said he supervised Caleb as part of a team from Whole Home Solutions. He said the operation was aboveboard because they enrolled only eligible Medicare beneficiaries, and that a teledoctor would consult with the person's treating physician before the tests were sent in. The tests were handled by Pathway Labs in Colorado Springs, Colo.

Pathway Labs CEO Rene Perez confirmed his lab handled about 20 tests sent in by Whole Home Solutions. But he said he cut ties with the company on July 6 on the advice of his attorneys after receiving complaints about how seniors were being solicited for the DNA tests. The lab worked with the outfit for about 45 days, Perez said. Such experiences make him "reluctant to take on new business" from similar entities sending in DNA tests, Perez said.

"We strongly advocate and believe in the benefits of genetic preventative health," he said. "But the problem that we see right now is that it's really picking up momentum on the national level. Unfortunately, when that happens, you get a variety of different sorts of groups that essentially may see dollar signs." To seniors curious about these DNA tests, Richmond of the inspector general's office has this advice: "If anyone calls you, or sends you an unsolicited request for your Medicare number or to convince you or scare you into taking a genetic test, either hang up the phone or say no."

Seniors interested in the tests should call their primary care provider, he said: "Don't give into the manipulation or the scare tactics to get this health care test from someone you don't know."

If you suspect Medicare fraud, [contact the OIG Hotline online](#) or at 1-800-HHS-TIPS.

CORRECTION (August 1, 2019, 6:06 p.m. ET): A previous version of this article misstated the terms of a bankruptcy case involving Millennium Health. As part of its case, the firm paid a government settlement in response to accusations that it billed Medicare for unnecessary tests; it did not declare bankruptcy after agreeing to repay the government, leaving taxpayers on the hook.



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