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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: **Apr. 16th**

**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: **Apr. 2nd 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: **Apr. 9th**

The **May** meeting will be on the **3rd Sunday (21st)** due to Mother's Day. **Patti Langenbach** will be our speaker.

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

No meeting in April due to Easter
Next Meeting: **May. 21st**

**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 (Lobby area)

Free parking

Next Meeting: **Apr. 10th**



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

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

March 2017: (US events): Colorectal Cancer Awareness month(!); Daylights Savings Time begins (12th); St. Patrick’s Day (17th); Linda’s Spring Break (20th-24th); Spring begins (20th); Linda & Bruce’s 31st Anniversary (30th)

It’s Marvelous March! What makes it marvelous?! Not the usual *Madness* of time, battery, season changes...instead, we will *Spring forward* with our next RED hot *marvelous* stoma story *write* now!...we feel lucky, indeed to bring you **Babby!”Tommy:**” YOU have already met them previously...yeah, every time you read about “Funny, YOU don’t LOOK ‘Ostomish” in Gutsy’s Gab’s “Postsurgical Acceptance” section about naysayers’ insurrection, you will think of them! so, here is their story, as shared with Gutsy, reprinted with their permission!...[with some Gutsy asides]

...

“Tommy’s” Bio:

My path to meeting Tommy (my ileostomy) can’t be unique, but it’s pretty rare. I had been diagnosed with breast cancer in October 2014, and my surgeon felt it would be better if I had “neoadjuvant therapy” (meaning, chemotherapy ahead of surgery). She felt that a course of 8 chemo treatments would shrink the tumor (or even kill it off). If there were surgery afterwards, it would be on something smaller than the golf ball growing in my right breast. My first thought was, “Nah, just cut ‘em both off.” Or do the usual thing, surgery-and-then-chemo. But, I consulted with my sister-in-law who had had breast cancer, and my brother who had had lymphoma, and both attested that chemo was uncomfortable but worth it. So my husband and I agreed to go ahead with the plan, and I had my first chemo treatment November 14 (Taxotere and Cyclophosphamide), with a shot of Neulasta on the 17th.

Diarrhea began. [Barb/Tomela told Gutsy that it was actually “dire rear!”] On the 21st I was in the emergency room. I remember that, and in a few hours being admitted to a nice room in the hospital for the night. Then it was pretty much a blank for a week. Apparently, I suffered respiratory failure, then renal failure, and they told my husband I wasn’t likely to make it. I remember hallucinating with the face mask on (I guess I hated it and fought having it on). I had supercankles. My hair was falling out and I looked like Darth Vader when Luke took his mask off (puffy and hairless, although minus the scars). I remember the ICU curtains. And that my brother and his wife were there with my hubby. I couldn’t keep anything solid down yet... I remember three

separate thoracenteses (they stuck a needle into my back—not into the lungs), and out came 600 cc of fluid, each time. It helped with the breathing. I got down to a “2” from a “3” on the oxygen bottle.

By the end of the second week they were thinking I was getting better and there was talk of my going home after I could prove I could eat. Then my pain level shot up to what I called an 8 and I was getting breathless again. I remember that my heart rate set up camp at 130 for several hours. Fortunately, athletic training had made my heart a superhero and it was going, “Nah, I can do this for another couple of days, piece of cake.” But the good team took a look at another CAT scan and realized something was not right in my gut...

Another four days are missing. I awoke with tubes and wires all over the place, a big bandage from sternum to bikini line, and a BAG. I was told that my colon had ruptured, that I was septic and that it took them a long time to wash out my insides, before they were okay with sewing me up. They didn’t want to sew up one bit of infection by accident—I guess I was kind of open with a tent thingy over me for a while. The surgery was December 5, 2014. It was all touch and go still, but my heart kept pumping and I kept breathing, so I stayed here among the living.

And thus Tommy was born. I had TPN (intravenous feeding) for two weeks. I peed in bed. I couldn’t sit for more than ten minutes. I lost 20 pounds. But the chemo finally finished doing its thing and it looked like I could finally get outta the Big House after 30 days and go to a nursing home for rehab.

I liken what went on to a Space Shuttle launch: once you ignite the fuel there’s no unlighting it—the Shuttle lifts off and goes until the fuel burns out. So too, chemo does its thing, then burns out, and then you get the next chemo round. For me, however, it was the Challenger disaster! And it just kept unfolding in the hospital...

I looked up “TC Chemo and Pancolitis” and discovered that maybe one percent of people taking that particular chemo cocktail get what I had. And of that one percent, fewer than fifty percent survive the rupture and sepsis. I don’t know of anyone who is an ileostomate with that history, but there might be a few of you out there who get to read this. I’d like to hear from you; contact barbszabo@gmail.com. [Gutsy encourages YOU to contact them...lovely ladies...Tommy?]

...

So it's been over two years since Tommy was born. I did have the breast lump removed ten months after, when I was recovered enough to face surgery again. Then I got a second lump show up in a few months. Since my "treatment options" were limited, I went for the double mastectomy. Then in another few months ANOTHER lump showed up, in that 1% of breast tissue left that they never get after the mastectomy (Oh, lucky me!) and I had that excised in October 2016. Then at Christmas 2016 I noticed yet another lump. Sigh. Had that excised January 2017. The surgeon told me I should consider other options, since I was running out of real estate, and she couldn't guarantee good margins anymore.

So now I'm on the docket to start radiation, and my oncologist wants me to get on pills for ten years (read: ten years or the rest of my life, whichever comes first)! I'm at peace with it. We'll see how it goes.

Anyway, being on the tennis courts whenever I can has helped me physically and mentally. I am also pumping iron, which is kinda fun in a way. Tommy has taught me how to care for him; and although he's teardrop-shaped and not very tall I have learned how to use convex wafers and deal with the ever-difficult 4 mm of skin along his bottom edge. My journey has been from thinking I was never going to get out of the hospital; never going to walk; never going to leave the house; never going to take a car trip; never going to eat out; never going to fly; never going to play tennis again... blah blah blah...this post-op journey is probably common to many. The journey is the part that really matters.

Probably what I learned most from the surprise ileostomy is that I'm a lot more resilient than I knew. I pretty much immediately went into okay-this-sucks-but-it's-done-so-learn-to-move-on reality mode. And I also remember telling some visitor in the hospital, with one bleary eye fixed on them, "It's really hard to kill a Norwegian." With that, I sign off for now.

Cheers to you all,

Barbara and Tommy (February 2017)"

Now, Gutsy is poised proudly to bring YOU the many FUNNY LOOKS of Barb/Tommy...but, don't dare say ANY of them *look*... 'Ostomish!' ...[she did say something about "crackpots" and such...hmmm! Hahaha]...



barbszabo@gmail.com

blog info: www.amazon.com/author/barbszabo.com

But, now that YOU have read "Tommy's Bio," you know there is nothing "Funny" about Barb's journey to ostomy... for what she has endured...Many have survived colorectal cancer [especially in March: Colorectal Cancer Awareness month]...or bladder cancer that led to ileostomy/colostomy/urostomy...Barb is unique for her bouts with breast cancer and ensuing effect on colon that led to her ileostomy...she was "lucky" to have excellent medical and loving family care...as well as applicable advice...and, WE are also "lucky" that she shared their ongoing "triumph over tragedy" story...but, she has something else: an indomitable "never-say-die"...if, she can help it!...positive attitude!...she, like the rest of us did not WANT an ostomy...but, Barb/Tommy epitomizes what Gutsy [and Linda] so admires: she is active, proactive, reactive, and attractive!...[Gutsy says that describes EVERY CONTRIBUTOR thus far...and in the future!...WAY TO GO, BARB/TOMMY!!!!]...

4 Not-So-Common Reasons For Ostomy

Surgery By Editorial Team, ostomyconnection.com

The word "ostomy" is slowly becoming familiar in the media, but still very misunderstood. You may know people suffering from Inflammatory Bowel Disease (IBD) or colorectal cancer who require a temporary or permanent ostomy as part of their treatment, however there are other illnesses in which ostomy surgery may be needed. Here are four not-so-common reasons some patients require ostomy surgery:

1. Familial Adenomatous Polyposis

Familial adenomatous polyposis (FAP) is an inherited condition in which numerous adenomatous polyps form mainly in the epithelium of the large intestine. While these polyps start out benign, malignant transformation into colon cancer occurs when left untreated. According to an [article](#) from the National Center for Biotechnology Information, "Surgical management of familial adenomatous polyposis (FAP) is complex and requires both sound judgment and technical skills. Because colorectal cancer risk approaches 100%, prophylactic colorectal surgery remains a cornerstone of management." Patient advocate and blogger, Jenny Jones writes about her diagnosis with FAP, ileostomy and reversal straight pull-through surgery her [Life's a Polyp blog](#).

2. Colonic Inertia

Colonic Inertia (also known as slow-transit constipation) is a motility disorder that affects the large intestine (colon) and results in the abnormal passage of stool. It is a rare condition in which the colon ceases to function normally. A [study](#) from the NCBI shows, "Patients with severe constipation due to colonic inertia who remain symptomatic after extensive medical therapy or partial colonic resection have occasionally been treated with ileostomy as a last resort."

3. Chronic Intestinal Pseudo Obstruction

Intestinal pseudo-obstruction is a clinical syndrome caused by severe impairment in the ability of the intestines to push food through. It is characterized by the signs and symptoms that resemble those caused by a blockage, or obstruction, of the intestines. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) [explains](#), "...when a health care provider examines the intestines, no blockage exists. Instead, the symptoms are due to nerve or muscle problems that affect the movement of food, fluid, and air through the intestines."

[Sara Gebert](#) was diagnosed with Chronic Intestinal Pseudo Obstruction (CIPO) and Gastroparesis which required her to have ileostomy surgery in December, 2014. To raise awareness for CIPO she created [Sara's Army](#), a nonprofit

organization created to fund her own medical treatments as well as research towards a cure for this disease.

4. Hirschsprung's Disease

Hirschsprung's disease (HD), also called congenital megacolon or congenital aganglionic megacolon, occurs when part or all of the large intestine or antecedent parts of the gastrointestinal tract have no ganglion cells and therefore cannot function. It is a disease of the large intestine that causes severe constipation or intestinal obstruction. According to the [NIDDK](#), "People with HD are born with it and are usually diagnosed when they are infants." As a result, "some children with HD can't pass stool at all, which can result in the complete blockage of the intestines, a condition called intestinal obstruction." Thousands of people fell in love with 2-year-old Jameus after a post from his mom, Dallas Lynn went viral on Facebook. The family documents his journey to raise awareness for Hirschsprung's Disease.

UOAA's National
Conference
August 22-26 2017
in Irvine,
California

[http://www.ostomy.org/
2017_National_Conference_Page.html](http://www.ostomy.org/2017_National_Conference_Page.html)

Hernia and the Ostomate

by Eugene Broccolo; via Orange County (NY) Ostomy Support Group

Hernias can develop postoperatively through any surgical incision. Incisions that are not closed tightly are more prone to hernias. Colostomies represent surgical incisions that cannot be closed tightly because to do so could result in a stricture or narrowing of the bowel opening.

Hernias of colostomies, or pericostomy hernias, can occur frequently. They can be apparent in the immediate postoperative period, or more often, develop years after the original surgery. They can be recognized as a bulge forming around the colostomy, most noticeably when the patient is standing. Good bowel function is dependent on good abdominal musculature and is especially dependent on the muscles around the colostomy site. Therefore, a colostomy hernia would give symptoms of poor colostomy functions, e.g., incomplete evacuation, difficulty in irrigation and discomfort during elimination.

Most hernias will cause fewer symptoms with some external support, e.g., an abdominal binder, but the colostomy itself and whatever appliance is used will interfere with good compression. Therefore, surgical repair has to be considered for the hernia.

Since the very same problems exist at the time of repair as were present at the original surgery, e.g., inability to obtain

a tight closure, the recurrence rate for this type of hernia is much higher than with other hernias.

Because of the possibility that even in the best of circumstances a colostomy hernia can recur, the decision to proceed with surgery should be made only after consideration of all the factors, such as general health and nutrition, the degree of disability and the level of physical activity required.



6th National Conference
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