

The MailBag

**August 7-10, 2013
Fourth UOAA National
Conference
Jacksonville FL**

Jacksonville group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street.
Ocala support group 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).

Please take the time and visit UOAA Website <http://www.ostomy.org>.

**Welcome Ocala Support Group Members.
The Mailbag is now a joint effort of Jacksonville and Ocala Chapters.**



*Join Us in
Jacksonville*

2013 National Conference Info Blitz

Have you registered for our 2013 Conference yet? We hope that you have, because Jacksonville, Florida will be THE happening place in August.

Along with Basic Ostomy sessions from Dr. David Beck, Jacksonville has so much to offer! The riverfront is right outside the doorstep of the hotel. Just a short walk down Baseline Drive from the hotel, you can take the water taxi across the river to the Friendship Fountain, and the Museum of Science and History. Right next to the fountain, you will also find River City Brewing Company.

If you are an art aficionado, you can visit the Jacksonville Museum of Contemporary Art, which has one of the largest collections of modern and contemporary art in the Southeast.

Cummer Museum of Art & Gardens lies across the river from Downtown Jacksonville and houses over 5,000 works of art spanning more than 8,000 years

There will be so much to do and see in Jacksonville this August! Stay tuned for our next Blitz in just one week from now, where we will let you know all about the dining options in Jacksonville, and what's happening on the beaches and waterways.

To register for the 2013 National conference, go to http://www.ostomy.org/conference_2013.shtml

NOTE: Early registration begins on **August 6th**. We recommend you travel to Jacksonville Aug 6th. Conference events will begin the morning of **August 7th**. You must book your room with the hotel no later than **July 12th 2013** to receive the conference rate.

<http://www.ostomy.org>

1 (800) 826-0826

Jacksonville Contact Information:

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

patti@ostomymcp.com

The Jacksonville UOAA chapter meets the 3rd Sunday of each except when otherwise posted.

To help offset the mailing cost you may now receive the MailBag Newsletter via email.

Please contact:

Patti: patti@ostomymcp.com
(Newsletter will be in PDF format)

Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting June 16th

Ocala Contact Information

Lynn Parsons
(352)245-3114

www.ostomyocala.com

Ocala support group 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 9th

Visiting a Patient with a Temporary Ostomy - A Personal Reflection

from Regina (SK) Newsletter; via S Brevard (FL) Ostomy Newsletter

As a certified visitor with the local ostomy chapter, I have had many occasions over the years to visit patients who have just undergone surgery that left them with a temporary ostomy. Usually a temporary ostomy is done on an emergency basis, as the result of a blockage or obstruction in the colon. This may be the result of diverticulitis, colon cancer, inflammatory bowel disease or Crohn's disease, and the result is a temporary ostomy to allow the bowel to heal. The intent is to reconnect the bowel at a later time, and many patients are told by the attending physician to expect to have an ostomy for anywhere from three to nine months.

My first thought as I headed off to visit a patient with a temporary ostomy was that this would be a piece of cake, and the visit would involve lots of questions about management of the ostomy. I also figured that the patient would be greatly relieved knowing they would not have to deal with an ostomy on a permanent basis. Boy, was I wrong!

This particular patient was angry beyond all belief, upset with what had happened to her and definitely not prepared to deal with anything as disfiguring as a colostomy. To be sure, she wasn't angry with me, but the medical profession as a whole suffered her wrath and it was quite evident that the nursing staff gave her a wide berth. She was NOT going to like this ostomy thing! Not having encountered this kind of reaction before, I wasn't exactly sure how to proceed, but I found myself listening to her frustrations and empathizing with her situation. This calmed her somewhat and she told me that I was the first person who had not treated lightly her fears about the ostomy. She felt people did not take her seriously because hers was only a temporary situation.

The visit actually went fairly well after that and although she was still angry with many things, I left feeling that she would manage her colostomy quite well in the short period of time she would have it. It impressed upon me that people with temporary ostomies struggle with the same fears and anxieties that all of us who have permanent ostomies do. In addition to this, because the surgery is done on an emergency basis, they have absolutely no time to prepare themselves for the eventual outcome, the ostomy.

Do I sound like an all-knowing and understanding saint?? Well, I don't feel like one on some of these visits. In general, I find most persons who have just had surgery resulting in a temporary ostomy to be very upset and unusually angry. They just hadn't expected this! I am sympathetic, as mentioned before, but the thought also crosses my mind, "Deal with it!" Recently, I paid a visit to a woman who, after her emergency surgery, asked me how I could tolerate having a permanent ostomy! At that moment it seemed bizarre that I should be counseling her when I am the one who has to live with this thing on a full-time basis. She could look forward to a reversal. On the other hand, hard as it may sound, her comment actually helped me and I didn't have to hesitate a second for the answer. I know I cope with it because I wouldn't be here if it weren't for my surgery for colorectal cancer. I was 37 at the time and I suppose I had every reason to be angry but I wanted so desperately to live. The surgery and colostomy gave me a second chance at life, for which I am grateful.

I would like to be able to remind some of the people who have to live with temporary ostomies that their surgery likely saved their lives too, and that a few months is really not such a long time to live with an ostomy. But I also have to remember how very frightening this surgery is and how it is still considered such an awful thing to have an ostomy. Despite our attempts to educate the public about the normal lives we lead, who among us wouldn't choose not to have an ostomy? So I internalize my thoughts and sympathize and try to make the patient feel better about coping with their new situation. But a question still lingers: Why do some people marvel at their good fortune while others retreat into anger and disgust? We humans are a complex lot.

OSTOMY OUTPUT

via NV Town Karaya; and Green Bay (WI) News Review

What to do if your ostomy output becomes thin, watery, or greatly increases in volume:

- Never limit your fluid intake in order to thicken the drainage, since this can lead to dehydration.

- Avoid food which you know from experience makes drainage too loose and too frequent.
- Begin a low-residue diet, avoiding especially green beans, broccoli, spinach, highly spiced foods, raw fruits and beer.
- Add strained bananas, applesauce, boiled rice, tapioca, boiled milk and peanut butter to your diet. Pretzels help in thickening and add bulk to the drainage. The salt, also, helps to stimulate thirst.
- Many people lack an enzyme which is responsible for the metabolism of milk sugar (lactose). This condition can cause diarrhea, gas, bloating, nausea and cramping. The elimination of milk products may cause a dramatic improvement in the symptoms.

What to do if your ostomy output becomes thick, or if you develop constipation:

- Increase your fluid consumption, especially fruit juices.
- Increase the amount of cooked fruits and vegetables you are consuming.
- Very few foods need to be omitted from your diet because of fear of food blockage. Perhaps more important than the food in avoiding blockages is chewing well. You can reduce your intake of foods which are very high in fiber, and foods with seeds that are hard to digest if they appear to be a problem. Examples are Chinese vegetables, raw onions, nuts, pineapples, corn-on-the-cob, raw carrots, raisins, celery, mushrooms, popcorn, coconut macaroons and coleslaw.

Stomal Complications

by Gloria Johnson, RN, ET, Charlotte, NC; via Metro Maryland

Complications related to the stoma may range from a minor inconvenience to a surgical emergency. Many problems can be prevented if the stoma is correctly constructed and properly placed, which involves a combination of the skills of the surgeon and ET nurse. First will be a description of the normal stoma followed by possible stomal complications. Keep in mind that all changes in your stoma should be reported to your physician or ET nurse.

Normal: Red or pink, moist appearance. Slight bleeding is normal with cleansing. Swelling should decrease over a period of 6-8 weeks after surgery. Movement of the stoma is normal, and it may move in and out with changes in your position. Stomas are fairly hardy, but should be protected from physical blows, tight clothing, and rigid objects. The stoma has no feeling; therefore, it can be injured without pain. Always check your stoma with each pouch change, and report any change to your physician or ET nurse.

Change in Color (Ischemia/Necrosis): Caused by an inadequate blood supply to the stoma. Sometimes a stoma will "pink up" as swelling decreases. If the stoma continues to darken--turns dusky blue, dark brown or black, you should report this to your physician immediately. If the stoma does not improve, surgical revision may be needed.

Disappearing Stoma (Retraction): This is when the stoma pulls back into the abdomen which can be caused by scarring, adhesion or weight gain. Treatment may be the use of an appliance with convexity, topical products or surgical revision.

Protruding Stoma (Prolapse): This is caused by weak abdominal muscles, and the bowel appears to hang out of the abdomen. Sometimes pushing the stoma back in (by someone trained) followed by use of a binder will help. Surgical revision may be needed as the stoma may lose blood supply or stop functioning.

Bulging Around Stoma (Herniation): This is caused by protrusion of the bowel around the stoma. It is most noticed when sitting or standing. It is associated with weak muscles or obesity. Treatment may be weight control, increase of exercise slowly, exercises to strengthen abdominal muscles, supportive binder or surgical revision.

Narrowing of the Stoma (Stenosis/Stricture): This can be caused by repeated dilatations (opening the stoma with a finger), alkaline urine causing a warty growth, repeated skin breakdown resulting in scarring or a disease process. Surgical revision may be needed if narrowing is severe. If recommended, dilatations should be done correctly and gently. An ET nurse should be consulted for recommendation regarding alkaline urine, a properly fitting appliance, or products that prevent skin damage.



“Gutsy’s Gab:” “Speak Out and Be Heard”

By Linda Blumberg AKA “Mrs. Lips

May 2013: all about remembering: mom and prom, discarded fighters and backyard biters...at our May 19 Jax ASG meeting, we saw ostomate/spouse friends, old and new, including a very newbie, full of wonder and blunder about her colostomy, hoping this was a rehearsal for its reversal(!)...“Gutsy,” Linda’s ileostomy stoma visited with “Pepe,” and “Oscar the Pouch,” whose host, Jim Mc is quite debonair, seemingly devil-may-care, with a signing flair, who loves to share!...We discussed the Volunteer Planning meeting attended on May 18 by Patti, Kimberly, Joe, and Linda, of Jax ASG, et al, at the Hyatt Regency in Jax, site for August 7-10, 2013 UOAA Conference: “Bridge to Acceptance.”...Still looking for VOLUNTEERS!...Hmm; it’s almost June...and we plan to bug you...about it!

SPOTLIGHT ON: June 2013: warmer temps, summer vacation, Flag Day (14th), Father’s Day (16th)...Yes, summer’s coming and temps are warmer and people are warming up to temp-tations...shedding clothes/inhibitions...Still too “inhibited” to “shed” your fear of having life-saving colonoscopy?...Continuing to “flag” your responsibilities to check for blood in stool/urine?...School’s out (until August in Jax)...kids, teachers/this “Speaker” (“Mrs. Lips”)...all free!!!...But, education doesn’t stop just because you’re on summer vacation! Many will travel on highways and byways...By the way, you don’t have to “travel” any further than the “information highway” AKA Internet to learn about colonoscopy and ostomy!...Don’t remain “dumber” and have your summer be a bummer!: as Gutsy says: “Knowledge is Power!”...OK, not so original...But, it helped Linda to have life-saving/affirming ileostomy surgery (or your colostomy or urostomy)...the “Best Decision She NEVER Made!”...Gutsy was born because LINDA IS A SURVIVOR!...and, she owes that to her father, Harry!...not the TV show (hahaha)...Father’s Day!...The day we honor Daddy...first man in a little girl’s life...Harry lived a long, albeit arduous life, the penultimate survivor of unimaginable adversity...he instilled honesty, integrity, and perseverance in his children...Linda misses him dearly!...Don’t let your dad have to miss YOU...instead of giving him the proverbial tie, be vigilant, and follow through with colonoscopy/ostomy surgery...so you might LIVE to give him grandchildren...the ultimate gift!

BOTTOMLINE/MARK YOUR CALENDAR: Speaking of Father’s Day...our next Jax ASG meeting is Sunday, June 16, 2013 (AKA Father’s Day!)...Planning more discussion about “Bridge to Acceptance”...especially seeking volunteers for the Conference. Gutsy reiterates the importance of “bridging the gap between ostomy awareness and acceptance!”...Great opportunity to make your Dad proud: your dedication and edification about all things ostomy at the Conference, will help bridge the generation gap between past ignorance/denial, present awareness, and hopefully, future acceptance(!)...which would ultimately save and improve lives...including yours...and, as a bonu\$, volunteering helps you get partial/total \$ reimbursement of entry fee!...Remember, too, that you can Share Your Stoma’s Name, like “Gutsy,” “Pepe,” “Squirty,” “Herbe Hind,” “Oscar the Pouch,” and, now, Garnet of MI adds: “Shorty2”...via email: Patti@ostomymcp.com, or Linda: blumbergl@duvalschools.org... for inclusion in future “Gutsy’s Gab” column...You don’t have to be a father to come CELEBRATE BEING ALIVE with ostomate friends/spouses!...Come “Just because it’s ‘June, June, June!’”

JOIN US IN JACKSONVILLE IN 2013
Fourth UOAA National Conference
August 7-10, 2013
Hyatt Regency, Jacksonville Riverfront



Welcome to the history and charm of downtown Jacksonville, situated on a four-mile riverfront boardwalk close to area attractions in the center of Florida life. Plan to arrive by **Tuesday, August 6**. Registration begins at noon on Tuesday, August 6. Programming begins Wednesday morning August 7 and continues through Saturday, August 10. Come and see what the [Jacksonville area has to offer](#) and join us as we build the "Bridge To Acceptance!"

Featured events include:

- **7th** – 1st Timers Orientation and Reception
- **7th** – 1st Night Ceremonies and Welcoming Ice Cream Social; Guest Speaker Brenda Elsagher
- **7th thru 9th** – Stoma Clinic
- **7th thru 10th** – Educational Workshops of special interest to: All attendees; 30+; Young Adults; those with Continent Diversions; Gay and Lesbian ostomates; Affiliated Support Group leaders
- **8th** – Basic ileostomy, colostomy and urostomy panel
- **8th & 9th** – Exhibition Hall on Thursday (8th) & Friday (9th) with breakfast in the Hall on the 9th
- **9th** – Brenda Elsagher, "It's in the Bag and Under the Covers"
- **10th** – Closing Ceremonies and Awards "Bridge to Acceptance"
- **10th** – Closing Banquet with Entertainment

Registration: [Register online](#) now, or [print form](#) and mail to UOAA office. Costs are:

- **\$125** individual
- **\$75** spouse/companion
- **\$25** children 5-17 and children under 5 free
- **\$50** Saturday night Banquet Only

Hotel:

- **\$99** per night, plus tax (rate guaranteed only until July 12, 2013)
- Special rate includes 3 shoulder days on each side. [Reserve your room now](#) or call 888.421.1442
- Mention "**United Ostomy Associations of America**"

Parking: **\$10** for self park and **\$20** for valet

Airport Transportation:

- Taxi Cab flat rate \$29.00 – Checker Cab provides service in the baggage claim area of Jacksonville International Airport (904.493.5229)
- [GO Shuttle](#)
- [SuperShuttle](#)

Walk to nearby restaurants & shops, many of them at [Jacksonville Landing](#), a short distance west of the hotel, or travel across the St. Johns River by [Water Taxi](#) to experience area nightlife.

We will continue to post more information here, such as the C.A.R.E.S. Program. If you have any questions, contact the office at **800.826.0826**.

Use this form to join our chapter! You do not have to be an ostomate to be a member and/or support the work of UOA. All information on this form will be kept confidential.

Name _____

Address _____

City _____ State _____ Zip _____

Phone# Home _____ Work# _____

Email Address _____

Type of intestinal or urinary diversion: Colostomy __, Ileostomy __, Urostomy __, Ileoanal Pull-thru __
Continent Ileostomy __, Continent Urostomy __, None __, Other __

You may use my name in chapter Newsletter & Directory: Yes __ No __

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