

# 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 <a href="http://www.ostomy.org">http://www.ostomy.org</a>.

#### JOIN US IN JACKSONVILLE IN AUGUST

Fourth UOAA National Conference August 7-10, 2013 Hyatt Regency, <u>Jacksonville Riverfront</u>



Online registration available at <a href="https://www.uoaa.org">www.uoaa.org</a>.
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 <u>Jacksonville area has to offer</u> 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

Ist Timers Orientation

**Ist 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

#### Continued on page 5

### 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 August 18th

## 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"

<u>July 2013</u>: midsummer night dreams and schemes; plans for "spans"...at our July 21 Jax ASG meeting, we had a genial gathering of ostomate friends/spouses, including 2 newbie colostomates, and 1 admiration-deserving returnee whose colostomy had been "desrever" (reversed)..."Gutsy," Linda's ileostomy stoma hopes she put the wary newbies at ease with humor to dispel scary ostomy rumors...and pleased to interact, among others, with "Pepe" and returning "Oscar the Pouch"...Discussion quickly turned to "Plans for Spans," Gutsy's nickname for "Bridge to Acceptance": UOAA's upcoming Conference, August 7-10, 2013, at Jax, FL Hyatt Regency...Last advance chance to seek volunteers among our ostomy peers!...

SPOTLIGHT ON: August 2013: UOAA Conference (7<sup>th</sup>-10<sup>th</sup>); "Mrs. Lips" resumes work as long time public school Speech-Language Pathologist (12th); public school begins for students (Jax: 19th)...In July MailBag, Patti enticed us with printed daily Conference itinerary of the 4 days' literary workshops: seminars both educational and inspirational, for all ages, on various hotel stages...A year's planning and preparation!...something for everyone!..You know, education is a lifelong process and shouldn't stop just because you become an ostomate!... You CAN teach an old stoma new "tricks!"...This Conference has promised to do just that...and, more...regardless of your proclivities, it also encourages fun in the sun activities!...sessions with intent of valuable information dissemination on all things OSTOMY: e.g., yoga/meditation/body image—offering exercises/exorcises for mind and body; problem solutions/resolutions for questions about peristomal skin care, hernias, blockages, pregnancy, intimacy, etc.; exhibits and tidbits from major ostomy manufacturers; a daily stoma clinic as assistant even to the most resistant long time ostomate cynic, with CWOCN (Certified Wound Ostomy Continence Nurses), this time not in our "purses(!)"...in addition, Brenda Elsagher's sessions so full of humor, likely geared toward us "Baby Boomers;" help will be available to improve nutrition condition, including Gutsy's keen interest in "joy of juicing;" and, also sessions offering ways to mentally cope, reduce those days without hope, when you feel like a dope, at the end of your rope; and, sessions to enlighten by medical docs, or lighten our bodies by sports/fitness jocks, and a big gala to dance off your socks while wearing fancy shmancy frocks, and consume incredible edibles...And, if all this wouldn't be enough to entice attendance, the Colon Club is exhibiting its life size Colossal Colon, in which you could be crawling through this sprawling luxurious replica! Gutsy is certainly curious to explore this inner core...but, won't be furious if Linda deems this a chore potentially too injurious! (hahaha)... Incidentally, despite all Gutsy's venting about Conference entry fee \$pending, she finally relented, buoyed, as could be you, that by volunteering, a hospitable considerable way to "pay it forward," she would be gearing up for a "substantial financial" total/partial reimbur\$ement dispersement, at which she was overjoyed. (hahaha)...

Gutsy was looking forward to meeting <u>YOUR</u> stoma...and <u>YOU!</u>...Did you find Juy MailBag's list of Conference daily events hard to resist? Did it assist you in choosing to attend? Gutsy realizes that at the time of this August MailBag printing, the Conference may already be a happy, memorable experience, for you the reader, as, too, for her...WOW! Gutsy knows that all this expenditure of inspiration, perspiration, and perspication should have been enough to whet any ostomate's appetite, or quench one's thirst for ostomy knowledge, and satiate our hunger to meet new ostomy friends, to make lifelong connections and help ostomy advocacy go in new directions!...An absolutely awesome opportunity to learn and realize OSTOMATES ARE "NORMAL" PEOPLE, TOO; AND, WE ARE ALL UNITED AND EMPOWERED JUST BY BEING AN OSTOMATE! (refer to Linda's Phoenix article, June 2011)...no matter the "road traveled" to get there (IBD, cancer, emergency, war, etc.)...Yes, lots of stomas planned to travel from their "home-a-s," with their hosts, coming down to Jax's Southeastern Florida coast, taking planes and trains, enduring \$trains, pain\$, and drain\$...or thriving due to striving to be alive, choosing to drive...(home the point of their decision to have life-saving colonoscopy, with/without consequent/subsequent "excision-incision" ostomy surgery)...and to arrive in Jax to attend this life-changing/rearranging exciting event...Were YOU one of them? If not, Gutsy still hopes to meet you someday, maybe in person, maybe in print(?)...We all need each other...and, are only as far away as (s)miles and hearts will send us!

<u>BOTTOMLINE/MARK YOUR CALENDAR</u>: Gutsy's ambition for those "Plans for Spans" has now come to fruition! She is delighted!...Our next Jax ASG meeting is Sunday, August 18, 2013...a time to reflect, with much respect, on the "AUGUST-ness" of the empowering ostomy Conference!...Did it meet/exceed your expectations?...Caring and sharing... what both the Conference and our Jax support group are all about...Speaking of sharing...How about sharing YOUR stoma's name!...email Patti@ostomymcp.com or Linda: blumbergl@duvalschools.org... Join with "Gutsy, Pepe, BOB, Oscar the Pouch, HerbeHind, Shorty2, Squirty, and \*#!!"...for inclusion in future "Gutsy's Gab" column...August is a time to share what you learned at the Conference or learned how to share with new friends and loved ones...We are all students of LIFE...Come join us and CELEBRATE BEING ALIVE!!...See YOU there!!

# HOSPITALIZATION 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 xray, 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 xrays 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 ileoloop 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.

#### 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.

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#### **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 CWOCN

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 Pharmacuticals FOCUS Group(TPN Patients-SB)

STOMA Clinic Open 800am - 400pm

#### **SATURDAY August 10**

COLOPLAST Medical Chair--Margaret Goldberg CWOCN

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

Pregancy with an Ostomy---Dr. J. Trudel

IBD Kidz

Closing Cermony 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 <u>Jacksonville Landing</u>, 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  |                             | Zip                           |   |
| Phone# Home   | Work#                       |                               |   |
| Email Address   |                             |                               |   |
| Type of intestinal or urinary diversion: Co<br>Continent Ileostomy, Continent Urosto  |                             | rostomy, Ileoanal Pull-thru _ | _ |
| You may use my name in chapter Newsle   | etter & Directory: Yes No _ | <del>_</del>                  |   |
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