



Guest speaker for Jacksonville meeting (July 17th) will be the Hollister Representative

“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’
The Birth and Death of Waldo: A story about perforated diverticulitis Continued from the June issue...

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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: **July 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: **July 3rd 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: **September 11th**

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: **September 18th**

Amelia Island Area Ostomy Support Group
 (904) 310-9054
 Meets last Monday of each month at 6:30pm Bapt Medical Center Nassau board room.
 Free parking
 Next Meeting: **July 25th**

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“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’” “Speak Out and YOUR WORDS WILL Be Heard!” By Linda Blumberg AKA “Mrs. Lips”

July: Busting out all over with our next “RED” hot stoma story! But, not of ostomy “glory”...No!...ostomy “gory:” from caretaker Barb of hubby Jon’s colostomy...it follows “Waldo’s” “birth” to his ultimate “death:” “RIP Reversal: Waldo!”...Long(er) LIVE a healthier and happier Jon and Barb!...as shared with “Gutsy,” Linda’s 9 ½+ year old ileostomy stoma!...

The Birth and Death of Waldo: A story about perforated diverticulitis Continued from the June issue...

How were people getting 3 and up to 7 days with just one pouch? That was my goal. That’s what we wanted. I looked online for answers with every spare moment I had. We never got more than 2 days and 2 days was pushing it. We visited a wound care nurse in the next city whose set up lasted a day and a half. Yet when I attempted the same routine I got 3 hours.

New words were being added to my vocabulary daily, words like pouches, wafers, pancaking, mucocutaneous separation, convexity, barrier wipes, crusting, etc. We tried convex and no convex. We tried a silicone convex ring and barrier. We tried barrier rings and no barrier rings. We tried Pepto Bismo which really helped his burned skin but I was advised by a Wound care nurse on one of my support sites not to use these because in her words most home remedies are “hog wash” That didn’t keep me from trying some though in desperation of a solution. So we also tried Milk Of Magnesia, butt paste-also a real help and once I even sprayed Bactine on the burn. The same wound care nurse I mentioned friended me on Facebook and was a huge support in my attempts and also morally.

Most of the nurses were as helpful as could be but I don’t think any of them knew anything about the type of fistula Jon had and most of them did not know how to pouch either so I walked in many times during his stay where poo leaked on him. I did find out during all this that wound care nurses are few and far between.

Probably the worse time I remember of all these times is when Jon was crying because he was in so much pain and I said to him in not such a nice tone of voice “please stop crying” and I think that hurt him more than the burn on his skin. I explained to him later that I wasn’t trying to keep him from feeling I was just trying to get him to stop shaking (from the crying) because I thought it might be what was making his stoma active and the reason I couldn’t pouch it.

We were up many a night at every hour from midnight to 6 a.m. with problems. We cried. A lot. We screamed. A lot. We cursed. A lot and at each other. We yell and scream at God. A lot. We continue asking and screaming “where are you God, why have you abandoned us?” We hurt each other’s feelings. A lot.

I get four weeks of vacation each year and every one I had scheduled for the year of 2015 was spent in the hospital with Jon. It wasn’t planned that way. We were “supposed” to spend those weeks at our weekend lake home. We only got to spend one week there this summer and Jon was probably at his sickest during this week.

In October I sent a friend I knew that had colon surgery a private message asking if she had a fistula when she was recovering. She replied immediately asking me to call her. I did and she told me whatever she told me was to be in confidence and explained her whole ordeal which believe it or not was even worse than my husband was going through. She did ‘not’ have a fistula and didn’t even know what it was. She couldn’t impress on me enough to get ahold of Cleveland Clinic and the doctor who she said put her “all back together” She gave me the doctor’s name, his nurse’s name and the phone number. I started calling and leaving messages as to what was going on. I thought 7 visits to the hospital in four months was excessive to say the least.

Most of October was wait and see with most all problems stemming around pouching Waldo. I was on support sites non-stop obsessed with finding a solution for pouching that would work. I was reading the stories of triumph and troubles to Jon to ensure him there was hope and to let him know he wasn’t alone. He would mostly ask “why is God allowing all these people to go through this?”

Jon wore sweats and pants with suspenders during this time or he would sit in his underwear with bag out. Any other type of clothing would rub on his bag. He took only sponge baths because he didn’t want to get his wafer wet and get a leak sooner than later. On all the support sites I visited, all of Jon’s symptoms were the same as people with Crohn’s or cancer yet he had neither. A huge blessing if we are to find any in all of this.

I continued calling all the suppliers and talking to their wound care nurses who were extremely helpful. Most sent samples of something I hadn’t yet tried. Still we had no success. Some days we changed 3 and 4 times a day. This went on for the whole 8 months of Waldo’s life. I didn’t stray far from home for fear of a leak. I worried every single day.

A few wound care nurses said Jon's colostomy acted more like an ileostomy because it was almost always liquid, very few times was it firm. We believe now this was due to the fistula. There were a few times during the change that if he coughed which always seem to happen during a change, his stool would shoot straight out of his stomach into the air. It reminded me of a whale. (attempts to change the pouch standing up proved to be too difficult and not safe). We missed Thanksgiving. We visited his mother at the Assisted Facility where she lives but Jon still couldn't or wouldn't eat. Christmas was the same. We didn't feel like celebrating. We didn't feel that there was anything "to" celebrate.

The 8th or 9th time (I lost count) Jon's stomach erupted was the night the surgeon put a Penrose drain in him to help with the draining. It was outpatient surgery and that night at about 9:00 he told me his skin was burning. I got up and looked and sure enough blood and stool had come through onto the gauze that was placed over the stitched up opening. I went through 3 rolls of paper towel when I said, "I can't do this anymore" I called 9-1-1 and had an ambulance come and take him to the hospital at 11:30 p.m. I called the Cleveland Clinic nurse to let her know what was going on. I called her again at 2:30 a.m. and left another message saying "I have GOT to get him out of here!" because they were admitting him again. She called my cell phone at 8:00 the following morning and asked if I knew I could do a hospital to hospital transfer. I did not know but asked her what to do. She said to have our doctor call Dr. Kalady and the Clinic and she provided the phone numbers. I texted our local doctor and asked him to do this. He texted me back about 20 minutes later, said he just got out of surgery and he would make the call right then.

Moments later he texted me back saying a transfer was being arranged. That was at 9:00 a.m. The Clinic would not have a bed available until 6:30 that evening when the ambulance would arrive a few hours later to transport Jon from our local hospital to the Cleveland Clinic, a 4 hour drive but one well worth it. My sister drove me since I had already been up 48 hours and didn't want to drive on so little sleep. When we walked into the room at 1:30 a.m. there was already a doctor in the room with Jon. The next morning I met Dr. Kalady who said he would be able to do surgery in 6 months as the bowel still needed time to heal, as did Jon, and because they saw the best success rates with doing reversals after waiting a good period. I asked him if he thought the fistula would heal by then and he said "it's not likely" Cleveland Clinic had him for a week and when they sent him home, sent him on 12 hour TPN with instructions to document input, output, weight, temperature, etc....daily and email the report to them each Monday. A Hickman is installed for the TPN. This is like a PICC line but this one is inserted into the chest. The PICC line previously used had been removed about 2 months prior. I am so nervous with these knowing they go straight to the heart. But I take care to put it on each evening and take it off the following morning faithfully using the alcohol wipes and flushing as instructed. On Monday Home Health also came and took blood for labs and sent that to the Clinic as well. Not sure why our local hospital never did this when they had Jon on TPN. The very first week Jon was on TPN and Cleveland got the report they called and said that according to his input/output recordings he was dehydrated so they changed the formula on his TPN bag to correct that. They continued with a weekly call to Jon each Wednesday after they had received lab work and our input/output records. We were very impressed with how thorough they were and Jon started getting stronger.

On December 21 we went back to Cleveland for a follow up visit and the doctor was very pleased with his progress. He was also given permission to eat real food today. The Penrose drain and stitches were taken out of his stomach. We were able to stop using the huge wound pouch around the end of November as drainage stopped. They scheduled us back in March for a scope, study and scan to see if surgery is a go. Before our March appointment Jon has put on 25 of the pounds he lost and is actually right where he wants to be and was allowed off TPN. In March his lab work was all outstanding and all was good to go for a takedown and surgery was scheduled for April 13. Also in March we had an amazing wound care nurse who told Jon "don't hate your stoma!" she said she is superstitious so if you say you hate it you would have problems, "just like you are having now" she said. She said in her Chinese accent, "so don't hate it! You don't have to like it but don't hate it!" And then she applied a technique that would work 24 hours for us from then until surgery in April. And actually the one I put on days before surgery lasted for 2 days! Even though for an entire month we were able to pouch without output every morning like clockwork, this final morning Waldo decided to have one big last hoorah I guess, we went through 3 set ups before he would stop enough to get a seal. If we didn't know better we would think Waldo had a mind of his own and knew he was coming to his end.

He also told us before surgery that Jon might get a temporary ileostomy in order for his colon to heal from surgery. After all the problems we had with the colostomy the last thing we wanted to see was another bag. We prayed and asked everyone we knew to pray he would not need an ileostomy even if it was only temporary.

After a three hour surgery Dr. Kalady called me on the house phone, told me what he found and what he did and his last words were "he does not have a bag". He said there were a few places he had to put back together, the fistula being one I am sure.

I started crying and thanking him and God Blessing him! It would be a while before I could see Jon but I wanted to see for myself. I even thought maybe I heard the doctor wrong and then I *really* wanted to see proof.

I only saw him for a brief moment after surgery which was fine because he was still quite out of it and I needed to catch the shuttle back to the hotel. We started the day at 10:30 a.m. and it was now 10:30 p.m. and I was exhausted. Waldo is now dead. Gone. No longer. Jon was in the hospital for 6 days. Day one and two he was still in a lot of pain and he has a low tolerance to pain. We did get him up walking though. Day 3 he was doing better. Day 5 and 6 he was eating a diet of everything but high fiber and wheat. Day 8 after we were home he finally pooped and I never saw anyone happier. That assured him that everything was "really" ok and that the bag is no longer needed and really gone. He did have to take a half dose of Milk of Magnesia which the Clinic told him would be ok to get the first movement.

Through all of this and as miserable as my husband and I both were he couldn't tell me enough how wonderful I am and I am still amazed that he would just lie there and trust me to do whatever I felt I should, could or might do. He said to me once "you didn't sign up for this" and I replied to that with "when I said "I do", I signed up for whatever comes my way so yes I "did" sign up for this".

Our friends and family and neighbors were very helpful as well. They sent cards to Jon and our neighbor helped several times with our yard work. I called Jon a guinea pig many times as many times I was told it's all trial and error. Most all of our nurses were amazing but some I still felt a need to keep a close eye on. We nominated one nurse in particular for an award for outstanding performance, which she won. She openly shared her experience in having a temporary colostomy at one time and was extremely helpful in answering so many of our questions.

Jon has now pooped about 4 times since day 8 post op and I have never seen anyone so happy. He said it's like he got a new transmission. We still don't have answers for why any of this happened but do believe we will be able to help someone else going through similar struggles and we are still waiting to be shown what our purpose is in all this because we know there is one. Life is getting better and we will continue to enjoy it and take it one day at a time.

Ode to Waldo

Gone are the days we need Hollister, Convatec, Coloplast, Nu Hope and Edgepark.
 Gone are the days we need barrier wipes, adhesive removers, wafers, pouches, paste, liquid band aid, belts, tincture of benzoin, tape, barrier rings, adhesive spray, stomahesive, and home remedies for the skin you burned.
 Gone are the days of worrying not "if" a leak would happen but "when"
 Gone are the days you interrupt our lives and sleep.
 Gone are the terms leak, crusting, it burns, pancaking.
 Gone are the days I can't use lotion for fear it will compromise the adhesives on pouching.
 Gone are the days when the only soap I feel safe using is Ivory.
 Gone are the days of you ruining our bedding, our towels and our carpets.
 Gone are the days of poop being splattered on the front of my toilet where Jon emptied his bag.

Gone are the days of driving through the country and wondering if you smell manure or if the "bag" is leaking.
 No more having our dresser covered in ostomy supplies.
 No more having our spare bedroom full of ostomy supplies.
 No more having to tear up paper towel to have it readily available for possible spewing.
 NO MORE YOU
 RIP Waldo...



(Jon and Barb) Nelsonb2258@yahoo.com

In May, newly renamed "Gutsy's FAB Gab-About" (by Trish) challenged YOU to share your "Birth of a Stoma"...well, Barb answered the call "espousing" Jon's story of ostomy "gory:" of triumph over extreme adversity undying LOVE!...

Who will be next to "regale us with YOUR ostomy tale?!"...School's out for summer...but YOU can still "educate" us about your "story of ostomy 'glory/gory!'"...email your WORD document attachment to Linda: blumbergl@duvalschools.org or patti@ostomymcp.com... There is no "write" or wrong way to do this! (hahaha)..."Gutsy's FAB Gab-About"...YOU supply the "Gab"...Gutsy will make it "FAB!!!"... CAN'T WAIT TO HEAR FROM YOU!...

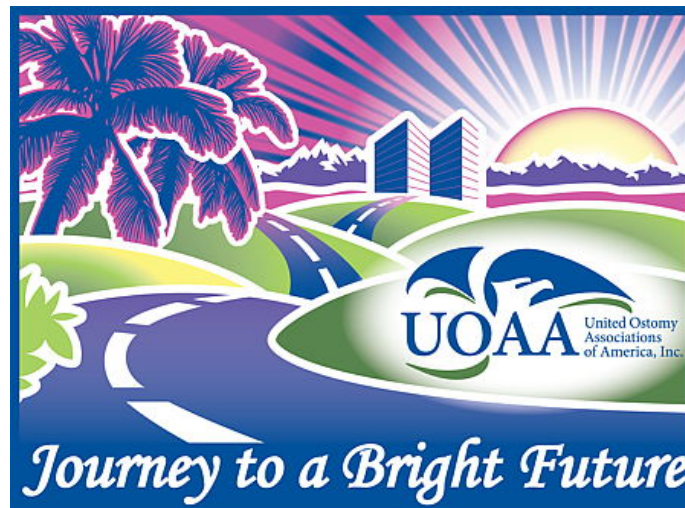
Short-term Ostomate: A Point of View

by Katy Duggan; via Pomona Valley (Upland, CA) *News and Views*; and Chippewa Valley (WI) *Rosebud Review*

One day I was on vacation in New York and simply feeling constipated. The next day I was in a Seattle emergency room signing a consent form for a resection (surgical removal of part of my bowel) and a possible ostomy. As an RN, I took care of many a child with a colostomy and could only remember the awful skin breakdowns that many of the kids had on their abdomens. I remembered the struggles to keep the old style appliances on their fragile bodies. I was feeling scared, confused and incompetent to take care of one on my own body. My surgery resulted in no ostomy, and I was relieved. I had only a colon cancer diagnosis to deal with post-operatively.

Five days later, I found myself again faced with a consent form for emergency surgery for complications. This time there was no doubt that I would have an ostomy — an ileostomy. The surgeon assured me that it would be only for eight to ten weeks, and then it would be closed. The assurance vanished with the first visit of the oncologist. He did not want me to have a third surgery, recover from that operation, and **then** start chemotherapy.

Now my challenge was to face nine to ten months of taking care of the ostomy on my body. Even as professionally trained as I was, I had all the same fears as those who must face living a lifetime with an ostomy. I kept telling my family I just wanted to pay a nurse to come in each week to deal with the bag change and any problems. I wanted someone else to deal with "it." I had to have help for several weeks but gradually became less "scared," not as "confused," more "competent" as each week passed. Although, as I write this, I am closer to the surgery date to reconnect my bowel, I have walked the road each ostomate walks. Between chemotherapy side-effects and learning new skills for managing an ileostomy, I am a stronger, more competent individual.



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