



Patti Langenbach will be the guest speaker at the Ocala Support meeting on a special date due to Mother's Day.

Sunday May 21st at 2p.m.
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 between Ocala and Belleview.

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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 21st**

**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 7th 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.
 The **May** meeting will be on the **3rd Sunday May 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
 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: **May 8th**



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

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

Our next RED hot stoma story for May was supposed to be Jennifer’s colostomy reversal. Jennifer is not only gracious, but tenacious...and chose “Appealing” instead!...call it a “Rehearsal to learn about her Reversal!”...for “A-MAY-ZING” May!...[mea culpa; Gutsy pleads “Spring Fever” as the ruse for her excuse!]

So, who “chirped” and ultimately usurped this space?!...well, Carinne W “careened” in with bella “Stella the Stoma”. But, who IS Carinne? A medical professional ileostomate who is battling Crohn’s Disease...multiple hospitalizations and surgeries...ports, PICCs, ileostomy surgery...near-death Sepsis...now, with all this happening, you might think her attitude would lean more toward “Appalling?”...NO!...despite horrific hardships, Carinne has a “never say die...if I can help it”. So, without further adieu, herein, Carinne/Stella’s story of remarkable resilience as shared with Gutsy, and now all of you, reprinted with their permission:

“Here is my story that is on my personal page for the Take Steps fundraiser. My personal site for donations is: <http://online.ccfa.org/goto/carinne>...Thanks!

I knew at a very young age, 5 years old in fact, that I was going to go into the medical field. Twenty years later I completed my school to do just that. In 2009 I received my license to practice medicine as a Physician Assistant. I met my best friend five years prior, in 2004. We had our lives planned out. I was going to finish my schooling, we would move to North Carolina, get married and continue on our path to live our dreams with a few kids added to the mix later on. However everything changed the fall of 2011.

I can remember to this day laying on the gurney looking at the television screen of my colon during my colonoscopy. Unfortunately the medication they had given me did not put me to sleep. I then heard the doctor say, “yep that is definitely Crohns.” I began to cry.

I was officially diagnosed with Crohns disease fall of 2011. I met with a few different doctors in the area to get additional opinions since nothing was working to make me feel better. I was put on many different medications, none of which were helping. I became increasingly ill. I was having difficulty functioning on a day to day basis. I remember getting IV fluids in between seeing patients while I was working in the ER just to function. My mom insisted I get another opinion and pushed me to go to Mayo Clinic. We were not sure how I could even get to Mayo from NC in my condition, a two hour flight was concerning. Once getting to Mayo I was immediately seen by a doctor who admitted me

to the hospital since I was so sick. Shortly after I was diagnosed with severe Crohn’s disease when just a few months earlier I was diagnosed with mild to moderate Crohns disease. They immediately started me on an infusion that I would get every 8 weeks and a weekly injection which allowed me to feel better for a very important event in my life - my marriage to my best friend, Chad in June of 2012.

After our wedding I began to get more sick. The doctors began a regimen of medications including pills, injections, and infusions trying to find just one that would put this awful disease into remission. No such, luck. I was prescribed all of the traditional medications and still no relief. The doctors discussed trying clinical trial medications, however this meant I would not be able to get pregnant for years which really was not an option for me. After many discussions with doctors and family I had my first surgery in 2014 getting rid of the most diseased part of my intestines. Although this helped my symptoms for a few months, my symptoms came back with a vengeance. I was once again put on high doses of steroids with other medication and we still could not get my Crohns under control. Early 2015 my doctor recommended getting a temporary ileostomy and a colon resection to give my body time to heal. Reluctantly, I agreed to the surgery but I had so many questions. How was I going to function with an ileostomy? Would I be able to do the same things? Would my husband still want to hug me? Would I ever feel pretty again? Unfortunately, I was so sick I did not have an option so surgery it was.

Surgery did not go as planned. My intestines were much more diseased than what the surgeons thought. One month later I went back into surgery to revise my ileostomy. This began the scariest time of my life. The next three months were spent in the hospital. I was in so much pain and was physically unable to eat. I remember the doctors, my mother, and husband just begging me to eat but I physically could not - it was not a matter of choice. I lost 80 pounds in 3 months. It is such a scary feeling knowing that you are literally wasting away and you have absolutely no control over it. The surgeons, doctors, and residents did not know what was happening either. Since they had no medical reason why this was happening they began to doubt me wondering if I was intentionally not eating. It was a very hopeless feeling knowing that the nurses and doctors were judging me, not believing my symptoms. During this time my mother was flying from Chicago to North Carolina multiple times to stay with me. I remember sobbing when she had to leave, this meant I would be in the hospital all by myself since my husband had to work and take care of our furry family at home.

After 3 months of wasting away I was finally consulted by another surgeon at a different hospital and he initiated TPN (food through an IV) right away. This allowed me to get some key nutrients which allowed me to gain some strength and heal a little. Finally, I was able to get out of the hospital and go home although I was still unable to eat and in a lot of pain. I remember how hard it was to just take a shower. It took me over an hour because I would have to sit down multiple times because I was so tired and weak. I was still unable to work and sat at home 24 hours a day just waiting to get better. I struggled watching my husband work 9 hours a day only to come home and take care of me and the dogs day in and day out. I couldn't help but think how much stress I was putting on him and that he would be better off with

someone else, someone who was healthy and could enjoy life, someone who could be a 50/50 partner. I was incredibly depressed.

In October 2015 I was still unable to do much on my own so when my husband had to go out of town for work I flew to Chicago so my mother could take care of me. The night before my flight home to NC I developed a 102 temperature and became very ill. My mother called the ambulance and I was admitted into the hospital for sepsis (infection in my blood stream) from my port. This turned out to be a blessing in disguise. After treating my infection they transferred me to Northwestern Hospital to be further evaluated for my Crohn's disease.

While at Northwestern I was consulted by Dr. Strong, one of the best Crohns surgeons in the nation. He was able to take me to the operating room in November 2015 to fix my ileostomy and take some more diseased intestine out which was a huge success. After the surgery my mother and husband felt that it was best to stay in Chicago for 4 weeks while I healed. My mother was able to help me since I was still getting my food and fluids from an IV as well as giving myself IV antibiotics at home. I remember calling Chad daily the first week just sobbing, begging him to allow me to come home, I was so homesick.

2015 was a rough year for me and my family to say the least, but I fought through it with the help of my family and friends. After numerous wound infections, port placements, PICC placements, 80 lbs weight loss, sepsis, bacteremia, septic emboli, TPN (nutrition from an IV), and over 100 days in the hospital I can officially say I am on the road to recovery. I will always have Crohn's disease but I am finding ways to manage it which includes getting a 45 minute IV infusion monthly and take injections weekly. My recent colonoscopy in January 2017 showed no disease in my intestine and mild disease in my esophagus and stomach which is an improvement.

I am not a believer in the phrase "things happen for a reason." I do not believe that God gave me Crohn's disease and allowed me to suffer. I do believe though that he has given me the choice on how I handle the situation I was dealt. I chose to fight this head on and to make the best of it. I have learned so many valuable lessons over the past few years but I think the biggest one is pretty easy - life is short and can change in a moment so live it to the fullest. Chad and I have done just that in 2016. We were able to travel, deep sea fish, watch the Cubs play in Atlanta, see my sister play flute for the Thanksgiving Day Parade in Orlando, FL, and be with family and friends. We truly do not take life for granted anymore. We are once again living out our dreams and hope in the near future we can start a family.

I still do have an ileostomy and if given the choice in the future to reverse it I would decline. I am very proud of my stoma who I have named Stella. She has given me my life back. Stella does not define who I am as a person, she is just a part of me. [Gutsy says: "Way to go; that's the spirit!"...]

I thank you for reading my story and would greatly appreciate any donation you are able to give that will 100% go to Crohn's and Ulcerative Colitis research. I hope one day we are able to eradicate this painful disease. My hope in the future is to work with young adults who are faced with the same life changing event as I was - living with an ileostomy. While going through this experience I found out there was not enough support and education for new ileostomy patients. It is a very traumatic experience and something that is not spoken about openly. I want to educate others that there is life on the other side - you are able to do everything you did pre ileostomy, you will feel pretty again, and your husband will definitely still hug you.

I would like to thank all my family and friends for their love and support on my journey. I personally want to thank my husband Chad and mother Pam who have been my biggest supports and have truly been my angels. I thank God for them every day. Thank you to my Dad and friends for the visits and support as

well. I sincerely thank Generations Family Practice for being so supportive and holding my job while I was out most of 2015. I can honestly say I have the BEST work family! Thank you to Bob Sweet and Streamline Plumbing for supporting my husband while we were on this difficult journey. Lastly to all my friends and family for their prayers, good wishes, cards, and visits. I am truly blessed!

Carinne Woodworth PA-C
Generations Family Practice
(919) 852-3999"



Gutsy met Carinne/Stella on Inspire.com: [ConvaTec's 24/7 social media website]...Linda had longtime suffering with IBD "indeterminate Colitis" AKA combo "Crohn's Colitis"... but, it leaned more to UC...so, she could not relate to Carinne's Crohn's severity, Rx, surgeries, etc...However, both Gutsy and Stella were born(e) out of this...and, Gutsy found a kindred spirit...[as she always does!] in their mutual "Aptitude for positive Attitude!"..."Appealing" aptly applies!...certainly not just for April...check out Carinne's website/fundraiser for information on 4/29 event/to make donations...a worthy cause with hopes to fund further research to someday find a cure for Crohn's Disease and Ulcerative Colitis life-consuming chronic conditions!...

We hope YOU will continue with us on this ostomy journey of self-discovery and realize how "Appealing" Gutsy finds YOUR story! EVERY STORY IS WORTH TELLING!!!...and, no worries...Gutsy will continue to maintain the "integrity of your celebrity" by compiling, composing header to entice reader to story, and footer to entice reader to become future contributor with Gutsy as distributor...compacting but never "composting"...complimentary, complementary, completely complete!...with YOUR contributions, we will continue to share upcoming stories where YOU supply the "gab," and Gutsy's distribution via email helps us "SPEAK OUT AND OUR WORDS WILL BE HEARD!"...to be mentor to dissenters...and ultimately makes it "FAB!"... always eager to hear YOUR "story of ostomy 'glory/gory'"...nothing is "meager!"...email your WORD document attachment, including photos, website, etc. that makes YOU "shine"...to Linda: blumbergl@duvalschools.org... There is no "write" or wrong way to do this! (hahaha)...[YOU may notice Gutsy's BOLD/CAPS' writing/approach beginning to encroach...well, paraphrasing 1960's Star Trek tv: how else could Gutsy "BOLDLY" 'go' where NO STOMA has ever gone before?!...and, it's Gutsy's way, okay?...to seem like she's SHOUTING at YOU when she is only guilty of the ability to be "SPOUTING!"...hahaha]...

Carinne Woodworth and company!
carinnemckeever@gmail.com <http://online.ccfa.org/goto/carinne>

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

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

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



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