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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: May 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 Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: May 6th at 2pm

Ocala Support

Contact info:

Shirley Gonzalez-Day 352-209-4986

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: May 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: May 20th

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
Parkway Jacksonville, FL 32218

(Meeting Room 3-4)

Free parking

Next Meeting: May 14th

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“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

Jo/Stella’s story:

“Hello Gutsy ...guessing you have a real name too [You betcha!...”my” girl is named “Linda!” hahaha...]

I'm thinking this feels a bit odd ...just spilling my own gutsy kinda story to someone I don't know ...but I'll give it my best shot and hope you don't think that I'm over extending my welcome 😊 [“Appropriate<d>” spirit!]

Jo is it 😊 and the Seaside part is because we're blessed to live in a great home on top of a cliff overlooking a surfing beach and South Australia's Gulf St Vincent on beautiful Fleurieu (pron Flew-ree-oh) Peninsula, a fantastic foodie and world renowned wine region [sounds lovely!]

My Stoma is actually my 3rd 😲 [wow!] My first unnamed reversal was back about 27-28 years ago after around 7.5 years with minimal remission from UC I was the 21st person to undergo JPouch surgery here and all went very well ...for quite awhile anyhow.

Quite a number of years later I found myself exhausted 😞 An old and favoured GP at the time diagnosed HLA B27 ...little did I know of that at the time 😞

And with an array of testing I was quite iron deficient ...little did I know this would stick around and be the cause or side step to bigger things 😞 I started on the yo-yo run of having iron infusions ...feeling great then slipping back to exhaustion again.

Over maybe 8 years and MANY infusions I accepted the fact that this was 'It' and as the infusions were spread out more ...well maybe things were improving. I was lucky to be having the Inf. on an extended time frame so things were ...well, fine by me.

During this period of infusions we moved home and during construction, excitedly walking through the site watching my footing, I slammed my head into the scaffolding, resulting in me seeing stars ✨ literally and later, apparently that night (I don't remember) I had a stroke ...a week in Intensive Care and being a rather determined woman, and it being Dec 19 and my discharge day, I insisted I go finish my Christmas shopping ... so against Greg's better judgement we went across the road from hospital and I actually did finish our Christmas shopping 😲 [This is kinda Ironic, if not chronic: while having a stroke <of genius!> is no joke...but, going Xmas shopping right after just stopping being hospitalized...though revitalized...is usually in-“appropriate<d>” and ill-“advised”...but, in Jo's cases...it was hilarity...and, guess what?!...with some similarity, after Gutsy was d/c from 8-days' hospitalization, WE went Rx shopping by popping across the street to Walgreens! Hahaha...kindred spirits!...]

A number of years further on and I'm getting a bit of hip pain, quite a bit really but I'm never fond of heading to the Doctor to find out something new 😞; although this happened really quickly in the whole scheme of things I, in hindsight should have been at the doctors sooner 😞.

The first GP, a younger and not my regular at the clinic suggested, like I thought, that it was sciatica So I went home on mild painkillers and 'waited for an improvement'. [Linda's beloved mom, Esther, wore a neck brace to deal with her sciatica...for a time]

Ha ...I managed a week before my 'husband' Greg (we're not married but have been together for 20 fabulous years) insisted, with me howling in pain that we should head to the Doctors again ... his idea was actually the ED but I finally agreed on the GP; so, with an emergency appointment made were off around the corner for a 500meter drive and in the Surgery seeing my regular GP. Yaayyy; someone who knows me and a bit of my history.

Whilst in the consulting room the GP calls a Colorectal surgeon whom I saw a few months prior with a minor niggly tail end procedure 😞 [Gutsy says “whilst” is “awesome Aussie” version of “American” “while” excursion diversion incursion!...]

Well that was it!! Off to hospital I go; if I could have had a bed that night I'd have been in there and then but I did manage another night in my own bed for the time being, for an 11-day stay, testing for everything beyond belief and seeing so many specialists I lost track. A hole in the bowel was determined but I needed to be reasonably well to undergo surgery so I was sent home with the

strongest Australian available antibiotics and a fantastic home nurse to regularly administer through a pic line ...along with painkillers. [oy!]

Over a period of nearly 5 years and my very determined Professor Colorectal Surgeon operated to try and fix the hole, so many times I can't remember; stitching (with Stoma no. 2 for 9 months), clipping, gluing, nothing worked, with many visits/stays about 6 months in total actually in hospital, for the ongoing infection from the obvious bowel matter escaping into my peritoneum and resting on my spine creating such incredible pain.

I ended up having my JPouch removed along with my R n A 😞, with a left sided Ileostomy and about 15 abdominal scars with 4 or 5 used multiple times ...I'm no bikini girl thankfully. [You GO, girl!...Gutsy wears a 2 piece, never ever tried a 1 piece...and, modesty prevents her from wearing a bikini, too: "appropriate<d> attire"...hahaha KINDRED SPIRITS!]

Turns out the offending hole resulted in a missing staple from the JPouch surgery some 27 or so years prior 😞

Now I'm just thankful to be getting back on track with life. My wonderful Greg wants an early retirement (I'm 50 and he's 56) and to be able to spend some healthy years together ...before old age sets in 😊 [You're only as old as you feel...or so they say..."write?!"...and, if that's the "real deal," let's ALL "approach" our olden golden years with EMBOLDEN-ed zeal!!!...THAT'S Gutsy's most "appropriate<d>" spiel!...]

Thank you so much for me being able to spill my guts ...ya know it's rather a good feeling ...getting it all out there. [See?! Cathartic... whether you're in the Arctic, are Sephardic <Gutsy is Ashkenazy!>...take your pick...nothing iconoclastic or too bombastic, but certainly classic...well, the "appropriate<d>" rumor is that humor helps when you've been sick!...of course, it helps even more if YOU are a smart "alec!" hahaha...]

I hope you are as well as can be.

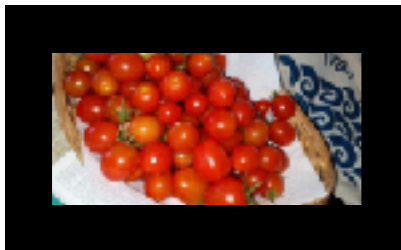
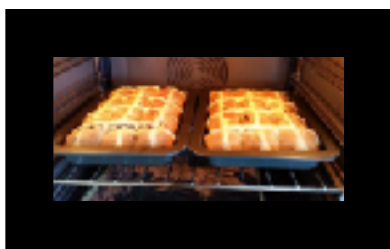
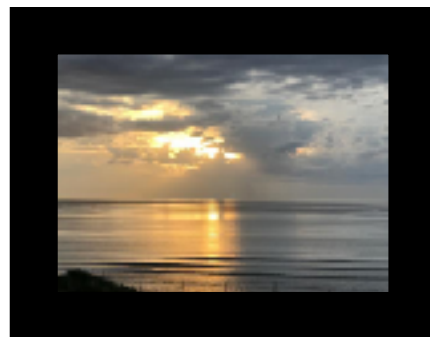
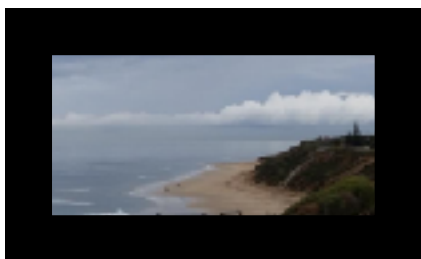
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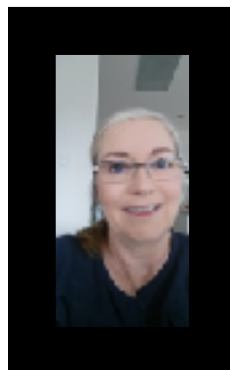
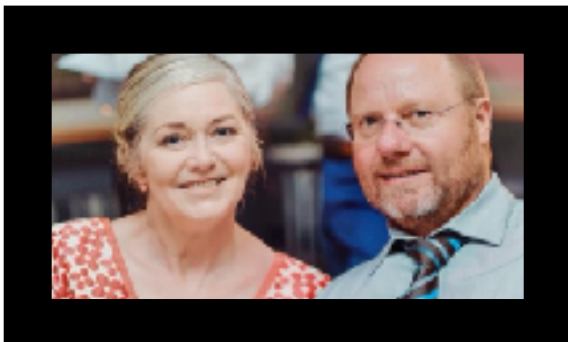
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Best wishes

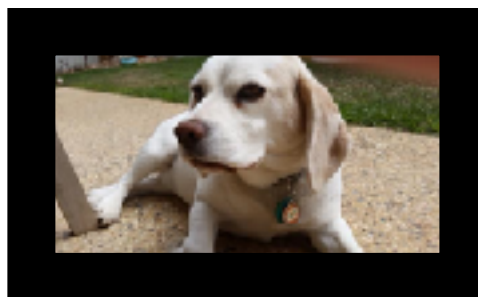
Jo 😊🇦🇺"

OUTDOOR SCENES: "Awesome Australia!"..."Appropriate[d] Adventure!"

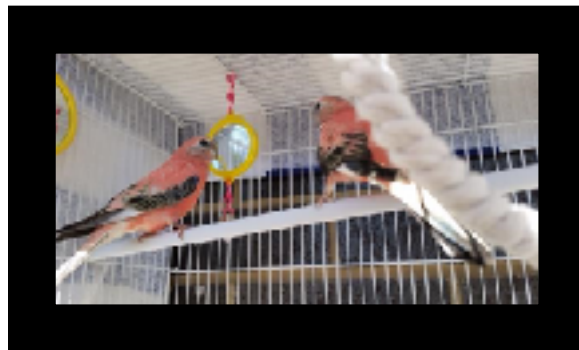
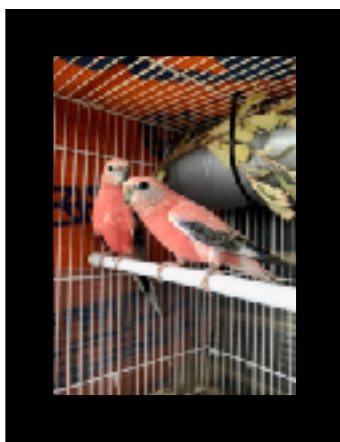




People: Jo & Greg...her beau...see them “glow?!”...”Appropriate[d] Affection!”



Pets/Vets: Pups/Parrots: “Appropriate[d] Acquisitions”



Email: jolang466@gmail.com

Gutsy “met” Jo/Stella, like most endearing others “appearing” in Gutsy’s FAB Gab-About on Inspire.com [ConvaTec’s 24-7/365 social media website]... so, what is Gutsy’s connection to them?...Gutsy found their story so “appealing” and “egg”-ceptional...and quickly “appropriate[d]” and dated as “appointed” for April!...with much “affection” in their direction...and reflection, Gutsy noted their introspection...but, it’s been “taxing” to find more similarities than differences...oh well, isn’t that what makes our world go “[a]round?!...”Continent[al]” differences “abound” first: oh, the “apparent” of Linda’s N “America” to Jo’s “Australia” [hahaha]...”Actually,” we both suffered from Colitis: Jo’s Ulcerative, to Linda’s “Crohn’s” combo...and, were buffered by ostomy surgery...but, Linda’s been lucky to have “appropriate[d]” only 1 stoma [Gutsy!]; while Jo “admits” to 3...Gutsy’s “brevity” [of life... never ever of levity!] is only 11.5 years old; Jo’s ostomy longevity is nearly 30 years old!...so, back to “Continent[al]”: JPouch [internal, sometimes infernal, reservoir]: Jo had one, but it only went so far; Linda was supposed to “achieve” one, but too ill, “ended up” with external, hopefully eternal(!) traditional transitional Brooke’s ileostomy [Gutsy!!]...Jo’s forsook her, and through revision excision incision decision, her second stoma was born...but, then her body had complications and forlorn, though “torn” [oy; literally AND figuratively!...], JPouch was taken down, and once “free,” along came #3!...on the left was created [Gutsy was elated for them...even though it was not on the “right” site...but, this one got a name: bella “Stella” along with their fella, Greg...a claim to fame!...must have been in reference and deference to “A Streetcar Named Desire”...from decades prior?!...

The nerve(s) of those stomas!

posted by user "Mike ET" on the [UOAA Discussion Board](#), May 11, 2009

The question or comment about stomas lacking sensory nerves, or the more broadly stated claim that stomas have no nerves, is a myth that dies very hard. Allow me to borrow from one of my presentations that partly addresses this issue:

"...most of the information carried by gastrointestinal primary afferent neurons is not consciously perceived. This is nicely demonstrated by tests on fistula patients who report no sensation when the healthy stomach is probed or in patients that have had the intestinal lining cut to take a biopsy." quoted from: Am J Physiol Gastrointest Liver Physiol 277:922-928, 1999. John B. Furness, Wolfgang A. A. Kunze and Nadine Clerc. page G924.

Additionally, we have: "There are more than 100 million nerve cells in the human small intestine, a number roughly equal to the number of nerve cells in the spinal cord. Add in the nerve cells of the esophagus, stomach, and large intestine and you find that we have more nerve cells in our bowel than in our spine. We have more nerve cells in our gut than in the entire remainder of our peripheral nervous system." quoted from: The Second Brain by Michael Gershon, M.D. page Xiii.

Alas, stomas do have nerves!

So, now let us put to rest the misstatement about the bowel and nerves, and bother to reeducate those who have misspoken early on. There are nerves; but the sensory nerves of the bowel between the esophagus and the rectum, for certain types of painful stimuli, such as cutting or cautery, are either very low in number and caliber or the brain is not readily able to perceive the pain. Of course, one can still be in pain in the a**; however, this is a topic for other times and places.

Editor's note: For some earlier articles we've published on this topic, see [Does Your Stoma Hurt?](#) by Victor Alterescu, which appeared in our January 1999 newsletter; and a reply by Mike ET (same author as the present article above) titled [Stomas and Pain Response](#), that we printed in our February 1999 issue.

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