

# The MailBag

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).  
 Amelia Island Area Ostomy Support Group meets last Monday of each month at 6:30pm - Bapt Medical Center Nassau board room.  
 Gainesville Support Group meets the 1st Sunday of each month (except Holidays)  
 Hope Lodge 2121 SW 16th St Gainesville

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Contact MCP (800) 741-0110 For More Info

Jacksonville Contact Information:  
 Patti Langenbach  
 (800) 741-0110  
 (904) 733-8500  
[patti@ostomymcp.com](mailto: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](mailto: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 Apr. 19th**

**Gainesville Support Group** meets the 1st Sunday of each month (except Holidays)  
 Next meeting: **Apr. 5th at 2pm** at Hope Lodge 2121 SW 16th St Gainesville, FL 32608  
**Contact info:**  
 Brinda Watson (352) 373-1266  
 Nelson Griffiths (352) 376-8703

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 Apr. 12th**  
**Contact info:**  
 Lynn Parsons (352) 245-3114  
[www.ostomyocala.com](http://www.ostomyocala.com)

**Amelia Island Area Ostomy Support Group** meets last Monday of each month at 6:30pm (except May, June, July & Aug) Bapt Medical Center Nassau board room.  
 Free parking (904) 310-9054  
**Next Meeting Mar. 30th**  
 Convatec Rep will be present

Upcoming Apr 27th  
 Patti Langenbach Speaking



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

By Linda Blumberg AKA “Mrs. Lips”

**March 2015:** all about *luck*. At our March 15 Jax ASG meeting, ostomates/family gathered, caring/sharing ostomy concerns/products/experiences, welcomed prebies/newbies as we CELEBRATED how LUCKY we are to be ALIVE and munched on Kimberly’s Konfections. “Gutsy,” Linda’s ileostomy stoma encouraged everyone to *march* right over to ConvaTec’s 24/7 inspirational/informational social media Inspire.com for issues and answers. Also for prebies poised to have ostomy surgery, newbies’ needs in recovery process, or anyone vested in virtual hugs, humor, and well-wishers. It’s almost April...time for “egg-ceptional egg-sperience” to learn to live well with an ostomy! (Or are you an April fool?!)

**SPOTLIGHT ON: April 2015:** April fool’s Day (1<sup>st</sup>), Passover/Good Friday (3<sup>rd</sup>), Easter Sunday (5<sup>th</sup>), Taxes Due (15<sup>th</sup>), Earth Day (22<sup>nd</sup>), and AAA (Awareness/Acceptance/Advocacy)

Awareness involves not being an “April fool:” 1) check for blood in stools/urine, 2) *hop* on over to have life-saving colonoscopy, with follow up life-affirming ileostomy, colostomy, or urostomy surgery, if needed. Don’t be *fooled* into thinking colorectal/bladder cancer can’t happen to you. As *taxing* as drinking the prep is, if you *pass-over* this responsibility, you could be plagued by early preventable death! *Dyeing* Easter eggs is preferential to *dying* from ignorance/blatant disregard! This surgery can give you an *extension* on your life!

Postsurgical Ostomy Acceptance occurs when we realize that even with a stoma; WE are still normal, beautiful, loveable people who can feel EMPOWERED to live well with an ostomy! STOMA ARRIVAL=YOUR SURVIVAL: the “egg-ceptional egg-sperience” allowing us to CELEBRATE BEING ALIVE! The *pay off?* Accept YOUR stoma, and nonostomates likely will, too! True ostomy acceptance is non-judgmental! (See Linda’s 1<sup>st</sup> Phoenix article/photo, June 2011, p.30).

Don’t *pass-over* the opportunity to Advocate for Ostomy (!): Gutsy saved Linda’s life; but, humor and a (com)passion for writing/others continue as her salvation! 1) Share YOUR ostomy journey: a) at support group meetings, b) on Inspire.com, c) by submitting your unique experiences/perceptive perspectives/humor, in writing, to this (or YOUR local) newsletter, or publications, e.g., Phoenix mag, and d) by educating general public to dispel their negative preconceived notions; 2) drive loved ones to and from colonoscopy while remaining loving and loyal if they have ostomy surgery; 3) Advocate for YOUR stoma: *show* them with “April Love” a) in a beautiful pouch cover from Koolostomy.com, b) Make your stoma a STAR!...email your stoma’s name: [Patti@ostomymcp.com](mailto:Patti@ostomymcp.com) or Linda: [blumbergl@duvalschools.org](mailto:blumbergl@duvalschools.org) for inclusion in future Gutsy’s Gab column...In April, Gutsy proudly welcomes the “egg-ceptional:” “THE DUDE” and “Homer” from Inspire.com. Both cathartic and fun! (See Linda’s 2<sup>nd</sup> Phoenix article/photo, December 2013, p. 78).

**BOTTOMLINE/MARK YOUR CALENDAR:** Our next Jax ASG meeting is Sunday, April 19, 2015. We hope you will join us and *hop* on over to Patti’s MCP store to CELEBRATE BEING ALIVE. For contagious camaraderie and to share how “egg-ceptional” and full life can be with an ostomy! Come to discuss ostomy concerns/“egg-speriences”, enjoy Kimberly’s Konfections and each other. We guarantee to bring you out of your *shell*! See YOU there!!



**Sept 1-6, 2015 • Fifth UOAA  
National Conference •  
St Louis MO**

**World Ostomy Day**  
Saturday October the 3rd 2015.  
The theme for WOD 2015 will be  
**“Many stories, one voice.”**

**Kim's version  
Garlic & Herb Cheese Spread  
Home Made Tortilla Chips**

Recipes served at Jacksonville Ostomy Support Group Meetings

Stuffed Strawberries

Ingredients:

- 1 Pkg fresh strawberries
- 1 Pkg cream cheese
- 1 Sm tub whipped cream
- 1 Orange zest (or orange flavoring to taste)
- Powder sugar if not sweet enough (to taste)

Directions:

- 1 Cut strawberries in half (from top to bottom) & core them
  - to make them rest flat on the plate, cut a small amount off the back
- 2 Mix rest of the ingredients until smooth and taste great - best to make the night before
- 3 Spoon mixture on strawberries & refrigerate before serving



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## **HELPFUL HINTS**

AICM-Montreal

**Posture Matters:** When you return from the hospital, you will be feeling sore and uncomfortable. You may be anxious about the front of your body getting bumped, or self-conscious about the stoma which can lead to a habit of hunching over to "guard" that area. Try to focus on keeping your head up and your back straight.

**Walking Works:** Don't lie or sit about all day. Walking helps restore lost muscle tone, gets your circulation going and just generally perks you up. Get up and walk several times a day.

**Stomahesive Paste:** If your stomahesive paste becomes hard and will not push through the end of the tube, head a glass of water filled half way in the microwave for 45 seconds. Remove and place the tube cap down in the water. Let stand for a few minutes and dry. You should now be able to push the past out easily.

**Vitamins:** Vitamins should be taken on a full stomach. Otherwise, they irritate the lining of the stomach and produce the sensation of feeling hungry.

**Diuretics:** Try strong-brewed tea before the purchase of a "diuretic". Hot tea twice a day will wake up your sluggish kidneys.

**Juice vs. Gatorade:** Tomato juice provides as much sodium and 5 times more potassium and is a low cost alternative to Gatorade. Orange juice is another alternative providing the same amount of sodium and 15 times the amount of potassium to Gatorade.

**For Colostomies:** If you use just a pad instead of an appliance, use a little K-Y Jelly over the stoma to keep things soft and lubricated. If you irrigate, allowing too much water to enter the stoma too quickly may cause a sudden evacuation of waste, leaving much of the feces still in the colon, along with most of the water. Periodic evacuation may follow. This is not diarrhea, but is simply a delayed emptying of the colon.

**For Ileostomies:** Usually ileostomates experience hunger more often than other people. When this happens, they should drink fruit juice or water, eat soda crackers followed by a meal as soon as possible. If you do need to eat a snack at bedtime or during the day in order to ward off nausea, try to cut down on calories somewhere else in the daytime or you will gain weight. Never skip meals in order to lose weight. An ileostomy keeps working whether the ostomate has eaten or not.

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## **Simple Yet Profound Words From a Five Year Old**

By Kathy Ward, Admin. Asst.-UOAA

When my granddaughter was five, she had many problems with her digestive system. Her surgeon placed a stoma over her stomach so that a feeding tube could be inserted.

One day, she looked at me and said, "Grandma, did you name your stoma?"

I replied, "Yes, I did. I call it Rose, because it looks like a flower to me. Did you name yours?"

"Yes," she said. "But I named mine Jack."

Thinking this was an odd name for a little girl to name her stoma, I had to ask, "Why did you name it Jack?"

Her response, "Because Jack is the name of the lifeguard at the beach and my stoma saved my life."

## Ostomy Procedures that Can Backfire

There are times when we think we're doing the right thing, but get ourselves into trouble. Here are some instances to think about:

- Alcohol: Alcohol is a powerful drying agent. Prolonged contact with the skin can have serious consequences.
- Clamp Usage: Wrapping the drainable pouch tail around and around the clamp before closing it. This will not make the clamp work any better. All it will do is spring the clamp out of shape, which will ensure that the clamp won't work for future application and it will make releasing excess gas more difficult
- Releasing Gas: Snapping the pouch off the face plate to expel gas. This doesn't do much for odor control! It's much better to hold the tail of the pouch beyond the clamp with a tissue, open the clamp and allow the gas out through the tissue with deodorant. Then use the tissue to clean out the end of the pouch and replace the clamp.
- Normal Wear Time: You shouldn't wear the appliance until it leaks. The object is to change the appliance before leakage occurs. This way, the skin gets the best protection and care. Three to five days is normal wear time.
- Some people report seven days, but manufacturers feel that this may be pushing their products to their limits.
- Washing Pouches: Washing pouches and using the same pouch for months will eventually saturate the plastic of the pouch with odor of the chemicals and no amount of washing will get rid of it. It is recommended that you throw the pouches away when you throw the face plate away.
- Experimenting With Appliances: Although it's fine to experiment with new appliances, especially if you're unhappy with your usual equipment, you'll generally get the best service from the equipment you have the most experience with.
- Ignoring Skin Problems: All skin problems are easier to manage if they are treated early.
- A Full Pouch: Letting your pouch get full before emptying it can separate a two-piece system. Try to empty your pouch when it's one-third to one-half full.
- Seat Belts: A well-placed and adjusted seat belt shouldn't interfere with stoma function or damage your stoma. True, in an accident your stoma may be damaged, but it's a lot easier to repair a stoma than a crushed skull.
- Wound Ostomy Nurse: It's not a good idea to try to live with a condition you can't correct yourself. When in doubt, see your friendly wound ostomy continence nurse (WOCN) or your doctor.

**Celebrate!**

*UOAA's 10th Anniversary at  
Our National Conference  
September 1-6, 2015  
in St. Louis, Missouri*

[http://www.ostomy.org/2015\\_National\\_Conference\\_Page.html](http://www.ostomy.org/2015_National_Conference_Page.html)

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To: