



Important Information for Medicare Beneficiaries:

The Centers for Medicare & Medicaid Services (CMS) is removing Social Security numbers from Medicare cards. Beginning in April of 2018, they will replace the current Health Insurance Claim Numbers with a unique, randomly generated number on new Medicare cards. Look out for your cards. This transition will take about one year. When you get your new card in the mail please call your ostomy supplier and physicians to let them know your new number.

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Jacksonville

Contact Information:

Patti Langenbach
(800) 741-0110
(904) 733-8500

patti@ostomy MCP.com

Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting: **Dec 17th**

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: **Dec 3rd 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: **Dec 10th**

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: **Dec 17th**

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: **Dec 11th**



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

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

Janet/”Pia’s” Story:

“Hello all; my name is Janet. I am 43 years young with spina bifida. I have three children and two grandchildren. I wasn’t diagnosed with spina bifida until I was three years of age. I had a very rare case; so it was not diagnosed right away, or the doctors were just not that aware of it. I was sent to Chicago to have surgery to remove the tumor almost immediately. From then on my mother was told I would not have a “normal” life and not have much of a life expectancy for that matter. I believe that I turned out the way I am as an adult because of how loving, accepting, and dedicated they were to making sure I was not treated differently.

My young years were spent in and out of hospitals to correct my feet mainly. When the tumor was removed, only 75% of it, it damaged the nerves and muscles to my feet. I had no sensation or movement from the knees down. I used AFO braces for many years to help me walk and at the age of twelve I had my first below knee amputation (BKA) due to constant wounds I kept getting. This was also around the age I started having problems with my bowels. The doctors were always so worried about my legs that none of the other spina bifida issues were ever addressed. To be honest, I know very little about what I have. At the age of 26 after my youngest child was born I started having issues with wounds again and had to have the same leg amputated above the knee. My son was one and a half at the time of the amputation and I was not able to walk anymore after that. I tried with many failed attempts. My remaining leg was just not able to handle the weight of a prosthetic.

Long story short, I got use to the wheelchair life; however, my bladder and bowels did not. I am very active in the wheelchair, but it is not the same when you are not able to “run” to a bathroom when needed. I had seen several doctors looking for help but with no success. I had many colonoscopies done throughout my time only to be told everything looked fine. With spina bifida neurogenic bladder and bowels were a guarantee basically and not much could be done. There is no muscle to help push the bowel out. I was basically on my own to deal with this. I finally found a wonderful urologist who suggested Botox injections in my bladder which has helped tremendously! Still, no suggestions for the bowels.

In 2015 I married a wonderful man who is very involved in my health. He would always come up with suggestions to help (thinking I have not already tried) when I would have terrible stomach pains from not having bowel movements. I could go up to two weeks before my intestines would have no choice but to finally release. I could just never get a break it seemed like. Out of those two weeks, I would be lucky to have at least three good days. We are both very active: we like to go on hikes, trails, and travel to different places. But of course we could only go as far as my bowels would let us.

A few months after we were married, we moved to New Mexico. I was originally from Indiana, my husband from Arizona. Being in a wheelchair, I was wanting to get away to some place where there was little to no snow and a place that did not rain often. My kids did not want to leave Indiana but understood why I was wanting to move. I waited until my youngest was eighteen so he had the choice to go or stay.

Moving was the best thing that has happened to me (besides my children). I developed wounds from being in the wheelchair and was referred to a plastic surgeon who highly recommended a colostomy before he would consider doing the procedure. I was thinking, yeah don’t think so buddy. The more I thought about it and mentioned it to my wound doctor, she said that with spina bifida it would possibly happen in the future at some point. She also said some of her patients that had the procedure actually learned to like theirs.

I went to see the Colorectal Surgery (proctology) Specialist. He was surprised and actually tried talking me out of it. He had never had a patient come to him seeking this kind of procedure. I did enough research to know I definitely wanted and needed it. The WOCN, a wonderful, kind woman contacted me shortly after the visit to discuss a few things and to also schedule a time to go over last minute things. On the phone I had asked her if it would be difficult where it would be placed with being in a wheelchair. That was when she got in touch with a great guy who was in a wheelchair and had his for years. After talking with this guy my mind was all for this positively happening. After all, I was told a colostomy could be a reversible procedure if I did not like it. A month before the procedure my bowels became so difficult that I was actually

looking forward to the procedure. I could take laxatives but it left me in more pain from the bloating and terrible gas build up. Not only did I have a hard time having a bowel movement but I also had a hard time releasing gas. I was really tired of my stomach controlling my life!

On April 4th of 2017 (also my grand son's birthday), "Pia" was brought to the outside world. The first time I saw her I thought she was the cutest thing, not what I thought it would look like at all. I was pretty surprised how well my husband adapted to this new thing as well. I spent three days in the hospital because the doctor was wanting me to pass gas before releasing me to make sure everything was working properly. By the second day he was consider in hours after the procedure. After an x-ray, he found I was still swollen inside as well as the stoma, said he should have thought about that because he had never seen a colon as tiny as mine.

At my two-week check-up the doc was pleased with how well everything was coming along; so was I. It was like a whole new world for me. I remember the first time my husband and I went to the store after coming home from the hospital, I had a bit of a stomach ache and said I wasn't sure if I wanted to go, he said why not? You poop in a bag now...let's go! I had to chuckle at the thought of knowing I could now go anywhere and just do my business at my own leisure. Life is good.

My six-week mark was a good one for me; we went on our first hiking trail. I was only able to do half of the mile and a half trail, but for just getting back to "normal" I was very pleased. I was worried about the intimacy part with my husband as well; it bothered me more than it did him. We have definitely gotten some good laughs throughout the few months I have had this. I have had my ups and downs along the way; it hasn't all been a piece of cake.

The first leak I had was my fault; but at the time you couldn't convince me: I thought my stoma was just being evil trying to ruin my morning. I woke up and kept itching down by the wafer near my naval area. I was itching through my shirt so didn't notice anything but a smell. I blamed it on my husband...yes, I know that wasn't right, but I didn't want to believe it was me. I went in to take a shower, and it was everywhere from me scratching. I was absolutely horrified! After cleaning up, I realized that seven days with the wafer was my limit. I get such a good seal that I don't often worry about changing it. I do now. I change my wafer every 3-4 days and more often if I know we are going out for one of our journey's.

I think I have accepted this new life fairly well. I know I still have more to learn, but just like everything else I take it day by day. As far as Pia being reversed...it's never going to happen! I am sure I'll have my days with my partner in crime where I'll want to be free of her always making messes, me of course cleaning up after her. But to go back to a life where she controlled me from the inside is not something I want to think about."

Janet Lapomarda

Email: janetlapomarda@outlook.com



Gutsy "met" Janet/"Pia" on Inspire.com...[ConvaTec's 24-7/365 social media website]...she loved Janet's "inspirational," positive "Attitude of Gratitude"...in spite of what others might have considered overcoming overwhelming, incredible, perhaps insurmountable odds!...Gutsy always feels a kindred spirit with ostomates who accept and CELEBRATE BEING ALIVE to feel EMPOWERED to live well/better with an ostomy...that is a given on how Gutsy is "driven" towards like-minded.kind individuals...like a loud proud shout out of a mantra or motto, without bravado, or staccato, but with vibrato. It was a no brainer to choose Janet/Pia as they epitomized our theme from Gutsy's Gab's.



A Visit from St. Ostomy

by Marjorie Kaufman, Los Angeles (CA) Los Ostomy News, via Austin (TX) Austi-Mate, Dec 1995

'Twas the night before Christmas and all through the flat,
There was general confusion including the cat.
The bathroom was strewn with the ostomy ware,
That I had abandoned in utter despair.

The courage I'd had in the hospital bed,
To follow instructions, had suddenly fled.
It all looked so strange, and uncommonly new;
I swore I would never know quite what to do.

Now which goes to which, and what sticks to what?
I fumbled each step, with my nerves overwrought.
And then in my anguish, I went to my room,
To settle my brains for a night full of gloom.

With a household a-flutter in holiday matter,
I shut out the sounds of excitement and chatter.
When out in the hallway I heard from below,
The sound of a voice with a jolly "Hello."

As I peeked through the door, up the stairway she came;
And she smiled when she saw me, and called me by name.
And I, in my wonder, just couldn't believe,
That ostomy visits were made Christmas Eve.

And then in a twinkling she put me at ease,
And said she could lessen my anxieties.

She was dressed all in white, in a form-fitting sheath,
With nary a sign of what lay underneath.
So trim and well-groomed, a delight to behold,
No one would suspect, unless they'd been told.

That standing before me so calm and serene,
Was the very first ostomate I'd ever seen.
Her manner so friendly, with faith and good cheer,
Soon gave me to know I had nothing to fear.

My questions, like leaves in a hurricane flew;
And with each knowing answer, my confidence grew.
Then under her guidance each part fell in place,
As I conquered the problem I'd just failed to face.

And all of a sudden I knew I was free,
To live just as normal and happy as she.
For only an ostomate is really akin,
To the fears and frustrations that lie deep within.

Her time and her friendship so willing to give,
Will keep me remembering as long as I live.
And my family was grateful for what she had done,
For once more the evening was festive and fun.

Now each time I meet her, more clearly I see
The "Saint" who came calling with blessings for me!!



Hints from Alice

by Alice Bowman, Stillwater-Ponca City (OK) UOA Chapter

Here are a couple of new hints that I picked up in the Detroit area:

1. Even if you do not like wearing a belt, do so for about two hours after changing your appliance, as it will help the adhesive adhere and last longer. Don't forget to leave at least two finger width loose--too tight and it will pull the pouch right off.
2. Check your size and make a new pattern for your stoma. Get someone else to use a magic marker and stiff, clear plastic (You can save the clear plastic from flange packaging or from small purchases in stores). A perfect fit makes everything more comfortable.

OSTOMY OUTPUT

via NV Town Karaya; and Green Bay (WI) News Review

What to do if your ostomy output becomes thin, watery, or greatly increases in volume:

- Never limit your fluid intake in order to thicken the drainage, since this can lead to dehydration.
- Avoid food which you know from experience makes drainage too loose and too frequent.
- Begin a low-residue diet, avoiding especially green beans, broccoli, spinach, highly spiced foods, raw fruits and beer.
- Add strained bananas, applesauce, boiled rice, tapioca, boiled milk and peanut butter to your diet.
- Pretzels help in thickening and add bulk to the drainage. The salt, also, helps to stimulate thirst.
- Many people lack an enzyme which is responsible for the metabolism of milk sugar (lactose). This condition can cause diarrhea, gas, bloating, nausea and cramping. The elimination of milk products may cause a dramatic improvement in the symptoms.

What to do if your ostomy output becomes thick, or if you develop constipation:

- Increase your fluid consumption, especially fruit juices.
- Increase the amount of cooked fruits and vegetables you are consuming.
- Very few foods need to be omitted from your diet because of fear of food blockage. Perhaps more important than the food in avoiding blockages is chewing well. You can reduce your intake of foods which are very high in fiber, and foods with seeds that are hard to digest if they appear to be a problem. Examples are Chinese vegetables, raw onions, nuts, pineapples, corn-on-the-cob, raw carrots, raisins, celery, mushrooms, popcorn, coconut macaroons and coleslaw.



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