



The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala



# Jacksonville Annual Christmas Party

will be held at Patti's again this year. More information to follow in December's Mailbag.

**The The Fly Cover** is great for different size pouches. Pouch Covers are available for women, men and children. There is an opening on the front of the cover from top to bottom to allow for easy access. The front cover is made with 100% cotton or a cotton blend.

No other pouch cover is made with such craftsmanship and guaranteed to satisfy the customer. All seams are sewn so as the material will not ravel. The pouch cover is manufactured to match the shape of the customers pouch (bag). Pouch covers are made for either a drainable or closed end pouch. The pouch cover is not removed for drainage. The stoma opening is custom made to the flange opening. The back (next to the body) fabric is a "wicking" material. The "wicking" material is special formulated to assist with the removal of moisture and help keep the skin healthy under the pouch. The " wicking" material is color coordinated to the front side.



THE FLY pouch cover by our own VERNA with koolostomy.com

Medical Care Products, Inc. (904) 733-8500 (800) 741-0110

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#### Jacksonville Contact Information:

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

patti@ostomymcp.com

Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street Next Meeting: **Nov. 20th** 

# Gainesville Support Group Contact info:

Brinda Watson (352) 373-1266
Jean Haskins (352) 495-2626
Meets the 1st Sunday of each month
(except Holidays)
at Hope Lodge2121 SW 16th St
Gainesville, FL
Next meeting: Nov. 6th at 2pm

# Ocala Support Contact info:

Lynn Parsons (352)245-3114

www.ostomyocala.com

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. 13th

### **Citrus County Support Group**

Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building Next Meeting: **Nov. 20th** 

# Amelia Island Area Ostomy Support Group

(904) 310-9054
Meets last Monday of each month at 6:30pm Bapt Medical Center Nassau board room.
Free parking
Next Meeting: January 2016
(Date to be announced)





# "Gutsy's FAB Gab-About: Stories of Ostomy 'Glories/Gories'!"

"Speak Out and YOUR WORDS WILL Be Heard!"

By Linda Blumberg AKA "Mrs. Lips"

November: (includes US events): Daylights Savings Time ends (6<sup>th</sup>); (S) election Day (8<sup>th</sup>); Veterans Day (11<sup>th</sup>); GUTSY'S 10<sup>th</sup> BIRTHDAY! (17<sup>th</sup>); Thanksgiving (US-24<sup>th</sup>)

Let's "talk turkey:" but, not about a "bird, plane, or even Superman"...but, of a Super STOMA who is incredibly "grateful" to CELEBRATE BEING ALIVE 10 YEARS NOVEMBER 17, 2016!!!! 10 years attached to Linda's abdomen! Happy to be stuck TO her! [Paraphrased from Huey Lewis and the News

ATTITUDE IS EVERYTHING!...that's Gutsy's own story from 'gorious to glorious'! [Disclaimer for reader: Unlike Gutsy's FAB Gab-About story predecessors, THIS one is "rhyme all the time"...Gutsy thinks its sublime! With alliteration alternating as the words "chime!"...but, if with this issue YOU take issue, don't tell Gutsy/Linda...WE already went through a box of tissues! hahaha]...herein, is Gutsy's story, as told by Linda to Gutsy sometime after her "birth"

From the editor....This story has been edited to fit in several issues of the MailBag. The story in its entirety is available by request (call Patti Langenbach 904-733-8500 or email at <a href="mailto:patti@ostomymcp.com">patti@ostomymcp.com</a>). Please keep in mind that all ostomy journeys are unique. We are always happy to share real stories from our ostomy community and encourage anyone who wishes to contribute to contact me or Linda.

The June 2006 colonoscopy report was to purport certain doom: my very diseased, displeased swollen colon and rectum might have colorectal cancer! I had possible "high grade dysplasia" Outside of "aphasia" which I did not have, since I had all my "faculties" intact, in fact: I was working for the school system as a long time Speech-Language Pathologist, after all, as I recall! (hahaha); the only other "Asia" I knew was a "continent," and I was already "INcontinent" as it was! (hahaha).

I had to submit to every bit of a very painful, disdainful "trans anal excision biopsy" performed on my deformed uninformed refusing to reform rectum, with such precision, despite the pain my anal area already was suffering, with no buffering. I wanted to quit, being literally tired of being mired in so much sh\*t! But, they said the only answer even if by chance it was not cancer was to vouch for a total proctocolectomy with J Pouch, performed, as I was informed, laparoscopically hand-ass-isted by an out-of-town colorectal surgeon of whom we resisted. But, GI doc Harmon insisted on Dr. Steven Wexner of Cleveland Clinic in Weston, FL without question, offering no vocal local Jax suggestion. I took so many awful but lawful tests: X-rays of my chest and EKG, all for a fee, and foul bowel preps galore—a bore, a chore, through the floor, out the door, sickening and quickening me to my very core! (What the hell was all this for?!)

Aforementioned outpatient surgery there, we schlepped in July –more bowel prep: why, oh why?! My, oh, my! Will I die? I started to cry! I was in so much pain/strain/drain of my brain. After several months more both tearful and fearful, anticipating the worst, since I was convinced I must be cursed, so much so that I constantly burst into tears--that I'd wind up in a hearse, trying not to be a jerk at work, where people knew I was sick, but very few knew why. I did much research on line, not being internet savvy, trying not to whine. More bowel prep kept me heaving, weaving, and disbelieving.

In October, I got really sick with bronchitis and gastritis. Desperately and poor respiratory, I went to Decker, my moronic PCP, who not caring about my chronic colonic condition, at least by his omission: Erythromycin is the antibiotic this psychotic prescribed for me, the neurotic(?) to imbibe, but he wasn't the checker of how my IBD would be affected. I felt so neglected, and disrespected! And, on top of everything else, my colon got infected!! C Diff was the riff that made me so ill that I ended up in local Memorial Hospital, which almost lived up to the fame of its name, which would have been a terrible shame for my life to claim. For nearly a week (oh so weak and bleak!), I was up a creek! I lost 10 days of coveted sick leave with no reprieve I couldn't believe or conceive and felt very much deceived as he notoriously and vain gloriously would creep into my hospital room when I was finally asleep to do his cursory inspection of my infection. Because of this set back, I had 2 blood transfusions, and in my body's confusion and infusion, couldn't get back any chance of a semblance of health as my life began to unravel with hospital d/c just 2 days before the big 6+ hour travel.

They actually considered sending me hospital to hospital for the surgery: we were so furious with Decker, the wrecker of my injurious health that if put on the witness/whitless stand (hahaha) we would have committed "perjurious" stealth! My mind began to wander as I was to ponder so weak and weary, all that week with thoughts so dreary, the query: would I die as I lie on the table? What would I be able to do with my new label as "Bag Lady?!" It sounded like such a drag and shady! Even before we went, because of my illness' extent, my nutritional status was spent...but certainly not my "flatus! (hahaha)—ew and p-u!"



On November 17, 2006, I'll always remember the total proctocolectomy with permanent ileostomy date of Fate. Another blood transfusion was the solution. No internally created J Pouch allowed as they vowed, infernally, and not at all "ma/pa"ternally I had Crohn's and I moaned and groaned. I would end up with a "bag on my leg" for sure, which my surgeon had burgeoned indelicately to share prior, to ass-ure implying I would not want to be trying this externally situation, causing such consternation and confusion, in my delusion, of all my allusions, since he was renowned all around for J Pouch, an internal reservoir for "collection" of which he must have had affection. But, on reflection, with ongoing fear, a very painful rear, and constantly in tears, I was no slouch, as anyone could vouch, trying not to be a grouch about the external "ouch!" No laparoscopy for me. Could not be hand-ass-isted. Too sloppy? I suppose, but who knows?! So, I was in the throes, of laparotomy, where they "filet you like a fish," announced and pronounced by that bitch, Shelly, whose voice quivered as she delivered, like jelly! Both her attitude and so-called platitude were smelly! But, unriled and ever styled, as is my shtick, I wore red lipstick and make up, and combed my hair to look good on the way where I could not see, but still got to be ME! So, I began my "journey on a gurney" as I was wheeled into surgery!

I woke up in Recovery both groggy and foggy, but just alert enough to blurt out "I'm alive! I must have survived!" Naw, I doubt I was that glib, as I was likely drooling with saliva pooling on a hospital bib! As I eventually lay day after day in my hospital bed, I became depressed and rarely dressed. Lousy, crude food, I did dread. The blousy oversized gowns made me frown and stay down, with visions of tripping or ripping my incision stitches, dancing, ever enhancing, in my head. And, so began my "glitches with stitches" But, more on that soon enough. I wish I could share some pleasanter stuff! Alas, I was in so much pain, from my ass all the way up to my brain, Tried to think good thoughts, but they were fraught with the "railroad tracking" all stapled and steri-stripped down my abdomen, and the bulbous fluid filled drains hanging and dangling precariously and not so airily, causing tremendous strain whenever I had the nerve or verve to actually move from prone position to seated for food or pain meds acquisition.

Some would have tried to get "stoned" on that "cocktail" But, to no avail, since the "pump" only dispensed this assistance in a "timely" manner. So, even if it were bumped, jumped, or clumped, there was such resistance despite my clamor on its limited "dump" which helped keep me in a perpetual detrimental slump! Constant pain complicated by swelling and welling fluid dwelling throughout my body that would not drain! No wonder I did not want to walk. But, I certainly could talk and squawk and balk! I suppose the nurses said curses (under their breath) each time my call button lit up for I was still scared to death!

Some nurses were nice, all sugar and spice. But, then after about 3 days of my "lollygagging" and languishing and anguishing in bed, still in pain, still full of dread, and only getting out of bed to empty "bagging," which had to be done to side into a special beaker, even though I was faint and my complaint I was getting weaker and things seemed oh so bleaker, so they could measure with evil pleasure the "treasure" amount and count of "cc," while dragging the IV pole, my gown sagging, flagging them that I was fearful and tearful of falling, calling and sometimes bawling, they must have had a nurse's "powwow" and said now, it is time for Linda to get up off her ass and out of her room, where I was consumed by doom and gloom.

So, in one fell swoop, they stopped worrying about my "poop" long enough to exchange the sweeter nursing troupe for "Boot Camp" Ed and Marion to reroute and revamp my aversion to conversion from swallowing and wallowing in bed wishing I were dead to walking the halls, clutching the walls, fearful of falls. Unlike most hospitals so cold or old or even with mold, Cleveland Clinic Hospital in Weston, FL looked more like a hotel! Well, no wonder I deigned to remain in my room with ample space all over the place. But, when I was all but kicked to the halls by those two, I realized they had done me the biggest favor, as movement improvement I began to savor the flavor. So, I got more accustomed to adjusting to emptying my bag, I must brag. But, walking around with a tricord Tiki but not kicky-looking IV coming out of my NECK (!), well, heck, I couldn't afford such a drag. I had tried to prepare myself by viewing stoma photos online, trying not to be spewing. But it still was my undoing. Then, just after surgery, I looked down at this big purpley hulking thing in a clear "sandwich" bag skulking on the right side of my abdomen. Well, not quite a Ziploc, as I had originally feared. I was kind of repulsed by my stoma, which was basically in a "coma!"

On Shaz' page from Australia, those photos were downright scary. And, on the contrary, she said her stoma was "born" and had given it a name! I was forlorn, but decided to give the "name game" a try. So, well before I was given my hospital d/c "diploma," I managed to bond with my stoma! Once I settled on a name, I became more fond of her. I named her "Chai Gutsy" because she had saved my Life, and I had the "guts" to have the surgery. As she became more trusty, it was Anglicized to Hi Gutsy (!) and finally, Gutsy.

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# 10 Things I Wish I Could Tell Myself Before My Ostomy

By Amy Oestreicher, featured on ostomyconnection.com

When I first got my ostomy, I felt very alone. I felt self-conscious of the smell and sound, and sometimes I longed for my old body. When I couldn't take self-loathing anymore, I decided to make friends with it. I reached out. I inquired about support groups in my area and realized there are many people like me. I realized my ostomy is a beautiful thing and has enabled me to do all the things I've been able to accomplish over the years. It is my uniqueness.

These are 10 things I would have liked to tell myself when I first had an ostomy - 10 things I didn't know but eventually learned, which I am so grateful for today:

### 1. What it was

I had no idea what an ostomy was before I had one. But I have a confession: I didn't realize exactly what it was until a year later! Coming out of multiple surgeries, I had so many bags and new anatomical surprises to think about that a little pink bulge on my belly seemed to be the least of my problems!

I've learned things in the past 10 years that have shocked, scared and relieved me, such as: you can't actually feel your stomanonerve endings! I've had three ostomies and four ileostomies over the years. I didn't realize how different they were. Once I learned about the differences and functions of each. I was better able to take care of them.

### 2. What my limits were

When I saw that I'd have to live life with a bag stuck to my side, I assumed I'd be "fragile" for the rest of my life. But believe it or not, there are so many active ostomates out there! Swimming, karate, ballet, yoga - I've done everything I did before my ostomy and more.

#### 3. There are so many strong ostomates

I was privileged to be the Eastern regional recipient of the Great Comebacks® award and meet five other amazing ostomates doing incredible things. There is a huge, supportive ostomy community. Did you know Great Comebacks® was founded by former NFL linebacker Rolf Benirschke?

### 4. Ostomates excel at innovation and inventiveness

It turned out I was able to do all those things I thought I couldn't - but that didn't mean it was easy. Some of the best things in life take work, and that makes you appreciate it even more. Let's just say that ostomy wraps, stoma guards and pouch covers have become good friends of mine, all products that were created by ostomates. I've also created a workshop for ostomy patients and healthcare professionals!

### 5. How Amazing My Body Is

I have a new respect for my body and the way it can function now.

6. Judgment Hurts, But Fear Hurts More

Stay informed and know the facts. The more I actually understood how an ostomy worked, the more I realized how wonderful it was. After that, I took it as my responsibility to educate others. Instead of wondering if I was being "judged" by others, I took it as a privilege to inform them.

#### 7. Everything Is Connected

Take care of your full self: emotional, spiritual, mental and physical. If you're stressed, you might be bloated or feel pain or discomfort. Remember to take deep breaths in difficult times.

### 8. The People Who Love You, Love You



If you're just getting comfortable with your ostomy, remember that your support system loves you for who you are. You are more than your ostomy. Reach out when you feel alone and never forget how loved you are.

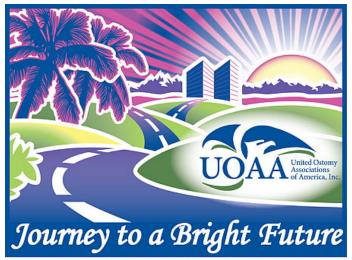
## 9. Eat Fresh

You are what you eat, so eat whole and nourishing foods. Your ostomy will thank you, and so will you!

#### 10. Life Can Go On

Throughout the years, I've been strong, determined and willing to do whatever it took to stay alive. I've dealt with tubes, bags, poles, you name it. And if this ostomy is all that I'm left with after everything, then I am truly grateful. More than that, I thank my ostomy for enabling me to live life to the fullest, to my fullest. I call it my Harry Potter thunderbolt scar: a symbol of strength, courage, individuality and life.

There are a few things I didn't know before my ostomy. But what I look forward to most is everything left to learn. Thank you, ostomy, for making the world a wide open door once again.



6th National Conference

Tues.-Sat., Aug. 22-26, 2017, Hotel Irvine, Irvine, California



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