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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: **June 18th**

Gainesville Support Group Contact info:

Brinda Watson (352) 373-1266
 Jean Haskins (352) 495-2626

Meets the 1st Sunday of each month (except Holidays)
 at Hope Lodge 2121 SW 16th St
 Gainesville, FL
 Next meeting: **June 4th at 2pm**

Ocala Support Contact info:

Lynn Parsons (352)245-3114

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: **June 11th**

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
 Next Meeting: **June 18th**

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 (Lobby area)
 Free parking
 Next Meeting: **June 12th**



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

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

Jennifer’s story:

My story reads like something out of Reader’s Digest. An exciting adventure! Near death experience! And the obligatory happy ending.

I had been visiting one of my best friends in Ohio, and was on my way back home of my solo trip. I was about 10 minutes into my 9-hour drive when the first pains began: minor cramping on my left lower side. I didn’t think much of it, so I just took a couple Aleve as I stopped to fuel up.

But as the miles piled up, it didn’t get better no matter how many pills I popped. I couldn’t figure out what it could be; I hadn’t had any medical issues lately, and I’d felt fine the entire time I was at my friend’s. I tried to analyze the pain: it wasn’t really pain, it was more of a nagging cramp. Nothing like the kidney stones I’d had before. So I shrugged it off & kept driving.

I got almost halfway through my trip and stopped in my old home town to pick up a few souvenirs. I noticed that I was feeling worse: sweating, walking slowly, diarrhea, stomach cramps. What the heck? I finished my errands and told myself that if it didn’t get better I would just stop at a hotel and spend the night. I pressed my GPS to take me home and it pointed me in a totally different direction than I was used to. I had no idea where I was going but figured I could trust a GPS. As I kept driving, I couldn’t distract myself. I knew it had come to me having to stop. I kept hearing the word “Clarion” in my head and thought it meant the hotel. I passed several hotel signs until I finally saw Clarion-the town, not the hotel. This town was out in the middle of nowhere, but the hotel I chose had a hospital right next to it.

I tried to eat, take a shower, a nap...but nothing made it go away. I was feeling worse and worse and having no idea what was wrong with me, I had nothing with which to compare it. And I was alone so I had no one to help me. Finally, in the middle of the night, I could stand it no more & got up, checked out, and walked over to the hospital.

As I checked into the ER, they told me they would do a CT scan. I had no idea what to expect. After that, the doctor came over and told me the startling news: I had a perforated bowel and would have to go into emergency surgery. He would either be able to repair it or he’d have to put on a colostomy bag. Of all things, that was the last I expected. I had never had any issues and certainly never thought about my bowels. Those bags were for old

people, I thought. Not me, 46 years old and no prior issues. I called my husband from the ER, now 4 hours away, and left him a voice mail that I was going into emergency surgery.

I woke up with the bag. And zero clue what to do. This hospital that God had steered me to was very small, rural. They did not have the staff or expertise to teach me about dealing with a colostomy. One nurse actually read the instructions from the box right in front of me. Instead they wheeled in a video and made me watch it. I did, with tears down my face, as my husband finally showed up.

I ended up being in the hospital for a week. During that time there was a patient with MRSA next to me, someone dying in the room on the other side, and someone screaming constantly across the hallway. Oh yes, and a drug addict who fought with the same surgeon who had done my surgery. I felt like I was in One Flew Over the Cuckoo’s nest. They finally sent us home at 8pm on a Friday night with 4 hours left to drive.

I gradually connected with my PCP who was a lifesaver: she filled me in on what to do and whom to contact to begin this life with the bag. I found out about visiting nurses. I got the bags and supplies delivered personally to my front door. And in one of those deliveries, I found an ad for Inspire.com. That began my journey to mental recovery-even more so than the physical. In Inspire, I found a community of others who were like me. Horror stories like mine-and worse. They shared stories, tips, told me about WOCN, and how to handle the daily issues with a bag. I could not have survived without them!

I ended up getting my reversal 3 months later and have been healthy and issue free 2 years now after.

I have to believe that God was truly looking out for me when he sent me the “wrong way” with my GPS and right to a hotel next to a hospital. He saved my life! And the people I met through Inspire.com saved my sanity. I can’t thank all the people involved in my “story” enough.

Here is a link to my blog about it: <https://wordpress.com/stats/insights/bag2014lady.wordpress.com>

UOAA’s National Conference

August 22-26 2017

in Irvine, California

<http://www.ostomy.org/>

[2017_National_Conference_Page.html](http://www.ostomy.org/2017_National_Conference_Page.html)

Photos: Jennifer Repine:



Hospital with colostomy
colostomy Reversal!

Smiling, happy POST

Jennifer's blog: <https://wordpress.com/stats/insights/bag2014lady.wordpress.com>

Jennifer's email: freedom07j@aol.com

Gutsy met Jennifer on Inspire.com [ConvaTec's 24/7 social media website] Linda had suffered with long time IBD Crohn's Colitis that resulted in permanent ileostomy [YAY!...ME, Gutsy!]...Jennifer's emergency surgery for [as then undiagnosed] diverticulitis, gave her a temporary colostomy, reversed 3 months later...and 2 years later, enjoying good health with no further digestive issues. Sandy-Colostomy/"The Dude," another of Gutsy's good friends on Inspire.com, recently posted about having sensitivity toward and respecting, not suspecting others' choices: some journey to ostomy from chronic illness, like Linda's IBD, and are pleased to readily remove diseased complaining colon, wrecked rectum, annoyed anus, and anxious anal sphincter muscles and, accept this little red "alien's" permanence. Some have colo/rectal/anal cancer or emergency situation, e.g., diverticulitis, like Jennifer, and are glad to be "diverting" the pain to a colostomy, which could be permanent...or as in Jennifer's case, temporary. But, no matter the decision for further excision [reversal] or learning to accept that you kept your stoma as a part OF you. For the duration of YOUR stoma's life, however short or long, there should be no derision...from ANYONE!...especially NOT from ostomy community!...which should support and purport as UNITED, whether in the States/Kingdom, or anywhere else...alas, none of us have guaranteed immunity from NON ostomates' incredibly insensitive ignorance

Remember: [Gutsy reiterates AGAIN!]...NO ONE WANTS AN OSTOMY!...but, if you have one for a time [or many years], don't let ANYONE tell you that only reversal=return to "normal life!"...in fact, it was something similar in Evansville Indiana Ostomy Association publication "The Reroute"...way back around 2010, that Gutsy was incensed to read that "ostomates could wear

jeans...like NORMAL people!"...that spurred us to where we are today!...because WE are ALL still NORMAL, beautiful, loveable people who can feel EMPOWERED to live well/better with an ostomy.

Coronary Stents

by Bob White, S. Brevard (FL) Ostomy Newslette

A coronary stent is a hollow, artificial device of small diameter, which may be used to expand a coronary artery that has become obstructed for various reasons. The type currently in use locally is made of stainless steel mesh, which is inserted in the artery, surrounding a balloon. On arrival at the desired location, the balloon is inflated, expanding the stent, and securing it to the wall of the artery. This restores the blood flow in the area of the procedure. Stents can be used as an alternative to balloon angioplasty, and ideally, may lessen the need for cardiac surgery.

Three articles in the 23 December issue of the New England Journal of Medicine report on the use of stents. One article outlines the results of an analysis made by a group from Vancouver General Hospital, of data on all percutaneous(performed through the skin) coronary interventions in British Columbia between April 1994 and June 1997. Some 9600 procedures were analyzed. During the period, a large increase in the rate of stenting was associated with a significant reduction in the rate of "adverse cardiac events." This was felt to be exclusively due to a large reduction in follow-up revascularization [further action to restore an adequate blood supply], without significant changes in heart attacks or death. It was held that this reduction was at least coincident with the introduction and subsequent widespread use of coronary stenting.

In an international study headed by Dr. Cindy Grimes of the William Beaumont Hospital in Royal Oak, Michigan, patients with acute myocardial infarction, who were to undergo emergency catheterization and angioplasty, and who were judged to be suitable stenting risks, were randomly assigned to undergo angioplasty with stenting (452 patients) or balloon angioplasty alone (448 patients). After six months, fewer patients in the stent group than in the angioplasty group had angina or needed revascularization. In addition, death, disabling stroke, or reinfarction occurred in fewer patients in the stent group. It was felt that the latter result was due entirely to the decreased need for revascularization. The group's conclusion was that "in patients with acute myocardial infarction, routine implantation with a stent has clinical benefits beyond those of primary coronary angioplasty alone."

What's Normal... Answers from Your Stoma

to You by Liz O'Connor, RN,CETN, Metro Maryland; via Fairfield (CA) Solano Ostomy News

What is normal for my stoma? This is a frequently asked question. Here are some answers from your stoma to you.

My color should be a healthy red. I am the same color as the inside of your intestine. If my color darkens, the blood supply might be pinched off. First make sure your skin barrier/wafer is not too tight (this can vary according to the barrier type, as some require a small gap between your stoma and the barrier material, while others are intended for a snug fit where the wafer material actually touches your stoma). If I should turn black (very unlikely – but it happens occasionally), seek treatment AT ONCE. Go to an Emergency Room if you cannot readily locate your doctor. (Be sure to TAKE AN EXTRA POUCH ALONG so you can remove the pouch for doctors to examine the stoma.)

I might bleed a little when cleaned. This is to be expected. Do not be alarmed. Just be gentle please, when you handle me.

If I am an ileostomy, I will run intermittently and stool will be semi-solid. If you should notice that I am not functioning after several hours and if you develop pain, I might be slightly clogged. Try sipping warm tea and try getting in a knee-chest position on the bed or on the floor. (Have your shoulders on the floor and your hips in the air. Rock back and forth in an attempt to dislodge any food that might be caught.) If I do not begin to function after about an hour of this, call your physician. If you cannot locate him/her readily, go to an emergency room. In the meantime, I might have begun to swell. Remove any pouch with a tight wafer and replace it with a flexible one with slightly larger stoma opening.

If I am a colostomy located in the descending or sigmoid colon, I should function according to what your bowel habits were before surgery (daily, twice daily, three times weekly, etc.). I can be controlled in most cases with diet and/or irrigation. This is a personal choice. There is no right or wrong to it, as long as I am working well. My stool will be fairly solid.

If I am a colostomy in the transverse colon, I will have a more loose stool than a descending or sigmoid colostomy. Because there is less remaining colon in this case to absorb water and solidify the stool, its consistency will be closer to that of an ileostomy.

If I am a urinary diversion, I should work almost constantly. My urine should be yellow, adequate in volume and will contain some mucus. If my urine becomes too concentrated or dark, try increasing your fluid intake. If my mucus becomes more excessive than usual, I might have

an infection. I will probably also have an odor and you may have a fever. Consult your physician if this happens.

If at any time, you doubt that your stoma is functioning normally, please seek help. The cause needs to be evaluated. If your problem is a serious one, it needs to be corrected. If it isn't serious, you will be relieved to know that your stoma is alive and well.

Defective Ostomy Products

via Evansville (IN) Re-Route

Finding a defective ostomy product is no fun. More often than not it tends to be a pouch whose leak does not show up until you have spent time and effort to get it installed and the contents have soiled your clothing.

When possible, change your appliance and save the defective product. Using a felt-tip pen, mark the area where the problem is (clean the pouch of course first); use circles, arrows, etc. to mark the problem area. Put the clean item in a plastic zip-lock bag, attach a note explaining the problem, and mail it directly to the manufacturer. (Postal Authorities will be most appreciative if you emptied the pouch before mailing, no matter how much you'd like to "get even" with the manufacturer, also the postage will be less.)

It is normally not a good idea to return a defective product to the place where you bought it. The vendor may not welcome you with open arms--he has better things to do--and may find it cheaper to just throw the item away or keep it on the shelf for months until enough items have accumulated to make a return shipment to the manufacturer cost effective. In the meantime, the manufacturer may continue sending out defective items without knowing it. For speedy action and to help prevent other ostomates from running into the same problem in the future, you're better off going to the manufacturer directly. Remember, most manufacturers want to know if there is a problem with a particular product.

Drugs For the Indigent

from South Brevard (FL) Ostomy Newsletter

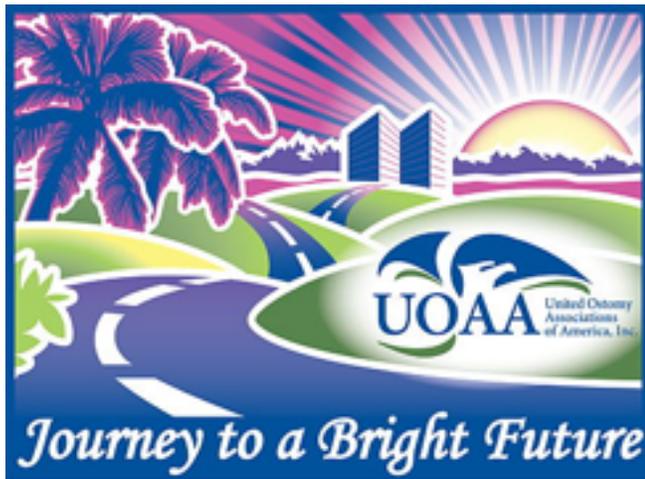
A relatively little-known program of the pharmaceutical industry will provide certain drugs at little or no cost to patients who are without insurance and/or have little disposable income. Participating manufacturers include such firms as Abbott Laboratories; Amgen Inc; Bayer; Bristol-Myers Squibb; Ciba; DuPont; Glaxo Wellcome; Eli Lilly; Merck; Pfizer and many other well-known names.

The procedure to be followed is outlined in the Directory of Prescription Drug Patient Assistance Programs, obtainable

from the Pharmaceutical Research & Manufacturers of America, listing programs of individual manufacturers. In each case, the request must come through your attending physician, who should have a copy of the directory. If you require prescription drugs and find it impossible or difficult to pay for them, don't hesitate to broach the subject to your physician and ask for his or her help.

Physicians who do not have a copy of the program may obtain one from: PhRMA, 1100 Fifteenth Street, NW, Washington D.C. 20005.

The directory may also be viewed online or downloaded from <http://www.phrma.org/patients/>



6th National Conference

Tues.-Sat., Aug. 22-26, 2017, Hotel Irvine, Irvine, California



Keep a Clean Medicine Chest

via Rambling Rosebud; Green Bay (WI) News Review

It's a good idea to clean house in your medicine chest once a year, according to St. Luke's Pharmacy Director. Medicines that are outdated or deteriorated should be disposed of properly, which means flushing them down the toilet after they have been removed from their packaging.

1. Remove and throw away all medicines which have passed their expiration date. Some deteriorated medicines can be dangerous.
2. Throw away all leftover antibiotics. Generally speaking, there shouldn't be any leftover antibiotics because, in most cases, every bit should be taken as directed.
3. Throw away all aspirin which smells like vinegar.
4. Throw out any medicines you don't recognize and any that aren't clearly labeled.
5. Throw away eye drops which aren't clear and any creams which have discolored.
6. Throw out any drugs you haven't used in the past year unless they are for familiar, recurrent conditions. But if the expiration date has passed, throw them out anyway.

Medicines should be stored in a cool, dry, dark place and one that can be locked if there are small children in the house.

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