

# 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 - Bap Medical Center Nassau board room.  
Gainesville Support Group meets the 1st Sunday of each month (except Holidays) Hope Lodge 2121 SW 16th St Gainesville

**The MailBag** welcomes two guest contributors this month along with our own Gutsy's Gab. We are excited to bring you a story by **Amy Oestreicher**. Much like Gutsy, Amy has written and been featured in the Phoenix Magazine as well as starred and directed herself in Gutless & Grateful - the one woman musical about her life. You can see a portion of it here: <https://www.amyoes.com/gutless-quick-facts/>.

Here are some additional links to her works:

[amyoes.com](http://amyoes.com),  
<https://www.amyoes.com/professional-portfolio/>  
[http://www.huffingtonpost.com/amy-oestreicher/my-messy-beautiful-detour\\_b\\_7834132.html](http://www.huffingtonpost.com/amy-oestreicher/my-messy-beautiful-detour_b_7834132.html)  
<https://www.washingtonpost.com/posteverything/wp/2015/09/09/after-organ-failure-a-coma-and-27-surgeries-i-wasnt-your-typical-bride-so-why-was-i-trying-to-be/>

We are also excited to get the **UOAA National Conference Report** from **Pinky O'Neil** (Ocala Chapter member). It was her first experience at a conference. Pinky is also affiliated with Ms. Senior America organization. Pageants are held for women who have reached the Age of Elegance 60 years and better to enhance the image of mature women in the USA since the early 1970's. The women serve as valuable role models to their families, peers and members of the community. Pinky received the title Ms. Virginia Senior America in 1996 & Honorary Senior America in 2006. She will be attending the national pageant in Atlantic City in two weeks mentoring our Florida representative.

We hope to hear more from Amy and Pinky in the future!

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(904) 733-8500  
(800) 741-0110

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 Nov. 15th**

**Gainesville Support Group** meets the 1st Sunday of each month (except Holidays) Next meeting: **Nov. 1st 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 Nov. 8th**  
**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) Bap Medical Center Nassau board room. Free parking (904) 310-9054  
**Next Meeting Nov. 30th**

## Waiting For Life

By Amy Oestreicher

I've spent a lot of time "waiting" in my life. As a kid I grew antsy with impatience, waiting until I was "older" to start dating, to go to the mall unsupervised, to learn how to drive. I was counting the days until I turned 18, giddy at the idea of college and independence at last. Two weeks after I turned 18, I was pulled into another realm where "waiting" took on an entirely new meaning.

When an unforeseen blood clot caused my body to go into septic shock, my life changed forever. Now, it was my devoted family who waited patiently and lovingly while I recovered from a three-month coma. When I awoke, I waited many more months before I could take a breath of outside air once again. I became extremely well-versed in patience -- little did I know that I've have to wait eight more months before I was discharged from the ICU, over three years before I could drink a sip of water or eat a morsel of food again and 27 surgeries before doctors could create a makeshift digestive system for me.

As a born go-getter, I've never been great with "patience." So I became extremely frustrated as doctors explained to me how "it would be a long road to recovery, but I'll get there." But healing physically and recovering my "self" emotionally, feeling my aliveness as well as being alive... I learned that this is a daily process, a life-long one. Life will not always be perfect, and there's no reason to wait until things are.

I had this fantasy that the day I was finally discharged from the hospital, everything would be "back to normal." I'd have my old body back -- devoid of any medical scars, tubes, ostomy bags or IVs. I'd be eating and drinking again. I'd be able to leap like I had in dance class just the week before my coma. These surgeries would be a "blip" in my life, and now it could proceed as it was meant to.

But I learned something far better: My life as I knew it had shattered, but I could reassemble the pieces differently, but still beautifully -- like a mosaic. These "imperfect" shards of a life I longed to reclaim could create a work of art even greater, using the grout of experience and newfound wisdom.

A decade has passed since my life took an unexpected detour. It was a messy detour that put most of my anticipated life plans on hold, if not changing them completely. But this detour turned into the richest time in my life. To this day, I am *still* healing physically and emotionally. Every morning I make a new attempt to find who I am and to discover who I am becoming. If I had waited for life to be "perfect," or at least for life to go back to "how it was," I would have missed out on so many things. I would have never mounted my first solo art show after learning to paint in the hospital. I would have never written a one-woman musical about my life that I've performed for three years. And best of all, if I hadn't had the audacity to set up an online dating profile for myself while still in my hospital gown, on IVs and recovering from a disastrous surgery, I would never be marrying the love of my life next month.

I've waited for ostomies to be reversed and fistulas to heal. Of my 27 surgeries, 4 of them were failed reversal attempts. I learned to love my body for the amazing work it is, and to live now, no matter what.

They say that all good things come to those who wait. But what for? Every day is an opportunity to learn, to grow and better myself. I love the imperfect twists and turns my life has taken, simply because they have made me who I am. It has been a mess, having life as I knew it shattered to pieces. But bit by bit it's reassembling -- different, imperfect, but beautiful all the same.



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

By Linda Blumberg AKA “Mrs. Lips”

**October 2015:** “Shocktober” “discoveries”...at our October 18 Jax ASG meeting, ostomates/family gathered...(s)caring/sharing...un”masked” ostomy fears...discussed World Ostomy/Awareness Day...munched on Kimberly’s “goblin(g)s”...”Gutsy,” Linda’s 8 11/12 year old ileostomy stoma, encouraged everyone to “discover” ConvaTec’s 24/7 inspirational informational social media Inspire.com: for ostomy issues/answers: for prebies poised to have ostomy surgery, recovering newbies’ needs, and to meet new ostomate friends globally(!)...it’s almost November...time of “rebirth,” to “give thanks” for being alive...to live well with an ostomy!

SPOTLIGHT ON: November 2015: Daylight Savings Time ends (1<sup>st</sup>), Election Day (3<sup>rd</sup>), Veteran’s Day (11<sup>th</sup>), Gutsy’s 9<sup>th</sup> Birthday! (17<sup>th</sup>), Thanksgiving (26<sup>th</sup>)...AAA (Awareness/Acceptance/Advocacy)...

Let’s “talk turkey”...Awareness is “time” to: 1) check for blood in stools/urine; “elect” to have: 2) life-saving colonoscopy, with follow up life-affirming ileostomy, colostomy, or urostomy surgery, if needed...”fall” back on good habit of turning clock back 1 hour...but, denial/avoidance of health responsibilities could lead to cancer...or premature death!...hope that scares the “daylights” out of you/loved ones and could “save” a life...maybe YOUR’S(?!)...

Postsurgical Ostomy Acceptance occurs when we realize that even with a stoma; WE are still normal, loveable, beautiful people who can feel EMPOWERED to live well with an ostomy! STOMA ARRIVAL= YOUR SURVIVAL to CELEBRATE BEING ALIVE...to honor military veterans, who may return as ostomates, AND OURSELVES...WE are “veterans,” too, having “embattled” to reclaim our lives!... Accept YOUR stoma and nonostomates likely will, too; true ostomy acceptance is nonjudgmental! (See Linda’s 1<sup>st</sup> Phoenix article/photo, June 2011, p.30)...

Gutsy “GIVES THANKS” for turning 9 YEARS OLD November 17, 2015!!!...her sense of “rebirth” is “time” 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, sharing YOUR stories of ostomy glories(!), in writing, to this (or YOUR local) newsletter, or publications, e.g., Phoenix Ostomy mag,: check out Amyoes.com for her “ostomiesome” journey!!, and d) by educating general public to dispel its negative preconceived notions; 2) drive loved ones to/from colonoscopy, “giving thanks” by remaining loving/loyal if he/she has ostomy surgery; 3) Advocate for YOUR stoma: a) Gutsy looks G-O-O-D in her 9 year old “birthday suit(!)”...but loves to wear beautiful pouch covers from Koolostomy.com(!), b) Make YOUR stoma a STAR!...email his/her 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 November, Gutsy is “thankful” for “Huffy Puffy” (Ocala ASG), “Fred,” “Famey/Feisty/Festy Amy,” and “RIP Reversal: Jabba the Gutt” (Inspire.com)...cathartic and fun! (See Linda’s 2<sup>nd</sup> Phoenix article/photo, December 2013, p. 78)...

BOTTOMLINE/MARK YOUR CALENDAR: November: a “time” to “give thanks”...honor “veteran” Gutsy’s 9<sup>th</sup> Birthday(!)...our next Jax ASG meeting is Sunday, November 15, 2015...join us to CELEBRATE BEING ALIVE...to “gather together” to “gabble gabble” about ostomy concerns/experiences and “gobble gobble” Kimberly’s Konfections...Don’t be a “turkey” or too “chicken”...We’ll be so “thankful” to SEE YOU THERE!!...

## 5<sup>th</sup> National UOAA Ostomates

Conference Sept. 1-6, 2015

Saint Louis, MO

Susan Burns, President

Conference Report

By Pinky O'Neil



2nd from left: Susan Burns from St. Louis, president of National UOAA; right, Pinky O'Neil from The Villages, FL and two other conference attendees; a happy looking bunch!

- More than 400 of all ages attended; quite a few were young people
- Attended: "Ask the Doc": Skin Care, eat marshmallows 20 min. before changing to deactivate stoma; lifting: 5 lbs limit; gas caused by beer, brussel sprouts, swallowing air, gum, incessant talking
- 1<sup>st</sup> Night Ceremonies: Met leadership; inspiring presentation by Joanna Burgess whose ostomy journey started at 3 yrs.; Shared her story & passion as a WOCNurse
- Wed. night ice cream social & dance; Sat. night Dessert Buffet & Dance; great way to bond with everyone and especially attending youth
- Signed up for Stoma Clinic Appointment: free evaluations by a Wound Ostomy Continence Nurse/Doctor (WOCN); very popular, one of the highlights of conference for this reporter
- Exhibition Hall Opened Thurs. afternoon with refreshments & open all day Friday
- Attended "Stones & How They Can Be Prevented"; Hydrate, Hydrate, Hydrate; causes: lack of activity, meds., rapid weight gain/loss; Kidney stones: severe pain, vomiting, symptoms lasting more than 8 hr. contact doctor
- Attended "Clothing for Ostomates" Mtg.
- Attended Social Life & Dating after Ostomy Mtg. & New Sexpectations; very helpful suggestions
- Walked to football game: Kansas City Chiefs & St. Louis Rams: K C won; loved the spirit
- Walked to Baseball Village, watched Cardinals & Pittsburgh; ate dinner in complex; Pittsburgh won
- Went sight seeing to top of Arch; cruised on Mississippi River; visited Old Courthouse; passed Union Station & Washington University; a beautiful city

- 2017 Conference: Irvine, CA August 22-26; this writer is interested in attending
- Annual Youth Rally; next year in Seattle, WA July 25-30: spread news to young people ages 11-17
- Attended Advocacy Mtg: there are approximately 1.4 million ostomates, many are young people; spread word locally, state & national; read Ostomate Bill of Rights;

Next Steps:

- A. Do something; Help yourself
- B. Tell your story: short & long
- C. Get involved with Affiliated Support Groups (ASG) UOAA, etc.
- D. Change the world's opinion of ostomates

Check out photos from the 2015 UOAA Conference: <http://uoaa.smugmug.com/Other/St-Louis-2015/>

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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."



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