The MailBag

Feb. 2017

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

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: **Feb. 19th**

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: **Feb. 5th 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: **Feb. 12th**

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: **Feb. 19th**

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: **Feb. 13th**

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

"Speak Out and YOUR WORDS WILL Be Heard!"

By Linda Blumberg AKA "Mrs. Lips"

January 2017: (US events): Happy New Year!!!!: New Year's Day (1st); Linda "Returns" to work early for 2 day Hurricane Matthew make up (5th,6th instead of 9th); MLK Birthday (16th); Linda's "29th" Birthday (x2+3:27th…it's the NewYear's Math… get over it! Hahaha)…

Inspirational story of courageous 'gory to glory' as shared through Sue's blog, humor, "Remarkable Resilience" with Gutsy, with THEIR permission!:

Sue/"VeSUEvius"' story: from website: www.analcancerisreallyshitty.com

I'm finishing the manuscript for my first book, Anal Cancer is Really Sh*tty. It's a darkly humorous, brutally honest, and sometimes insane rant about a disease that nearly drove me out of my mind, but so far hasn't driven me out of my body. I'm alive and well and living with an ostomy bag. And that will be the subject of my second book. A Colostomy's Not a Catastrophe, But it WILL Provide Many Opportunities to Have One. My ex had a relative who committed suicide when she was told she had to have a colostomy. On the anniversary of her death, her grief-stricken parents drove to her graveside and followed her out of this world with a shotgun blast to each of their heads. The way I figure it, if she'd had a book as funny and optimistic as mine to read, three lives would have been saved. Don't do anything crazy. You haven't LIVED until you feel a fart blow right through a hole in your abdominal wall, into a bag that muffles the noise, eliminates the odor, and lets the gas seep slowly through a filter, eliminating the chance that you'll look like you have a balloon inflating in your pants. I'll be publishing both books in one volume, soon to be available on Amazon.com. You'll envy me the cancer and the bag, by the time I'm done.

In my book, I tell you what it's like to have anal cancer so you won't have to learn first hand… or first anus. Here's a preview from Chapter One.

Not the "Tail" I wanted to Tell:

"She Had Always Been An Unusual Girl..." That was going to be the opening line of my biography, which I'd write, myself, under a pseudonym, because nobody else would be better equipped to tell my story than I. What sort of egotist writes her autobiography in the third person? I was eight when I wrote that line. It has stayed in my head for 47 years.

I was always planning to do something worth writing about. My life was going to have vital significance. Something would be different because I had been here. Somebody's life would be changed. The world would be a better place. Something I would do would give hope and life and meaning to somebody. It wasn't supposed to end like this.

I have made no significant contribution to the world. My name is not a household word. I didn't find the cure for a deadly disease. I didn't stop a war, solve a crime, bring about world peace, or invent a useful gadget to make it easier for people to do important work. I didn't achieve fame or fortune. My marriage didn't stay intact. My kids didn't grow up unscathed by multiple mistakes and offenses—my own and others. I haven't solved the problems of poverty and homelessness-- not even for some of the people I love.
Instead, I am writing a book about the latest in a lifetime of meaningless humiliations. I am writing about my encounter with my greatest nemesis to date: anal cancer. Ass cancer, if you'll allow me a moment of crudeness. I am not her to tell you it's going to be all right if you have been diagnosed with this scourge. I'm not here to tell you it'll teach you wonderful lessons you couldn't have done without. I'm not even going to tell you it's easier to survive than you think it's going to me, because some of us will beat it, some of us will barely survive it, and a few of us, unfortunately, may die from it.

I am here to give voice to your gripes. I am here to say what you might be unable to say to your polite, refined family and friends. I am here to give you a catharsis. I am here to declare boldly and angrily what you might feel like saying but are too reserved to scream, except into your pillow in the dark. Ass cancer sucks ass! In fact, anal cancer is really shitty!

This is a shitty disease. It hurts, it's bloody, it can be messy, and the treatments are brutal. It's okay for you to feel all the rage, shock, terror, and denial you're experiencing. It's okay to flip out for a while and need a little vacation in the loony bin.

Hey, it happened to me. Oh, yes, it did. It was a “brief, reactive psychosis”, the shrink said. I was better in a day or two, though it would take me a while to get myself out of the psychiatric hospital, once I regained my sanity. But for a day or two, I was as nuts as any lunatic character Robin Williams ever invented in his silliest improvisation. In fact, I felt like I WAS Robin Williams ever invented in his silliest improvisation. In fact, I felt like I WAS Robin Williams, that afternoon after my biopsy.

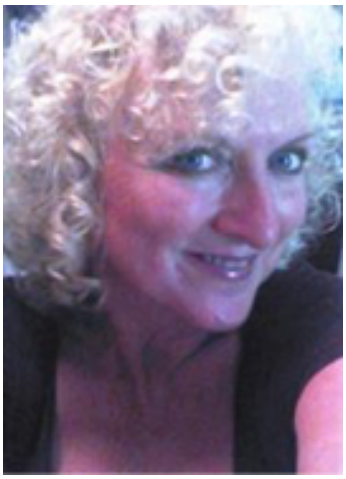
But before I tell you about that day, I’ll tell about some of the crazy-making symptoms and other stressors that led up to it. I won’t turn the book into a psychological thriller, exploring the depths of my own terror of disease and the death sentence we’re programmed from birth to believe cancer is. It’s not. More and more people are diagnosed with cancer each year, but fewer of us are dying from it. Still, some do, and it’s a crap shoot, whether we will ultimately succumb to cancer or not. But it’s not entirely up to chance. You can fight back and greatly improve your odds against cancer and other diseases.

A few years into the "patient journey" I am ever cognizant that remission can give way to relapse, and that I must take positive action to prevent a recurrence. I consciously, continuously battle for my healing. Every time I’d love to have a cookie or a piece of candy or a sugar-laden alcoholic beverage, I think about what it might do to my immune system, my body’s ability to fight disease. More often than not, I decline opportunities to compromise my health. And now, except for the annoying scar tissue that’s a continual and literal pain in my ass, I feel pretty fantastic.

I wrote the above paragraphs a few years ago. I’ve had two recurrences since, and am currently being treated for several inoperable tumors. There are more details in the book, and others will be revealed on my website as they happen. The book will be out soon, and it will end on a cliffhanger, because, while my cancer has been stable for months, my oncologist tells me I can’t make plans too far ahead. This disease can change in an instant. I’m still doing all I can to fight it, in addition to taking the chemo and enduring its side effects. I’m nearly seven years in. And I’m not giving up. Neither should you. Ever.

By Sue Molenda You can reach Sue at sue.molenda@gmail.com, or sue@analcancerisreallyshitty.com

~ From www.analcancerisreallyshitty.com Anal Cancer is Not a Dead End!
My illustrator Joe Russo wanted to "save me" from the flak I might get for using "Shitty" in my book title, so he proposed the line above as an alternative. I haven't led a scandal free life. I really don't think letting the "S" word grace the front of my book is going to ruin my reputation. I'll do a perfectly fine job of ruining it myself, by "oversharing" various aspects of my life, before, during and after cancer . And I hope to make you laugh, give you encouragement, and offer information you can peruse, if you are interested in alternative treatments. I have tried many, and I'll tell you about them and share supporting information. Let's learn to fight cancer to win.



~Susan Anderson Molenda

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

http://www.ostomy.org/2017_National_Conference_Page.html

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 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.

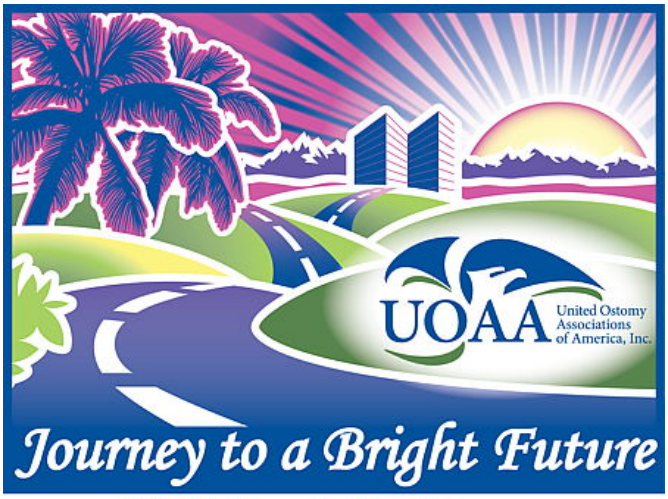
Kidney Stones and the Ileostomate

By Jill Conwell, RNET, Corpus Christi, TX.

Kidney stones are fairly common medical problems. They occur in about 5 percent of the population. They are more common in men with a sedentary lifestyle and in families with a history of kidney stones. The average age of first occurrence is about 40, but they can occur at any age. For ulcerative colitis patients, the incidence of developing kidney stones is about double that of the rest of the population. For ileostomates, the incidence is 20 times greater.

There are two basic types of kidney stones; uric acid and calcium. Both may occur in ileostomates since the underlying cause is dehydration. Uric acid stones are more frequent. One reason for this is the chronic loss of electrolytes, producing acid urine. The stones may vary in size and shape, some being as small as grains of sand, while others entirely fill the renal pelvis. They also vary in color, texture and composition.

Symptoms during the passage of a kidney stone include bleeding due to irritation, cramping, abdominal pain, vomiting and frequent cessation of ileostomy flow. When ileostomy flow stops, distinguishing between an obstruction versus a kidney stone may be difficult since the symptoms are similar. Treatment of most kidney stones is symptomatic and in most cases the stone passes spontaneously through the urinary tract. Medication for the spasms is usually administered. The urine should be strained in order to collect the stone for analysis. Once the composition of the stone is deter-mined, steps should be taken to prevent recurrence of an attack. The physician will prescribe medication or dietary modifications depending on the type of stone. The best preventative measure is to drink plenty of fluids (8 glasses) every day. If the urine appears to be concentrated, increase fluids and use a sport drink that is rich in electrolytes to replaces losses.



6th National Conference

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

UOAA Discussion Board

https://www.uoaa.org/forum/index.php

Medical Care Products, Inc
PO Box 10239
Jacksonville, FL 32247-0239

To: