



From the UOAA President

We strive to advocate at a national level for all of those living with an ostomy or continent diversion in the United States. At the start of this month, we took a major step by hiring Jeanine Gleba as our full-time advocacy manager. Jeanine knows that she is building on the legacy of work done by Linda Aukett, and that she has big shoes to fill.

In the past weeks you may have heard that the issue of including ostomy and urological supplies in Medicare competitive bidding has resurfaced. This is an issue UOAA has long opposed. We are working with a coalition of patient organizations, health care clinicians, and technology manufacturers to address concerns over the inclusion of these supplies in the President's FY17 budget proposal.

The coalition's plan is on a very positive track, but we will remain vigilant in monitoring this and any threats to the health and well-being of the ostomy and continent diversion community. We will let you know at the appropriate time if any advocacy action is needed from you.

For more information and news updates on competitive bidding visit our website:

http://www.ostomy.org/Competitive_Bidding_of_Ostomy_Supplies.html

We will continue to ensure that the voices of our community are heard in this and other matters of importance. Thank you for your support.



Susan Burns
UOAA President

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: **June 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 Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: **June 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: **June 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: **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: **June 27th**

Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel



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

June: 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

I dubbed my husband Jon’s colostomy Waldo. He didn’t want to name it. He didn’t want to look at it, like it, think about it, acknowledge it or accept that it was now a part of him. I only knew about naming stomas from being on every colostomy support site I could find while on our upcoming journey.

Waldo was born on August 14, 2015. We believe that he was in the process of being born when Jon was boating with a friend on Lake Michigan in July of the same year and was thrown in the air and slammed down onto the deck when the 26 foot boat they were fishing on was hit by five and six foot waves not once but twice. Jon is a handsome 5’6” sixty seven year old, sociable, likeable and retired man who dresses sharp and sometimes is mistaken for being much younger.

Jon had called me at work to tell me what happened on the boat and to let me know he was in excruciating pain. His friend Chuck, who he was fishing with delivered him to my place of business, a 45 minute drive, where I was waiting for him outside to take him to our local Emergency Room. This trip would be the first of several. The X-Rays showed a compressed fracture of his L3. He was given an ample supply of pain medication both orally and intravenously and sent home. That all happened on July 2, 2015.

Jon continued on pain medication for a little over a week when on July 11 he returned to the ER because the pain meds were not alleviating the pain. While there he complained of constipation even though he was taking a stool softener. The ER gave him a Dilaudid shot, Flexeril and Motrin then advised him to take over the counter Miralax if constipation persisted and then sent him home.

Two days later Jon returned to the ER complaining of constipation, continued back pain and nausea. In the middle of the exam he got up, went to the bathroom and threw up. He was given yet more pain meds and an enema and sent home even though he had told them “something was not right”.

Later that same afternoon Jon called me at work to tell me that he is in so much pain he can hardly stand it. I make a decision to leave work and take him back to the ER “again” When I pick him up at home he is sweating profusely and saying over and over “we got to go” meaning to the hospital. As soon as I get him in the ER the staff takes one look at him and says “he is in distress” and they immediately get him back to be seen. His heart rate was high and blood pressure was low. They started an IV and put him on Dilaudid again. Because of how he is describing his pain and the location of it the ER doctor determines a CAT scan is needed and orders one. This CAT scan would show he has severe diverticulitis with small amounts of intraperitoneal air. (perforation?)

The general surgeon on call was paged and he determined that “surgery would likely not be needed urgently however this may prove to be a surgical case in the future”-words and a decision that still anger me today.

Jon is admitted and remains in the hospital from July 13 to July 24 as an attempt is made to conservatively manage perforation. During this time he developed an ileus and rising white blood cell count according to the medical records. His heart rate remained high and blood pressure low. Another CAT scan was performed which showed a large fluid collection, presumably an abscess. This was drained and over the next few days his pain improved and ileus had been resolved. The surgeon’s plan was to let the acute abscess resolve (on its own) understanding that there would be a colonic fistula in the short term. This too is in the medical records but I am unclear as to its meaning.

Most of the medical terms I use here are understood, some are not and I am taking them directly from the medical records which I obtained-for a fee-from the hospital. Jon is treated with a JP drain (a tube surgically inserted with a rubber ball on the end that resembles a grenade and can be emptied). He is also on two antibiotics during this time and is instructed to empty and record drainage from JP drain daily. If surgery is needed, Jon has made it clear he wants to avoid getting a “bag” at all costs and the surgeon has agreed.

So we wait two weeks in which Jon is becoming sicker, weaker, losing weight and somewhat incoherent. Since all this began on July 2 Jon has lost 45 pounds, he will only drink Ensure, nothing tastes right to him and he can barely walk because he is so weak. I am pushing him in a borrowed wheelchair wherever we go. This is all while they are trying to “conservatively manage the perforation” We don’t know any better and think this is all part of the diverticulitis but have come to rethink that today after reading all the medical records.

I don’t know who this man I live with is, he sleeps almost all the time, does not eat, does not talk, does not care how he looks and basically just doesn’t care about anything which is totally opposite of all his behaviors. I miss my husband. He now looks and acts like a ninety five year old man. We would later come to find out he had become severely malnourished and dehydrated.

Since the drain had not been working for the 2 weeks of conservative management, and Jon’s condition was deteriorating surgery is scheduled although we still have to wait another 2 weeks! Reasons were the surgeon would be on vacation one of those weeks and didn’t want to perform surgery and then not be available so we had to wait yet another week to schedule after he returned from vacation because that was the first opening available.

The surgery took 3 ½ hours. There are a lot of notes in the medical records as to what a mess it was once they got in. It was noted that a small bowel resection was performed because "it appeared *the drain had been placed through his small bowel* and several enterotomies were created in mobilizing this"- again, not sure what these medical terms mean but reading the words in bold italics gives me great concern-especially since we had trouble with the drain and had to have it changed or replaced more than 3 times due to it coming out or plugging up. These trips are all documented in the medical records as well. I personally have lost track of some time because it is one thing after another and I am emotionally and physically drained so the dates I list may not be exact but are very close. One time they even told us they were really busy and asked if we could come back. Jon looked at them incredulously and said "NO!"

It was also noted that a good 500 ml of undigested food and feces were found once they went inside to operate. There is a very long description of how complicated this surgery was, how much damage had been done and describes how Waldo was born. The surgeon told me it looked like a World War had taken place inside of Jon. He also had to be given 2 units of blood to replace what he lost during the surgery.

Jon woke up to a stapled stomach, a tube down his nose, the JP drain still in place and the dreaded "bag" He didn't know about the bag until I told him. He was still too weak and incoherent to understand too much. But he "was" coherent enough to understand he now had a bag because he started to cry and said "Why, why didn't they just let me die? I told them I didn't want to live with a bag, I'd rather be dead". And he meant it. He stayed in this depressed state for quite some time, maybe even the entire 8 months until the death of Waldo. After surgery he still appeared to be malnourished and now his voice is almost gone making him "really" seem and sound like a ninety five year old man.

He has also started hiccupping which aids in his discomfort. The nurses are looking up home remedies and trying them. Some work but only short term. It wouldn't be until 2 or 3 weeks later when we see an internist that he is prescribed Baclofen, a muscle relaxer that finally remedies the non-stop hiccupping. I believe it was a few days after surgery when Jon was recovering that a green to brown discharge was noticed coming out of his JP drain. The nurse said something didn't look right and contacted the doctor to let him know.

Another CAT scan was administered that showed an enterocutaneous fistula. The easiest explanation for this type of fistula is it's an abnormal connection that develops between the intestinal tract or stomach and the skin. As a result the contents of the stomach or intestines leak through to the skin. Jon's fistula is leaking into his stomach behind the incision (place of least resistance) where it will eventually erupt. More than once. It cannot be surgically closed at this time due to the hostile environment in and around Jon's colon. They don't want to create any more damage to the damage that already exists. It was explained that it would be like trying to put a needle through a noodle.

Sometime around August 22, my birthday, I have to call my sister and ask her to come and stay the night with me as I can't stop crying. She comes and offers me comfort and support and spends the night. Jon is still in the hospital. He is still very sick. I miss him so much. I go every morning for an hour before work and return after I work every evening until 7:30 p.m.

The hospital has planted a robot in Jon's room to keep an eye on him and make sure he does not get out of bed and to report him should he doing anything harmful to himself. Is this also because there are not enough nurses on staff? He is very weak and does not move fast at all. They did have him on several various drugs and at one time I had to ask them to evaluate him as he was hallucinating and was also showing signs of delirium. He told me when I entered his room that he was chairing a meeting and that I was interrupting and shushed me. He told one of the nurses he was at band practice. After I demanded they evaluate the drugs being administered he was taken off some and that improved his knowing where he was and what was going on. I sometimes think the drugs are used as a way to ignore or not have to deal with a patient.

The doctor is managing the draining with the JP drain and watching it closely in the hopes it would close on its own and eventually send him home with the drain. Twice from August 14 until now Jon's fistula had caused distension in his stomach, pain and two trips to have it drained by needle. We catch these before they erupt from his stomach. It was drained once in the hospital and once in the surgeon's office where Jon is sure he left a fist size bruise on the doctor's side as he squeezed because it was so painful. The first time it was drained at the bedside by the attending physician who later told me Jon's condition would probably never be able to be reversed and that he would more than likely need surgery in 9-12 months at either I.U. or Mayo clinic as the local hospital would not be able to perform this type of operation. Then he looked me straight in the eyes and said "you do understand what I am saying?" I told him I did and then I had a bit of a breakdown with anyone that looked at me or talked to me for the remainder of that day. Our own doctor visited the next morning and his take on Jon's situation is not near as gloom and doom as the attending doctor reported originally. Our doctor said he would be able to reverse Jon in a few months and he expected Jon to have a complete recovery.

Jon got to a point where he required a PICC line to get him the nutrition and hydration he needs. Note: A PICC line is a thin, soft, long catheter (tube) that is inserted into a vein in your arm. The tip of the catheter is positioned in a large vein that carries blood into the heart and is used for long-term intravenous (IV) antibiotics, nutrition or medications, and for blood draws). He will wear this 24 hours a day. The bag is concealed in a back pack. The local hospital does not have us document anything during the time Jon is hooked up to this. When we arrived home "this" time from the hospital Home Health had delivered to our door a box of seven huge TPN bags in 4 boxes which have to be refrigerated along with all the syringes, vitamins and supplies. No one warned me I was going to have to find room and a "lot" of it in my refrigerator for this. I had to throw food out to make room for the TPN bags. I was totally unprepared for all this! I wished someone would have told me what to expect. I got everything unpacked and loaded into the refrigerator.

Jon's condition continued to worsen. He continues telling me he knows he is dying and tears just roll out of his eyes when he tells me. I too am getting depressed now. I believe him because he looks so bad and I feel so bad that he is in suffering every single day. I too don't understand why God is allowing this to happen.

Friends and family continue asking me how Jon is doing and I honestly don't know how to answer. Something seems to be constantly happening or going wrong. I hold my breath every day that I am at work waiting on the call where Jon says "it's leaking" or "burning" both words I came to both fear and hate. Several times I do leave work due to these reasons.

I smell crap. Everywhere I go and with everything I do, I smell crap. I wonder constantly if I got some on me while doing his change. One day after I walked into my office shared with 3 other people one of my co-workers said "It smells like sh-t in here!" I thought oh my God, did I some get on me and I am bringing the smell in here? Thank God my employer understands and I only live 8 minutes from work. A few small blessings anyway.

Jon's surgeon has texted me with his cell number so I can get and request updates from him whenever I need or want to. A week later the drain is removed as the draining has appeared to slow down enough to treat it with surgical gauze pads and Jon is released to go home. After Jon was home from the hospital for about a week I believe, we return to the hospital again due to his stomach erupting with poo and the draining is too much for us to contain with only gauze. This is not the first time it would erupt from his stomach.

The medical records say that on August 29th Jon's symptoms and draining seems to be worsening. When the draining first started it was moderate but has become severe. We went through all our paper towels and cried because it just would not stop. We are back in the ER at 2:30 a.m. and the wound care nurse has been notified to come as soon as she gets in due to Jon's skin now being excoriated. The aides keep picking up his backpack and walking away with it to get it out of the way. I had to tell 3 of them "it's attached! It's his TPN which is attached through to his heart!" At 8:00 the wound care nurse visits as well as our surgeon because he too has been notified. I start crying and telling them I am a failure because I can't get anything to work. Both the wound care nurse and doctor hold me and try to assure me that I am stronger than I think and doing a great job. I don't feel it. Besides not being able to contain the fistula drainage, I also am not able to pouch Jon's colostomy. It continually leaks and I continually change it. Every time Jon says "it's leaking" or "it is burning" which I hear every day, I feel like I have failed "again".

Jon still will not look at it and still hates it with every fiber of his being. Waldo is not easy to pouch either. He is named Waldo because he is not always easily seen. My understanding is that stomas that are "planned" are marked as to where their location will be and they stick out. Waldo was not planned and he does not stick out. He is actually retracted on the right side and flush on the left and he tilts to the right where there is some separation. His opening is also very small measuring only 1/2" x 15/16 wide so has an oval shape. The "planned" ones are round. Also it is located so that when Jon stands up it folds almost completely closed. More on that later.

The wound care nurse at the hospital hooks Jon up with a very large wound bag that has a part cut out of it that is the size of his incision because this is where the fistula is now leaking from. There is actual stool coming out of his stomach though his incision. We are told this fistula drainage could last anywhere from weeks to months and that much more healing will have to take place before they even consider surgery. Jon is still depressed and does not understand why God is letting this happen and not stopping it but continuing the agony.

When we first were home in September I had 3 wound care nurses in two days from Home Health come to try and pouch Waldo successfully. All 3 pouch attempts leaked. I felt I knew more than they did and had to re pouch after each one. Theirs only lasted one to four hours where I got at least 8-12 hours. One morning at work when I first walked in and one of my co-workers asked how I was I started crying and walked to my desk. I was angry and exhausted. She held me for a bit and we got back to work. When I looked down I saw a puddle of tears on my desk, I didn't know I had been crying that hard. Later another co-worker had told me they never knew if it was safe to look me in the eye. I didn't realize I was like that as I was just going on adrenaline I guess.

September 9, 2015. Jon smiled, first one I have seen from him since July 13. It was beautiful.

Stay tuned for the rest of the story in the **July** Issue of the **MailBag**...



Jon and Barb Nelsonb2258@yahoo.com

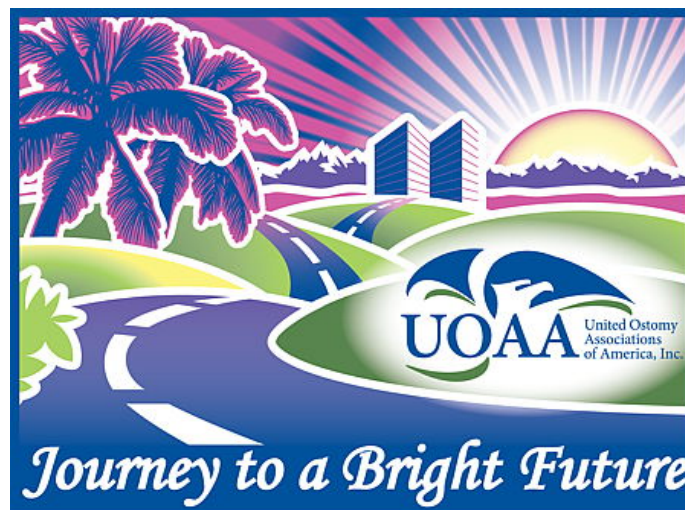
In May, newly renamed "Gutsy's FAB Gab-About" (by Trish) challenged YOU to share your "Birth of a Stoma"...well, Barb answered the call "espousing" Jon's story of ostomy "gory:" of triumph over extreme adversity undying LOVE!...

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!... Nothing "je-june" (dull) about that!...

Conference Planning Underway

The UOAA National Conference Planning Committee met this month at the location of our next conference, set for 2017 in Irvine, California. Our **6th National Conference** will be held at the [Hotel Irvine](#) August 22-26, 2017 with programming set to begin on August 23rd.

Committee leaders have been hard at work planning a schedule that builds on the success of the educational programming and fellowship of previous gatherings. "As the speaker coordinator, I am excited about the great medical professionals from California who have agreed to present at this conference," says Mille Parker. She adds, "We have some great motivational speakers lined up and some returning favorites! As the sessions get finalized we will be highlighting them for you.



6th National Conference

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



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