

The MailBag

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

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>.

JOIN US IN JACKSONVILLE IN AUGUST

Fourth UOAA National Conference
August 7-10, 2013
Hyatt Regency, Jacksonville Riverfront



Online registration available at www.uoaa.org.

The special hotel rate of \$99.00 is only good until July 12th.

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!"

WEDNESDAY August 7

- Yoga and Meditation Session
- Affiliated Support Group Leaders Session Part 1
- Welcome From Jacksonville Police and Convention Visitors Bureau
- Transportation Security Administration Meets the Otomate on Travel Issues
- 1st Timers Orientation
- 1st Timers Reception
- First Night Ceremonies
- Introduction of UOAA Management Board and Affiliated Support Group Advisory Board
- Brenda Elsagher Presentation
- Ice Cream Social sponsored by Hollister
- Youth Rally Video
- Top Reimbursement Issues Regarding Ostomy Supplies and Insurance 101
- Be Your Own Advocate
- Affiliated Support Group Leaders Session 2
- STOMA Clinic Opens at 100pm-500pm

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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 July 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 September 8th



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

By Linda Blumberg AKA “Mrs. Lips”

June 2013: Special events: dads and grads, blushing brides and rushing tides, ending of school, spending time at the pool...at our June 16 Jax ASG meeting, ostomate friends/spouses gathered...“Gutsy,” Linda’s ileostomy stoma was pleased to again visit with “Pepe”...but, she missed “Oscar the Pouch,” who was unable to attend due to a family emergency...We discussed the upcoming UOAA Conference: “Bridge to Acceptance,” to be held August 7-10, 2013 at Hyatt Regency in Jax, FL...But, this time, not just looking for volunteers: we completed UOAA survey of who is/isn’t yet registered and why(?)...to offset UOAA’s concern of fewer Floridian registrants than expected/projected...Patti suggested many are likely procrastinating...“Yeah,” admits Gutsy...like me(!)...guilty as charged...but, speaking of charge\$...on a deeper level...it comes down to ‘dollars and cent\$’...which makes a whole lot of \$en\$e!!”...

SPOTLIGHT ON: July 2013: Independence Day (4th), Bastille Day (14th)...summer vacation traveling around the nation, fun in the sun *activities* like swimming, tennis, golf, beach going...Temperatures rising...“80’s and 90’s”...wouldn’t YOU want to live into YOUR “80’s and 90’s?”...Fourth of July (Independence Day)...red, white, and blue...independence, freedom, patriotic parades, floats, and fireworks...time to go forth and check for that “red” blood in stool/urine...freedom to choose between having life-saving colonoscopy or risking cancer...or premature death...Gutsy reminds that you drink the prep, and crap an awful lot...and an awful lot of crap!!...your own personal “fireworks!” (hahaha)...easy for her to say never having had the procedure!...auugh!...as Linda winces in recall...who turned “white” as a sheet during the prep process(!)...But, like Linda, you parade yourself over to your white-coated GI Doc and float in twilight sleep...that’s independence!...that’s breaking free from the shackles of denial and ignorance!...and like the French (from Bastille Day) say: “C’est la vie!”...that’s life!...CHOOSE TO LIVE...and LOVE (yourself enough to make the commitment)!!!...even if you need ostomy surgery...which gave “life” (AKA “Chai”) to Gutsy!...then, you won’t be “blue”...because ostomates are “normal” people, too!...(see Linda’s article in June 2011 Phoenix magazine)...we are active in all the aforementioned fun summer activities!...THAT’S OUR INDEPENDENCE!!!!

BOTTOMLINE/MARK YOUR CALENDAR: Speaking of **CELEBRATING FREEDOM** and **CHOOSING TO LIVE:** our next Jax ASG meeting is Sunday, July 21, 2013...more discussion about “Bridge to Acceptance:” seeking volunteers, entry fees/reimbur\$ement requirements, # of registrants, and theories thereof...This Conference promises to “bridge the gap between ostomy awareness and acceptance...between ignorance/denial...a life-changing experience!...much like that life-saving colonoscopy/life-affirming ostomy surgery...it will be a wonderful way to quench your “thirst” for ostomy knowledge and satiate your “hunger” for meeting multitudes of new ostomy friends/making life-long connections...educational workshops, Jax area excursions, fun social activities...Gutsy is soooo excited!!...she’s a “first-timer” never having attended previously...and , as an added bonu\$, volunteering=total/partial reimbur\$ement of entry fee...a way to share...YOU can share YOUR STOMA’S NAME: “Gutsy” knows lots of stoked stomas(!): “Pepe,” “Squirty,” “Oscar the Pouch,” “Herbe Hind,” “Shorty2,” and “*#!”...from our favorite urostomate...so, how about YOU????...email: Patti@ostomymcp.com or Linda: blumbergl@duvalschools.org for inclusion in future “Gutsy’s Gab” column!...KNOWLEDGE IS FREEDOM and INDEPENDENCE!...feel “free” to exercise your “independence” and join us to CELEBRATE BEING ALIVE!...to enjoy our contagious camaraderie!...See YOU there!!!!

Adventures in Peru and Ecuador

By Debra Rooney, Vancouver Ostomy High Life

I have travelled much since colostomy surgery nine years ago but never anywhere as challenging as South America. I would not go so far as to say that South America is ostomy unfriendly, for it is not, but it is not a place that a person with an ostomy should take lightly if considering the kind of trip I took. Our itinerary included Machu Picchu in Peru, the cloud forests of Ecuador, the city of Quito and the amazing archipelago of Galapagos.

The **first thing** one learns, as any person with or without an ostomy does in such a country, is to have a bathroom map. Restaurants do not necessarily have bathrooms and those that do may frown on you asking to use the facilities if you are not eating or drinking there. Public restrooms, which are few and sometimes far between, not to mention difficult to locate for tourists with no guide or ability to speak Spanish, usually require the payment of a few coins to enter. These buy you the toilet and a small amount of weapons grade toilet paper.

Lesson One: Carry small coins, carry your own tissue and take note of anything that looks remotely like a public bathroom. **Tip:** Churches usually have free bathrooms that will usually be cleaner than public ones. If you are in South America it is a given that you are going to tour churches.

Lesson Two: Carry water. If it is being handed out on a tour, take as many bottles as you can carry. Any person with an ileostomy already knows enough to carry water when travelling, but I had to learn this the hard way. Once I spent a long bus ride staring longingly at others' bottled water until our guides handed out water at the next stop. I do not normally drink much water, but the minute it was not readily available, I was thirsty.

Lesson Three: Do not irrigate in a strange country, especially if you do not feel well. Seriously, you will be sorry because you must not drink or irrigate with the tap water. Americans are not used to the bacteria in the water in South and Central American countries. I had to ride all the way back to Quito lying down in a taxi.

Lesson Four: Pack many extra ostomy supplies, usually double or triple the amount you would usually use during this time. OK, I was prepared, but even so, it was a bit worrying to see how fast I could run through closed-end gear when I became sick. I had

drainable pouches too, but I brought them specifically to donate in Quito. Therefore, it was with alarm that I realized that I might have to start using them if my diarrhea did not clear up.

Lesson Five: Water sellers are your friends. I used much water to irrigate and became skilled at finding street vendors to sell me the required number of bottles. **Tip:** Check the caps on the bottles to make sure they are not just refilling old bottles with tap water. This was never a problem in the city, but I imagine that in remote locations it might be an issue. Agua, por favor, or, quatro, por favor, did nicely. At the Galapagos Islands, I had to rethink irrigating. We were on a small ship, 70 feet in length, which tossed and rocked with great vigor when underway. When anchored, it was reasonably stable, but anchoring meant all of us were scheduled for land tours and sometimes snorkeling twice a day. Irrigating at any time of the day when at anchor meant missing out on something, which I was loathe to do, and irrigating at night when underway and being tossed around was out of the question.

One needed two hands at all times just to avoid being thrown against the walls. Since one needs two hand to irrigate, I had to suspend this practice for eight days. Those of you who do not or cannot irrigate will laugh at my consternation at having to reorient myself about monitoring, emptying and changing ostomy gear. I developed the hang of it quickly. I did manage myself this way during the first year after all, but dear me, did I run through supplies! Even the one-piece drainable pouches did not last long in this environment. I worriedly counted down the dwindling supply that would be left to donate.

Lesson Six: Be flexible. So I could not irrigate. I adapted just fine.

Food in South America

Many of us must be vigilant about what we eat due to the risk of having a blockage at the site of the stoma. I found that there were many safe choices in restaurants for those who must take care to limit the amount of high-fiber foods. However, if one has an ileostomy, special care must be taken, especially when touring Galapagos. I can speak only for our ship, but there were no menu choices. Everyone was served the same fare, which tended to be vegetable- and fruit-heavy, with a surprising lack of starches. It was decidedly un-North American, but very healthy.

I wondered how people with ileostomies might manage such meals. Probably by eating smaller quantities, I did

THURSDAY August 8

Exhibit Hall Opens at 200pm --- 600pm
 ANATOMICAL Apron---Joy Hooper,WOCN 630pm--700pm
 An Evening with Brenda Elsagher---ADULTS ONLY! 700pm to 900pm
 YOGA and Meditation
 Short Bowel Syndrome
 Basic Ileostomy--Dr. David Beck
 Skin Issues--Bonnie Alvey CWOCA
 Basic Urostomy---Dr Togami
 Affiliated Support Group Advisory Board Meeting
 Basic Colostomy---Dr. David Beck
 Osteo Solutions
 Quality of Life
 CD Options Updates
 CD Wrap Up
 Veterans Outreach Network
 Ask the Pharmacist-How Drugs Affect an Ostomy
 STOMA Clinic Open 800am to 500pm

FRIDAY August 9

Exhibit Hall Open 830am to 1130am
 STOMA/Peristomal Complications
 Hernia Issues---Dr. David Beck
 Effective Affiliated Support Group Fundraising
 Male Spouses or Partners Focus Session-Non Ostomates
 Female Spouses or Partners Focus Session-Non Ostomates
 Males Urinary and Prostate Issues--Dr. Togami
 How Cancer Treatments Affect Your Ostomy--Dr. Hank Hill
 Self Image Psychology
 Female Ostomates GYN Issues---Dr. Trudel
 Your Affiliated Support Group WEBSITE and Social Media
 How to Make Your Meetings Fun and Interesting---Brenda Elsagher
 Return to Work After Surgery
 Massage Therapy
 Gay and Lesbian Open Forum
 Yoga and Meditation
 NPS Pharmaceuticals FOCUS Group(TPN Patients-SB)
 STOMA Clinic Open 800am - 400pm

SATURDAY August 10

COLOPLAST Medical Chair--Margaret Goldberg CWOCA
 Pain Management--Dr. David Beck
 Ask the WOC Nurses
 How to Prevent Food Blockages
 Nutrition and SBS--Dr. James Scolapio
 Positive Side of Internal Pouch--Girls with Guts
 Intimacy and Dating--Girls with Guts
 Colostomy Irrigation
 Sports and Fitness
 Pregnancy with an Ostomy---Dr. J. Trudel
 IBD Kidz
 Closing Ceremony and Awards
 Reception for Evening Banquet and Banquet to Follow

Don't miss the **Colossal Colon!** Brought to us by the Colon Club
 Wednesday through Saturday.

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 __

Mail to: Patti Langenbach, PO Box 10239 Jacksonville, FL 32247-0239

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WE ARE ON THE NET

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