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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: **Mar 15th**

Gainesville Support Group Contact info:

JoAnne Bell at 352-284-4214
 Meets the 1st Sunday of each month (except Holidays)
 at Hope Lodge 2121 SW 16th St
 Gainesville, FL
 Next meeting: **Mar 1st**

Ocala Support Contact info:

Karen Franco 352-304-1309
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: **Mar 8th**

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 **Mar 15th**

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: **Mar 9th**

The Villages Ostomy Support Group
 We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August)

Saddlebrook Recreation Center
 3010 Saddlebrook Lane
 The Villages, Florida
 Linda Manson
tvostomy@gmail.com
 865-335-6330
 Next Meeting: **Mar 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”

we bring YOU:

Merrilyn/”Riverdrekka” [yes, Gutsy actually factually truly duly named her!]...from “Down Under:” Australia!...she is a newbie ileostomate dedicated and predicated to relaxation through music, imagery, and positivity...hmm...does this sound like someone else??? well, herein, her email, as first shared recently decently with Gutsy...reprinted with her permission...

I have an ileostomy but haven't a name for it as I figured pretty early on that it was a part of me like an arm or a leg so I couldn't bring myself to name it. I am mostly OK with it but I have only had it since March this year, and do have some days when I wish life were different.

I live in the Australian outback. In February I was admitted to a hospital 30 mins away and by the middle of March a decision was made to get me to Melbourne which is the specialist hospital for Gastro issues. It was a 90 minute journey on a light plane with the Royal Flying Doctor service. My condition had gone downhill so much I was barely alive. When I arrived they worked out I had a perforated bowel and emergency surgery was performed resulting in a partial colostomy. My surgeon told me my bowel was black and the perforation was one of the biggest he'd seen. I was lucky to have survived but at the time I felt like I wanted to die!

The plan was a reversal in about 12 months' time. I was released from hospital way too soon, then the fun really started! Within 3 days at home my stoma was full of blood and I still couldn't touch food. What had originally been diagnosed as diverticulitis turned into a diagnosis of Crohn's but the medicos were puzzled. It was unusual for a 60 year old to get Crohn's apparently. I was taken by ambulance back to the local hospital and they immediately put me on IV antibiotics (you know how it goes) and mega doses of cortisone. When I didn't respond to the treatment I was flown back to Melbourne (500 kilometers away) and thus started a merry-go-round of much of the same with an abscess, fistula between stoma and abscess (yes, my poo was leaking into the abscess and they had to put a baby bag on the abscess site). Seven months later and in Melbourne yet again, 30 kilograms lighter (TPN & naso gastric tubes kept me nourished because I couldn't even look at food, I'd had C Diff and MRSA too!) the medications they were using weren't working - Infliximab, Cortisone and some other horrible chemo drug I can't remember (and don't even want to :-))

They did a colonoscopy and saw what they thought was a tumor. It turned out to be benign but they were concerned about the risk of developing cancer because apparently that is a side effect of taking immune suppressing drugs! Who knew!!! On a positive note, they decided that I had ulcerative colitis. My wife, who is an ex nurse told me that if you remove the large bowel, you no longer have ulcerative colitis. At that point I told my specialist that I wanted a total colostomy and my surgeon and gastro guy both agreed it was probably the best way to go. I remember the morning they came into my hospital room and I told them what they were going to say. They were trying to tell me I needed the colostomy but weren't sure how to go about it, so I told them I knew what they were going to say, and could we please get the hell on with it! The operation was very successful. The wounds are nearly healed but it has taken a while because I had been on Prednisone. My appetite is back and best of all, other than vitamin D, I take no medications. They still want regular checkups done on my rectum and there is a chance that may be removed further down the line.

I was just getting used to my colostomy and no longer having leaks when I had an ileostomy. To date it has been much easier to manage and leakage issues are rare. I have had great stoma nurses although they do contradict each other :-)

The Inspire site has been great to pick up tips etc but mostly to realize I am not alone. I thought it would be great to check your column out - you seem so positive about it all. I read about your experiences in your email and even though our experience is different, a lot of it is very similar. So I know you get the feeding thing, and the thing where your veins refuse to be abused any longer, and the not wanting to get out of the hospital bed and being forced to etc etc etc.

Three months in to my hospital stay, my wife brought in two of my favorite Native American style flutes. Each day I would play for a few minutes. Not only did it help my breathing but inevitably someone would appear the door to listen. These flutes have such an incredibly calming effect. I have just bought another from Odell Borg in Arizona and spend a lot of time out on my deck which looks over the Darling river, just playing to the laughing kookaburras and other bird life. It may sound strange that I live in the outback but have a river out front. It is the Darling River and is the longest river in Australia. I live at the end of this river where it joins the Murray River which is the water source for most of the south of Australia. We still have water here but most of the Darling has run dry due to the shocking drought we have experienced for the last few years. I live in a small town of about two thousand people and the water we see is back wash of the Murray. This year has seen numerous birds escaping the dry conditions and appearing in our town. Some have never been seen in the area before. Kangaroos come in the evening to find a nice lawn to munch on but the emus seem to have moved on. At the moment we are experiencing dust storms every week or so.

My two beautiful dogs and I are so happy to be reunited and they have barely left my side. One of them alerted me to the fact that I had developed an abscess. She was sniffing my side one day and just kept staring at it until I realised the area was very painful to touch. Within a few hours it had developed into a major issue and I was readmitted to hospital!

I am really enjoying preparing my own food again and have managed to put on 5 kg which is great but I probably don't need to put on any more weight than that! Best of all, I finally have the motivation to get back to making music and have been recording in my studio for an hour or so most days. I tire very easily at the moment but spend a little more time there each day.

Well, this is actually a short summary of what happened! I have forgotten much of it and I'm glad I have. I can't remember how bad the pain was any more either. I was in a really negative space until a friend reminded me about a book 'A Course In Miracles', and with plenty of time on my hands I had a look at it. It was really hard going, but what I got out of it is that there are two states: Love or Fear and I get to choose which state I want to be in. That turned it all around for me and I started letting go of the fear and my attitude improved too. I still have a way to go because old habits die hard. When I can remember too, I try not to think about the future (or too much about the past for that matter), but rather, stay in the moment. I am still getting my strength back after being so deconditioned. I am now in the middle of an outback summer with temperatures often above 113 degrees F and 122 degrees F is not unusual and learning to keep my fluids up. I have enjoyed the stoma nurses advice to eat salt and vinegar chips too!" ...



Blog: <http://www.rivertrackstudios.com>.

YouTube channel: https://www.youtube.com/channel/UCjPYL9w-QnV7rOfni8IDAKQ?view_as=subscriber

Email: merrilynair@hotmail.com

Life Goes On, and a Fantastic Week was Had

By Ellyn Mantell, The Union County Ostomy Support Group of New Jersey

It was difficult to shift gears from one of the most difficult months of my life to throwing myself into attending the United Ostomy Association of America's (UOAA) Conference in Philadelphia, Pennsylvania. My nephew Adam's terribly aggressive illness and death so fresh in my heart, and knowing the sadness that surrounds the life of my sister, Michele, and brother-in-law, Ira, were not forgotten, but safely put aside so I could do what needed to be done, and with that in mind, I moved forward. I had big responsibility at the conference, and that included speaking to the Advocacy session (dressed in a cape with a mask since the speakers were called Superheroes!) as well as working on the coordination of, and commentating on the Fashion Show. (Additionally, my goal is to Support and as an Affiliated Support Group Leader, there were other responsibilities.) Both went wonderfully, and my heart was full of love and appreciation for the opportunity to attend.

The term "life-altering" is used frequently, and I would never question what that means to each of us. But my experience TRULY was life-altering in that I met the most amazing people...those living their lives to the fullest despite having a pouch/bag (ostomy) for either urine or stool. The camaraderie was exceptional and inspiring, and I want to share a few memories with you:

- Melissa Marshall is a fantastic performer and she is very well-known in Atlantic City. She performed two nights for us, even writing her own songs about the UOAA and how it brings us together! Wonderful entertainment!
- Our Fashion Show was incredible because we had 11 models who not only looked gorgeous, strutted the runway, sashayed and waved, smiled and strutted, but a few even wore their ostomy pouches with glamorous and even fun covers. Some are professional models who actually model this way, some are authors, grad students, social workers, etc., and all are living their lives BEAUTIFULLY! I loved working with them and thank Marilyn Smith and Sarah Mays who brought the clothes from Michigan for the show. I was particularly thrilled to have my husband, Bruce, and my four children, daughter, Allison and her husband, Dave and daughter, Emily and her husband, Jeremy. They completed the experience and made my heart sing with gratitude!
- I met a young man who was suffering emotionally from the effects of his ostomy until he met other young people just like himself. These young people actually had their own classes and places to bond, and last I heard, will be staying in touch with each other forever!
- Spending time with ostomates, from Susan Burns, the president, to the people who simply wanted to share their stories and learn all they could from each other, the classes we were so fortunate to attend, to a Fun Run sponsored by Nu Hope, a vendor of supplies, was just incredible. There are no airs in a group like this...we are all the same, and thrilled to be alive!

The misconception is that an ostomy ruins one's life. In truth, our ostomies give us life, give us health, and give us strength. I am so proud to be an ostomate and look forward to many, many conferences in the future. A salute to the theme of this one...INDEPENDENCE IS IN OUR BAG!

How Do I Clean around My Stoma?

Source: Vancouver Ostomy HighLife

All you need to clean around your stoma is warm water and either a washcloth or a soft disposable paper towel. Using sterile gauze and wearing gloves to change your own pouching system can be expensive and is unnecessary. REMEMBER, YOU ARE NOT DEALING WITH A STERILE AREA.

Using alcohol to clean the area is equally unnecessary and can be very drying to the skin. Also, it is not recommended to use baby wipes or pre-moistened towelettes as they may contain chemicals that remain trapped on the skin and can cause a rash. Soaps, including ones that are moisturizing (Oil of Olay, Dove) are not needed and can actually hinder the pouching system from sticking well on your skin and contribute to leaks. If you are showering without wearing a pouching system and soap flows down onto your stoma and skin, just rinse the area well afterwards. This is not a concern.

When washing your stoma, you may notice small specks of blood on your cloth. This is completely normal and expected. The stoma tissue contains small blood vessels close to the surface that may bleed, especially if you are taking blood thinners. Do I need to "air out" my skin when changing my pouching system to keep it healthy? No, this is not necessary. It may feel good to "air out", for a while but this is not required in order to have the skin remain healthy. This may also be difficult if your stoma is active!

Visit the Peristomal Skin Assessment Guide for Consumers
<http://psag-consumer.wocn.org/#home>



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