

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!"

April 2013 issue MailBag-Jax, FL

By Linda Blumberg AKA "Mrs. Lips"

March 2013: all about the "green"...at our March 17 Jax ASG meeting..."lucky" gathering on St. Patrick's Day: nurse discussed Medicare Fraud, false/misleading media ads, "Obamacare" and its suspected effect on ostomy (supply) coverage. Gutsy turned "green" (sick)...not easy for a red stoma(!)...that more of Linda's "green" (\$) would likely come out of her pocket for fewer supplies...Just our luck!...Marvelous munching on green goodies...Determinedly discussed upcoming UOAA conference August 7-10, 2013 in Jax, aptly named "Bridge to Acceptance." "Gutsy," Linda's ileostomy stoma voluntarily accepted to drive across the bridge to the Hyatt Regency to offer Linda and hubby Bruce's ("Gusty") assistance!

SPOTLIGHT ON: April 2013: April Fool's Day, tax time...Linda feels like an "April Fool" and apologizes to Gutsy's readership who must be "hopping mad" that she forgot to include Easter in her March column!...Forgive her!...We all forget as we get older...Did YOU forget to have a life-saving colonoscopy in March during Colorectal Cancer Awareness Month?...Don't fool yourself into thinking "it can't happen to me!"...because it can...and it is only too late to have this test...if you die prematurely because you thought it too "icky"...or conveniently "forgot"...don't be an April Fool...or any other month, either!...

April 15...Taxes are due!!...Everyday life is taxing enough without ignoring changes in bowel/bladder habits...Gutsy says, "File your taxes instead of your nails!" (hahaha)...get early return on your investment...maybe a nice check!...so, too with checking for blood in stool/urine...get life-saving/affirming ileostomy, colostomy, or urostomy surgery, if needed...affords you an extension on your life!...

BOTTOM LINE/MARK YOUR CALENDAR: We'll be speaking more about "Bridge to Acceptance" at our next JAX ASG meeting Sunday, April 21, 2013! Bridge the gap between ostomy awareness and acceptance! A great way to accept your ostomy is to NAME YOUR STOMA as Linda did "Gutsy"...who previously mentioned "BOB," "Pepe Le Pew," and "Squirty"...Now, Gutsy has a new friend: "Salty Sue" who named her stoma

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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)

Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting April 21st

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 April 14th

“Herbe Hind” alluding to the “trouble men cause”...Gutsy encourages YOU to share YOUR stoma’s name!...email : Patti@ostomymcp or Linda: blumbergl@duvalschools.org... Join us to meet other stomas!...and their ostomate hosts/ hostesses/spouses...It’s Spring!...If you cannot have “April in Paris,”...unless you live in TX or SC(!)...don’t let those “April Showers” dampen your spirits!... PAT yourself on the back that YOU ACCEPT YOUR OSTOMY as a BOONE to CELEBRATE BEING ALIVE(!)...and feel the “April Love” with us!...See YOU there!!

Proper Care & Storage of Ostomy Supplies

from an article by Teresa Murphy-Stowers, Fort Worth, TX; via Dallas (TX) Ostomatic News

Ostomy supplies are not inexpensive, to say the least. So, it is important to understand how to apply them properly with the fewest errors possible and equally important to know how to take care of and store supplies until use. Proper care may avert the need to discard unused supplies and thus be as economical as possible.

- Be sure to read carefully the instruction sheet included in the box or guidelines on the container for specific recommendations for a given product.
- Generally, all ostomy supplies should be stored in a cool, dry location. Too much heat can melt or weaken many of the materials used in ostomy wafers, pouches, and accessory items. Avoid leaving supplies in a hot car or in direct sunlight.
- Review instructions periodically to refresh your memory and to see if any recommendations have changed over time.
- Keep supplies such as wafers and pouches in their original box. By doing so, you save the brand name, product identification number, and the lot and date information for those items. Perhaps you will never need this information, but in the event you do, the box you have saved will provide the information you (or someone helping you) will need for reorder or to report any quality control problems.
- Some ostomy supplies do have a “shelf life.” Be sure to check for dates that may be recorded on their containers. If you find you have a box with an expired date, check with the manufacturer, your local supplier, or an Ostomy nurse for advice on usage.
- While you do want to keep a “stock” of supplies so you are always prepared to change out your system, avoid the practice of stockpiling too much so your reserve will be as fresh as possible. This, of course, depends on factors such as the availability, proximity to a local supply house, or shipping issues.

- Purchase supplies from a trusted vendor—one you know will provide good service as well as stock/ship current stock.

Reporting Defective supplies

- If you determine your supplies are defective in spite of proper use and storage, contact the manufacturer at their toll free number to report the problem and receive product replacement or adjustment.
- Let your supply source know of your report to the manufacturer. They need to be aware of problems; however, the complaint needs to be directed to the manufacturer to ensure the defect can be addressed.

Hospitalization Guidelines for Ostomy Patients

by Dr. Lindsay Bard; via Chicago (IL) The New Outlook; and Hartford (CT) The Hartford Ostomy Update

It is important for a person with an ostomy to know how he/she should be handled differently than someone without an ostomy when you need to be hospitalized. It’s up to you. It is very important to communicate to medical personnel who take care of you, including every physician that treats you, that you have an ostomy, and what type of ostomy you have. Here are some rules to help you cover the details:

Rule 1 – The Cardinal Rule!

If you feel something is being done or going to be done to you that might be harmful, refuse the procedure. Then explain why to the medical personnel, especially your physician. They will then decide with you if the procedure will actually be in your best interests.

Rule 2 – Supplies

Bring your own supplies to the hospital. Never assume the hospital will have the exact pouching system or irrigation system you use. Most hospitals have some supplies available. These are used for emergency situations.

Rule 3 – Laxatives & Irrigations

Follow the points below concerning laxatives or irrigation practices, according to which type of ostomy you have. Medical personnel often assume all stomas are colostomies. But, of course, practices vary among the various types of ostomies.

- A transverse colostomy cannot be managed by daily irrigations. The only colostomy that can be managed by irrigations is the descending or sigmoid colostomy. However, sigmoid or low colostomies do not have to be irrigated in order for them to function; many people with sigmoid colostomies prefer letting the stoma work as nature dictates. If you do not irrigate your colostomy, let the fact be known to your caregivers. If your

physician orders your bowel cleared, irrigate your own colostomy; do not rely on others. There is a strong possibility that those caring for you will not know how to irrigate your colostomy.

- Bring your own irrigation set to the hospital.
- If you have an ileostomy or urinary diversion ostomy, never allow a stomal irrigation as a surgical or x-ray preparation. Remember that laxatives or cathartics by mouth can be troublesome for people with colostomies. For people with ileostomies, they can be disastrous—people with ileostomies should always refuse them. A person with an ileostomy will have diarrhea, may become dehydrated and go into electrolyte imbalance. The only prep needed is to stop eating and drinking by midnight the night before surgery. An IV should be started the night before surgery to prevent dehydration.

Rule 4 – X-rays

X-rays present special problems for people with ostomies, again, differently managed according to ostomy type:

- A person with a colostomy must never allow radiology technicians to introduce barium into your stoma with a rectal tube. It is too large and rigid. Take your irrigation set with you to x-ray and explain to the technicians that a soft rubber or plastic catheter F#26 or 28 should be used to enter the stoma. Put a transparent pouch on before going to x-ray. Have the technician or yourself place the rubber or plastic catheter into your stoma through the clear plastic pouch. When enough barium is in your large bowel for the x-ray, the rubber or plastic catheter can be withdrawn and the open end of the pouch closed. The pouch will then collect the barium as it is expelled and can be emptied neatly after the procedure. Once the x-rays are completed, irrigate normally to clean the remaining barium from your colon. This will prevent having to take laxatives by mouth after the procedure.

- A person with an ileostomy may drink barium for an x-ray procedure, but never allow anyone to put barium into your stoma.

- A person with a urostomy can have normal GI x-rays without any problems. Never allow anyone to put barium in your stoma. At times, dye may be injected through a soft plastic catheter into a urostomy for retrograde ureter and renal studies, often called an ileo-loop study. The same study may be performed on a urostomy patient with a Kock pouch. The dye will be injected via a large syringe; this can be a very painful procedure if the dye is not injected very slowly. Even 50 mL will create a great deal of pressure in the ureters and kidneys, if injected rapidly. Remember to request that the injection be done slowly.

- For anyone who wears a two-piece pouching system: you may remove the pouch just prior to the insertion of the catheter, and replace the pouch after the procedure is completed. If you wear a one-piece pouching system, bring another with you to the x-ray department to replace the one removed for the procedure. In the

event you are incapacitated, and cannot use your hands to replace your pouching system, request that a WOC nurse in the hospital be available to assist you. The WOC nurse will be able to replace the skin barrier and pouch for you before you leave the x-ray department.

Rule 5 – Instructions

Bring with you to the hospital two copies of instructions for changing your pouching system and/or irrigating your colostomy. Provide one to your nurse for your chart and keep one with your supplies at bedside. If you bring supplies that are not disposable, mark them “do not discard.” Otherwise, you may lose them.

Rule 6 – Communicate!

Again, let me stress that you must communicate with the hospital personnel who take care of you. You will have a better hospital stay, and they will have an easier time treating you.

The nerve(s) of those stomas!

posted by user “Mike ET” on the UOAA Discussion Board, May 11, 2009

The question or comment about stomas lacking sensory nerves, or the more broadly stated claim that stomas have no nerves, is a myth that dies very hard. Allow me to borrow from one of my presentations that partly addresses this issue:

“...most of the information carried by gastrointestinal primary afferent neurons is not consciously perceived. This is nicely demonstrated by tests on fistula patients who report no sensation when the healthy stomach is probed or in patients that have had the intestinal lining cut to take a biopsy.” quoted from: *Am J Physiol Gastrointest Liver Physiol* 277:922-928, 1999. John B. Furness, Wolfgang A. A. Kunze and Nadine Clerc. page G924.

Additionally, we have: “There are more than 100 million nerve cells in the human small intestine, a number roughly equal to the number of nerve cells in the spinal cord. Add in the nerve cells of the esophagus, stomach, and large intestine and you find that we have more nerve cells in our bowel than in our spine. We have more nerve cells in our gut than in the entire remainder of our peripheral nervous system.” quoted from: *The Second Brain* by Michael Gershon, M.D. page Xiii.

Alas, stomas do have nerves!

So, now let us put to rest the misstatement about the bowel and nerves, and bother to reeducate those who have misspoken early on.

There are nerves; but the sensory nerves of the bowel between the esophagus and the rectum, for certain types of painful stimuli, such as cutting or cautery, are either very low in

number and caliber or the brain is not readily able to perceive the pain.

Of course, one can still be a pain in the a**; however, this is a topic for other times and places.

Editor's note: For some earlier articles we've published on this topic, see *Does Your Stoma Hurt?* by Victor Alterescu, which appeared in our January 1999 newsletter; and a reply by Mike ET (same author as the present article above) titled *Stomas and Pain Response*, that we printed in our February 1999 issue.

Ostomy Tips for the Pool Getting Into the Swim of Things

via Orange County (NY) Area Newsletter

Can I go swimming with an ostomy? The answer is a resounding "YES!!!" Swimming is an excellent exercise—an opportunity for a good cardiovascular workout without overly stressing your joints (like knees and hips) or your spine. The pool is a great place to work on those range-of-motion exercises, too. The water helps support you while you move. And water exercises can be done in the deep end or while sitting in the shallow end of the pool. Best of all, swimming is an activity you can enjoy with family and friends of all ages and abilities!

So why are so many of us afraid to get back into the water? Here are some of our issues and solutions: I'm afraid that my appliance will leak or come off while I'm in the pool. This is by far everyone's number one concern. The thing to remember is that your pouching system is designed to be leak-free and water-proof, and your wafer adhesive actually gets stronger in water. As long as your seal is strong and intact, strap on your swim fins and jump in. TIP #1: Don't go swimming right after you've put on a new wafer. TIP #2: Make sure your pouch is empty. TIP #3: Picture framing your wafer with water-proof tape isn't necessary but may give you the extra confidence you need. TIP #4: Avoid wearing pouches with filters into the pool. Water may get in through the filter.

I'm concerned that people will be able to see my pouching system under my bathing suit. A dark colored suit with a busy pattern will camouflage your appliance better than light colors like white or yellow, which can become almost transparent when wet. Note: your pouch will dry just as quickly as your suit will, so no need to worry about a tell-tale damp spot. TIP #1: For women, choose a suit with a small, well-placed ruffle or skirt. TIP #2: For men, choose a suit with a higher cut waist or longer leg. TIP #3: You may wish to wear a smaller, non-drainable pouch (those designed for intimate moments work well here, too!). TIP #4: If you have a colostomy and you irrigate, you may try wearing a stoma cap while you swim.

I'm embarrassed about changing into/out of my bathing suit in the locker room and people noticing my ostomy appliance. Some of us don't care who sees what, while others are more modest when it comes to who knows about our ostomies and pouching systems. If you're a little on the shy side, try to find a spot that's out of the way or less crowded. Don't let the possibility of

problems arising when changing prevent you from an enjoyable afternoon swim with family or friends. TIP #1: You may wish to change and towel off in a convenient bathroom stall. TIP #2: Put on a dry, oversized T-shirt as a cover-up while you change. TIP #3: A dry suit is easier to take off than a wet one. Relax by the side of the pool with a good book or a talkative friend before heading for the locker room. TIP #4: Wear your bathing suit under a jogging suit or sweat pants and don't worry about changing at all.

What about using the hot tub or Jacuzzi? Go ahead. Again, as long as your appliance seal is good and your pouch is empty you should have no problems with your ostomy.

General Tips:

Do some planning – you know your body better than anyone and how long after eating your ostomy starts to work. Try to arrange your swimming for a time when your output will be minimal. If you are still concerned about entering the pool with your appliance, try this: put on your bathing suit, fill your bathtub with water and sit in it for half an hour. You'll feel more confident when you see there's no leakage. You'll also get to see what your suit (and your covered pouching system) look like wet.

A support garment or bike shorts under your suit or a snug, Lycra bathing suit can help to keep your pouching system in place and prevent your pouch and clip from migrating to the groin area. Some ostomates sew pockets into the inside of their suits as a way of providing additional pouch support, if needed. If you wear an ostomy belt, you should know that cloth belts stretch in the water – wear a rubber one if you want to wear a belt in the pool. Again, remember to get your doctor's okay before you take to the water or begin any exercise.

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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