

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.**



"Gutsy's Gab:" "Speak Out and Be Heard"

By Linda Blumberg AKA "Mrs. Lips"

April 2013: all about *taxes, fools, and showers...* at our April 21 Jax ASG meeting, we has a large lovely group of returning reliable ostomates/spouses, including "Gutsy,"

Linda's ileostomy stoma, "Pepe," and a couple of newbies, who shared how *taxing* adjustment to ostomy can be, having been *fooled* into believing it couldn't happen to them...blindsided by (emergency) ostomy surgery. We discussed upcoming UOAA Conference August 7-10, 2013 in Jax, aptly named "Bridge to Acceptance." We are looking for volunteers..."MAY"-be YOU?!

SPOTLIGHT ON: May 2013: May Day, Cinco de Mayo, Mother's Day, prom, Memorial Day—Celebrations: Mexican fiestas, HS dances, Mom, and remembering the dear departed..."May"-be: figures *prominently*, with *promises...* to take care of our loved ones...should include us...but more often neglecting ourselves!...No surprise! That's what Moms do! "Mrs. Lips," Linda's professional alter ego learned long ago, "Don't give 'lip' to Mom!"...yeah, well, Gutsy opens her mouth as only a stoma will and says: "Don't give lip service to saying you will have that life-saving colonoscopy...but keep putting-it-off because it is off-putting?"...So what?!...You drink the crap and crap A LOT. That's the worst of it...Really!...Linda wishes her beloved Mom, Esther, had been more aware and less self-sacrificing. It may have made a difference. She died in April, just over 24 years ago of colon cancer, which *prompted* Linda to be tested, that led to her Crohn's Colitis, and ileostomy surgery. Linda was born to Esther; Gutsy is borne by Linda! Who ever heard of ostomy back then? It was shrouded in secrecy...alas, it STILL is!!!!...Awareness: Ironic that May ends with Memorial Day...why?...Gutsy says that if you aren't AWARE about checking for blood in stool/urine, and ACCEPTING to have life-saving/affirming ostomy surgery if needed, YOU COULD DIE - YOUR Memorial Day! So, all you daughters, sisters, wives, and friends, do yourself and your loved ones a favor: Give the best Mother's Day gift possible: a life-saving

Jacksonville Contact Information:

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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)

Jacksonville support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street
Next Meeting May 19th

Ocala Contact Information

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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 May 12th

colonoscopy even to your mother-in-law (hahaha). Make Mother's Day memorable...not "Memorial-ABLE"

BOTTOMLINE/MARK YOUR CALENDAR: Awareness and Acceptance...we'll be speaking more about "Bridge to Acceptance" at our first planning meeting, Saturday, May 18, 2013, at 1 p.m. at Hyatt Regency in Jax, and at our next Jax ASG meeting, Sunday, May 19, 2013!...Gutsy is excited! She reiterates that we all need to bridge the gap between ostomy awareness and acceptance! What a wonderful opportunity to gain insight into ostomy at this Conference. There is an entry fee...but it is (part/totally) reimbursable if you VOLUNTEER!!!...Okay...but, what about ignorance or blatant disregard that keeps ostomy hidden?...and not just with beautiful pouch covers like Gutsy wears from Koolostomy.com!...think about the fact that the medical community, even those with daytime TV shows, is NOT doing ANYTHING to remove the stigma that keeps ostomy shrouded in secrecy!...We'll be discussing all of that, and more. Remember that you can share your stoma's name, like "Gutsy," "Pepe," "Squirty," "HerbeHind," etc. by email to Linda: blumbergl@duvalschools.org, or patti@ostomymcp.com... For inclusion in future "Gutsy's Gab" column...Come CELEBRATE BEING ALIVE with a great group of guys and gals, of all ages, and all backgrounds!...MAY-be we'll see YOU there?

CONTINUE YOUR SOCIAL LIFE WITH AN OSTOMY via Green Bay, WI, The Pouch, N. VA & GB News Review

Your social life can be as active as it was before surgery. restroom after eating, and nobody will think it is unusual if You can enjoy all activities: meeting people, attending concerts, sporting events, civic and social club meetings, parties, religious occasions, or whatever you enjoyed before. The first time you go out of the house after surgery, you may feel as if everyone is staring at your appliance, even though it is not visible under your clothing. You can feel your appliance on your body, but no one can see it. Keep these questions in mind: Did you know what an ostomy was or where a stoma was located or what it looked like before you had surgery?

For those with colostomies or ileostomies, you may also worry about your pouch filling with gas and sticking out under your clothing. A quick trip to the restroom can take care of this problem. If you are worried about your pouch filling up immediately after eating at a social event, remember that people without ostomies often need to go to the restroom after eating, and nobody will think it unusual if you do the same! You probably will find that you need to empty your pouch less often than you need to urinate.

You may be wondering about your relationships with others. Now that you have an ostomy, you may feel that it will change your present relationships and decrease new opportunities for friendship and love. True friendships and deep relationships on any level are built on trust and mutual understanding. These qualities depend on you and other persons. You have the same qualities you had before surgery, and your ability to develop friendships is unchanged. If you care about yourself, others will feel your strength and will not be deterred. If your ostomy does cause a break in friendship, a relationship, or even a marriage, this relationship was not built on trust and mutual respect, and would have crumbled some time in the future anyway.

Keeping Your Pouch Odor Proof

by Victor Alterescu, RNET; via Quad City (IL) Newsletter and S. Brevard (FL) Newsletter

Rinsing a pouch out each time it is emptied is primarily a waste of time. For one thing, it takes longer to empty the pouch and you need more materials around you. You also leave more odor in the room since the pouch is kept open longer. The water, especially if it is warm, may open the pores of the pouch material and encourage odor permeation. Also, rinsing can affect the seal of your adhesive.

Rinsing a pouch after each emptying serves only an aesthetic purpose; the interior of the pouch may be clean but it does not serve a functional purpose. Frankly, it does not matter whether the interior of your pouch is clean any more than it matters if the interior of your colon is clean. The pouch is replacing an organ of storage, the colon and/or rectum.

The most important portion of the pouch that should be cleansed very thoroughly is the tip of the drainable pouch.

Rinsing the interior can only increase permeation but cleaning the exterior neck will avoid any odor that may be present as a result of having fecal residue on the end of the

pouch. Therefore, I often recommend that a person carry an alcohol wipe (individually wrapped in foil) to clean the tip of the pouch. The pouch is emptied, the toilet flushed immediately, and the lower portion of the exterior pouch cleansed with toilet tissue and alcohol.

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.

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.

- Remove and throw away all medicines which have passed their expiration date. Some deteriorated medicines can be dangerous.
- 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.
- Throw away all aspirin which smells like vinegar.
- Throw out any medicines you don't recognize and any that aren't clearly labeled.
- Throw away eye drops which aren't clear and any creams which have discolored.
- 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.

Hernia and the Ostomate

by Jill Conwell, RNET, Corpus Christi; via Winnipeg (MB) Online Inside-Out

If you've noticed an unusual bulge around or under your stoma, you may have a hernia. A hernia, essentially, is a separation in the muscle through which the bowel was brought when the stoma was created. This separation allows a loop of bowel to slip into the area next to the stoma and puts pressure on the abdominal wall, causing a bulge that can be relatively small, or about the size of a grapefruit or larger.

Why do hernias occur? Usually they form after a person has done heavy lifting or straining, thus putting pressure on the abdominal muscles. Other causes could be coughing excessively without supporting the abdomen, or a weakened abdominal muscle due to previous surgeries. The hernia is not usually repaired unless there are problems resulting from the hernia. The surgeon can either repair the hernia and leave the stoma in the same location, or if the hernia is excessively large, the surgeon may decide to relocate it. In either case, it would be wise to use a support belt to prevent a hernia from reforming.

Another problem with a hernia, especially with colostomates who irrigate, is that the irrigation does not work as well as it used to. It may take longer to run the water in, or maybe it does not enter at all. If you use a catheter, be very careful

not to push it too hard if it does not slide in easily. It is probably up against the bowel wall and cannot turn sharply to accommodate the new route of the bowel, and you could perforate the bowel wall. A cone is better to use; however, the sharp curve of the bowel may not allow the water to flow in easily. Sometimes pressing the area around the stoma may open up the kinked area to allow the water to flow. I would recommend holding off on the irrigation procedure and trying to control the colostomy by diet.

There are support belts that are available for ostomates to wear. They are made to accommodate the pouch through a front opening, and they usually have a Velcro closing. They are available in several widths. It is important for all ostomates to be careful in lifting or straining post-operatively, as well as years later. There is always the potential for a hernia to occur due to the opening made in the abdominal muscle for the creation of the stoma. This does not mean that every ostomate should wear a support belt. Just remember that if you lift anything heavier than 5 kg (10 pounds), be sure to use the proper techniques. Use your upper thigh muscles instead of your abdominal muscle. Common sense goes a long way.

Safe Travel Tips

by Joseph Rundle, Aurora (IL) Ostomy Group; via Metro Maryland

With the terrorist alert on high and many concerned about safe travel at this difficult time, I thought I would offer you some useful tips:

- Do not ride in an automobile. Autos cause 20% of all fatal accidents.
- Do not stay at home. That is where 17% of all accidents occur.
- Do not walk across the street. Pedestrians are victims of over 14% of all accidents.
- Do not travel by air, rail or water. People have 16% of all accidental deaths because of these activities.

However, only 0.0001% of all fatal accidents occur at our local ostomy support association's meetings. Moreover, virtually none of these happen during the business meetings. Obviously, the safest place to be is at your local ostomy association meeting. You'd better go to the next one, just to play it safe.

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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