

Dec. 2016

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



Jacksonville UOAA Chapter **Christmas Party**

Sunday December 18th 3p.m. To Be Held At Patti's Home Please Call (904) 733-8500 To RSVP And For Directions

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

Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

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: Dec. 18th

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: Dec. 4th 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: Dec. 11th

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: Dec. 18th

Amelia Island Area **Ostomy Support Group**

(904) 310-9054 Meets second Monday of each month at 6:30pm UF North Campus UF Health North 15255 Max Leggett ParkwayJacksonville, FL 32218 (Lobby area) Free parking Next Meeting: January 9, 2016



Dec. 2016



"Gutsy's FAB Gab-About: Stories of Ostomy 'Glories/Gories'!" "Speak Out and YOUR WORDS WILL Be Heard!" By Linda Blumberg AKA "Mrs. Lips"

GUTSY'S Story! Continued from the November MailBag....

My body was still wrecked, but there was a rumor that I was keeping my humor in check. That surgery removed my diseased displeased swollen colon, my wrecked rectum, my annoyed anus, and anxious anal sphincter muscles. I called it my "going out of business sale!" And, the best decision I had (N)EVER made! Despite all the pain, the strain, the drain(s), stains, feeling like I was "chained," and the swelling and welling of fluid dwelling everywhere in my body, including in my legs and feet that did not make walking a treat, and had caused me to retreat, but not in defeat (but, yes in "de feet"—hahaha), and daily during my 8 day hospital stay, when the international fashionable group of interns/residents came to inspect my anal stitches, I would roll over and interject that they should "enjoy the view!" and I was NOT talking about the tv show! Hell, NO! Well, what else could I do?! I was a human guinea pig in this gig!

And, though I had no PICC line like back at Memorial Hospital prior when I was oh so very sick, I was considered a lousy "stick" By the time I finally was d/c, the bruising on my arms, hands, neck looked like I had been beaten/eaten up really bad. But, by then I had been cruising the halls with more self-confidence, even schmoozing at the nursing stations outside my door and every corridor on my floor! I had made up my mind to have a positive attitude, one even of gratitude! And, my well-developed, enveloped warped sense of humor was my absolute salvation, despite the indignities, rigidities, stupidities, and cupidities, in the early days of this Gutsy creation! I was now a survivor, a thriver, with time to CELEBRATE BEING ALIVE!

But, alas, when I could finally demonstrate to my ostomy nurses that I could change my appliance with better reliance, and certainly less defiance, and they finally d/c me which was to me to give my "ass a pass," we had to stay in interim Hotel Amerisuites next to hospital before the long drive home. A beautiful spacious "sweet suite" replete with only my second walk-in shower in all that time, so sublime with nothing to "climb!" I must have been all caught up and fraught with the splendor because unwittingly, unfittingly and against my wishes I unconsciously without a second thought had torn two anal stitches, you know how women "do" with #"1" since Gutsy's pouch took care of #2! So, now I was really scared when a drop of bright red blood hit the air! I thought it so unfair that I had come so far and we were soon to travel by car!

CCH would not allow me back in since I had been d/c! In the middle of the night, this was a real emergency!! But, they would not relent, so off we went to Emergency. A long long wait even though it was very late to see some stranger medical professional for \$\$\$. Who likely knew NOTHING about ostomy?! My new little Gutsy felt she was in imminent danger. My hero hubby Bruce managed to finagle a big roll of gauze and pads and back at the hotel he makeshift "mummified" me as I drifted off exhausted for the long ride. "Glitches with Stitches?" AKA "How I 'mooned' my 'crack' back while on a wound VAC!"(hahaha). You know, I wrote the gist of this list just after surgery, back home in recovery. Cathartic and even fun. November 2006, around a very heartfelt Thanksgiving when I was just thankful to still be living! So, back to the deep wound created that night which upset an otherwise elated Gutsy only in her infancy, not to mention how it affected a rather dejected, near ego-deflated Linda and poor Bruce who did not know what to do to give me a boost. Home Health wound nurse came 3x weekly in Jax. We were relieved to receive the orders by fax. From my voice I tried to rejoice that my life would soon be back on track as soon as the wound VAC literally drained out the crevasse crack. But certainly NOT that simple!

I was beginning to feel empowered! Not so much fun, however, when ignorant people asked if it was oxygen I was carrying. What? With tubing protruding and extruding from my ass through this "hose" and NOT through my NOSE!!! So crass; they certainly had NO class! (hahahahaha). Slowly, there was reduction adduction of the anal abyss by Xmas 2006! But, it was weird when both Home Health and wound VAC suddenly abruptly corruptly disappeared! Just because I decided to return to work in early January 2007, they jerked it all away! But, the care for my anal tear was not ended. Still, disbelief and grief were expended and extended. As poor Bruce was expected to induce this same care, of which he respected, but Linda still felt rejected and disrespected by the nurse who never even called to check on my progress with him! Had she done so, she would have been very proud of him, that although he protested so loud, he rose to the occasion and I gave him a standing "ass-in-the-air ovation!" (hahaha).

Continuous drainage, suddenly foul-smelling. Reeling and dealing with this new embarr-ass-ment at work, I certainly felt like a fool, welling up with tears, no longer "kvelling" about my good fortune, almost found myself yelling, feeling sorry for myself, for



where I worked in the schools, the ignorance was very cruel! What happened to the "Golden Rule?!" A long forgotten, misbegotten jewel! By early February, we knew something was very wrong, and I was not feeling very strong. Had the wound opened back up? I was convinced that I was jinxed and winced as I practically swooned at the thought of again being back with that wound VAC set up! When would this misery ever let up?!

Then, so distraught, we sought out the right doc to take stock of my situation and alleviate my constant consternation. Upon Dr. Rizk's initial inspection, his reflection was that I had a bacterial infection! Likely caused by all that cellophaning, profaning, since it could never "breathe" so it never got a "reprieve" So, he took my care in a new direction: I was neurotic with fear that he would be giving me an antibiotic injection in my rear. But, I did not need to sweat—not yet. Instead, I was taken to Dakin Solution as my "pollution resolution!" Off came the unbreathable unbelievable tape drape: finally, an escape! A simple bleach to leech out the bad I had brewing and spewing from inside: this had been a LOUSY ride! All this depravity within my anal cavity! Such "gravity." It took 2 full months for the Dakin solution to give me absolution. In April 2007, with excellent anal care, I no longer could despair, as Dr. Rizk gave my "ass a pass!!!!" Sound the brass: he gave my ass a pass! I was one buoyed and overjoyed lass!! Imagine my elation at this revelation!

But, sometime the following Spring of 2008 when I was feeling sedate, pretty great, and well-adjusted to Gutsy, I was suddenly "busted" and mistrusted at work! They say "Ignorance is bliss." NOT when it means accusing me of actions and infractions totally repellent and sullying my excellent reputation! A principal likely looking for a scapegoat from our group, with whom I had initially shared my surgical information happily, since I felt empowered, and with little consternation, suddenly "asked" if I had defaced and disgraced bathroom walls/sink/stalls, etc. with the stink from poop—as if to empty Gutsy's pouch I would slouch to detach it to "dump a clump" in the sink? What was she thinking? Maybe SHE had been drinking? So many things I had been able to take in my stride, but this really screwed with my pride, and was something I could not abide. But, the damage was done; I was not having any fun. She probably thought she had won! My spirit was crushed and my built-up ego totally deflated. No longer elated, and feeling jaded, I fell into a slump, "down in the dumps." Feeling like a fool, that life was so cruel. But, I would not quit just because she had treated me like... she retired—she should have been fired! And, I fought my way back, with old familiar positivity, as was again my proclivity. It took quite a while, but I again regained my "moxie" and not by proxy!

Gutsy got me all "wired" and "fired up!" She inspired me to be more independent and resplendent in good feelings of dealings with my permanent fervent ileostomy Gutsy. My surgeon, who was probably still reeling from being unable to do J Pouch on me, had burgeoned suggestion that in 1 year post op, I could stop with Gutsy to consider maybe a Kock Pouch correction. But, getting cut open once was enough for me, and besides, I had already bonded with Gutsy, who was now permanently on my "side," despite her penchant for being alternately trenchant, but also schmutzy" and she all but absconded with my heart, and oh so smart, knowing how to "push my buttons" and practically anticlimactically crowing that Linda would swear to never dare to "push" her's! (hahaha).

Patti, from local support group asked me to write about my experiences and adherences for her local newsletter MailBag in early 2011. She encouraged me to send to US Phoenix ostomy mag, which published my first article on empowerment, June 2011, p. 30. That was over 5 years ago, as this goes into publication! I was also encouraged to create a monthly column for MailBag dubbed "Gutsy's Gab," which ran from 9/12 to 1/16, tying ostomy awareness, acceptance, and advocacy to monthly events in a humorous, never drab way. But, then Patti said her readers wanted ostomy stories instead. Well, if familiarity is the breeder of contempt, then Gutsy thought she would be exempt! She could not wrap this around her "head," viewing the ensuing personally and urgently had a "pity potty party" Gutsy had no faith in this new venture and wanted to have it censored!

But, concurrent with all these changes, she had been meeting new stomas globally for a few years on Inspire.com, ConvaTec's 24/7 inspirational informational social media website. Many of these friends had eagerly sought STARdom by mere mention of their stoma names in Gutsy's Gab. This dovetailed via email on Linda's second published Phoenix article on naming stoma, December 2013, p. 78. So, Linda posed the question of ostomy stories and suggestions on Inspire. Newsy nosy Gutsy's Gab-About premiered in February 2016 in MailBag. Patti had given Gutsy permission for the Gab column submission via email to Linda's global recipients, allowing me to continue writing in well-established "Ostomy AAA: Awareness, (Postsurgical) Acceptance, and Advocacy" format. Linda began including the Gab-About in the emailings as well. In March & April, it began to take off with first "story of ostomy 'glory'" from Wild Bill/"Vesuvio's" unique urostomy journey that we hoped help at least one smoker stop.



EVERYTHING!"...

The MailBag

Dec. 2016

And, in May, it was Ed from Canada's day (month), an inspirational ileostomate. Linda began to receive other's stories of ostomy glories, but also ostomy "gories" and planned this for June, when Barb's story of

hubby Jon's colostomy, with "birth' and death of 'Waldo" eventually ran. But, at first, nostalgia and maybe neuralgia, stepped in when CCH phone # was requested from nearly 10 year old information divested and "digested" (hahaha). Linda uncovered a handwritten postsurgical poem, all but forgotten, but not misbegotten, embellished here for reminiscing and hissing at just how hellish it had really been! Linda planned to beg your indulgence for Gutsy's boldness to have her due, it's true, to paraphrase another meaning from CCFA: "I Can't Wait!"...for a later date than June's newly (re)named (by Trish) "Gutsy's FAB Gab-About: Stories of Ostomy Glories/Gories"...ah, but, ultimately, wait she did...and other stories premiered over summer and geared to early fall of 2016: July's "independently" remarkably resilient Trish/"Stomalina's" story of her chronic "Cdiff riff skiff tiff: Take a Whiff of Stoma Aroma!"...August's "august" story of Canadian colostomate Cathy's catastrophic experience and eventual reversal rejuvenating her health...September featured Amy O/"Feisty Amy's" incredible indelible ileostomy super survivor..."Shocktober" treated us to dual stories of Canadian Jo-Ann/"Percy's" colossal colostomy story...Each story is of tremendous strength, but most, just like Gutsy's are of longer length, and extend and expend beyond single month in publication variation [for MailBag, but emailed intact, in fact monthly!]...

But, Gutsy is now 10 years old, November 17, 2016! And, apparently much more mature and demure than Linda. Through having this little red alien attach herself to Linda and hang on for dear life, she saved Linda's life and helped her discover to be a lover of writing and (com) passion, as is her fashion, for others! Yes, this is positivity for an "Attitude of Gratitude!"...Without Linda, there would be no Gutsy, and without Gutsy, there would be no Linda! As simple and complex as all that!...For Linda and Gutsy: "Attitude of Gratitude" is not just the latitude of a platitude...it is indeed





So, now you see why Gutsy is sooo important to Linda! And why she is affectionately nicknamed "CozyRozy," "PalomaStomaforeverfriend," and the ever popular TMI: "Jamie Brown (i.e.): the hardest working ileostomy stoma ever!"...in tribute to James Brown...

Who will be next to "regale us with YOUR ostomy tale?!...Linda's "Attitude of Gratitude" was just revealed in Gutsy's own "Story of ostomy 'gory to glory" just in time for Thanksgiving...whether or not you feel the same, you are still a VETERAN...you fought a battle back from chronic illness, cancer, unforeseen situation, or emergency... always eager to hear YOUR "story of ostomy 'glory/gory"...nothing is "meager!"...email your WORD document attachment to Linda: blumbergl@duvalschools.org or patti@ostomymcp.com.... There is no "write" or wrong way to do this! (hahaha) ... "Gutsy's FAB Gab-About"...YOU supply the "Gab"...Gutsy makes it "FAB!!!"...CAN'T WAIT TO HEAR FROM YOU!

Newly re"(s) elected" "R"esident Gutsy encourages YOU to share BOTH columns INSIDE AND OUTSIDE ostomy community so we CAN "SPEAK OUT and OUR WORDS WILL BE HEARD/read/heeded as so sorely needed!!...help us change minds, as mentor to at least one dissenter at a time! Wouldn't that be sublime?!...Unlike those candidates competing for US "P"resident who ran a "smear" campaign...NOT "R"esident Gutsy! But, watch out! She can get "down and dirty," too...because she's sooo GOOD at her "job"



Dec. 2016

We are pleased to announce that the *Amelia Island Ostomy Group* will now meet at UF North Campus (Lobby area) on the second Monday of each month at 6:30 pm. This change, we believe, will make our group more accessible to those living north of the City and in southern Georgia. The change from the final Monday should result in less holiday interference with our schedule. We will attempt to arrange transportation for anyone who cannot make the drive from the Island. And, as always, Lynn and/or I are available to meet with, or call, anyone who cannot make the meetings.

UF North is located just east of the Airport Exit of I95A. It is also convenient to Rt. 17. There is ample, free parking. A number of our members are excited about the shopping and dining opportunities in nearby River City that can round out their evenings!

The first meeting will be January 9th at 6:30. Meanwhile, Lynn and I will be at Baptist Nassau on 11/28 and 12/26 at 6:30 (Lobby) to meet with anyone who may need information or support, or who attends based on meeting information in brochures we have distributed. We are printing new brochures with the updated information.

As always, we thank you for your support and remind you to share our information with your patients and colleagues.

We hope you have a wonderful Holiday Season and a great New Year!!

Eileen Widerman Lynn Oakes





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