

# The MailBag

Jacksonville group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street.  
 Ocala support group 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).  
 Amelia Island Area Ostomy Support Group meets last Monday of each month at 6:30pm - Bapt Medical Center Nassau board room.  
 Gainesville Support Group meets the 1st Sunday of each month (except Holidays)  
 Hope Lodge 2121 SW 16th St Gainesville



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Jacksonville Contact Information:  
 Patti Langenbach  
 (800) 741-0110  
 (904) 733-8500  
[patti@ostomymcp.com](mailto:patti@ostomymcp.com)

The Jacksonville UOAA chapter meets the 3rd Sunday of each except when otherwise posted.

To help offset the mailing cost you may now receive the MailBag Newsletter via email. Please contact:

Patti: [patti@ostomymcp.com](mailto:patti@ostomymcp.com)  
 (Newsletter will be in PDF format)

Support group meets the 3rd Sunday of each month 3 p.m.  
 4836 Victor Street  
**Next Meeting Mar 20th**

**Gainesville Support Group** meets the 1st Sunday of each month (except Holidays)

Next meeting: **Mar 6th at 2pm** at Hope Lodge 2121 SW 16th St Gainesville, FL

### **Contact info:**

Brinda Watson (352) 373-1266 Nelson Griffiths (352) 376-8703

### **Guest Speakers**

Patti Langenbach of MCP & Sara Bertrand physical therapist

Ocala support group 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 13th**

### **Contact info:**

Lynn Parsons (352)245-3114  
[www.ostomyocala.com](http://www.ostomyocala.com)

### **Amelia Island Area Ostomy Support Group**

meets last Monday of each month at 6:30pm (except May, June, July & Aug) Bapt Medical Center Nassau board room.  
 Free parking (904) 310-9054  
**Next Meeting Mar 28th**



## “Gutsy’s Gab:” “Speak Out and Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

**March:** *comes in like a lion...* well, Linda’s 9+ year old ileostomy “Gutsy” is not *lyin* to you when she *marches forward* and shares: “Wild Bill/Vesuvio’s” first installment of *his story of ostomy glory...* reprinted with *their* permission...

### MY OSTOMY:

I don’t remember exactly when this all started. Sometime prior to 1992 I began to experience a kind of burning sensation in my bladder. I wasn’t terribly concerned and assumed it probably was something I ate, or drank. My “drinking” was a purely social event kind of thing and I rarely drank any alcohol on a daily, routine basis at that time of my life. I did, and still do enjoy wine or beer as a kind of supplement to the food I might be eating as sort of go-togethers, like fish and Rose’ wine or beer and ribs.

I also was smoking about two packs a day also. More about that later...

Finally, I decided to see a Urologist regarding the burning bladder business. I explained the symptoms, a urine sample was taken and an antibiotic prescribed. End of story; or so I thought. After a period of time the burning was back. This time a device was used to look inside my bladder and also scrape off a tissue sample for analysis.

About two weeks later I reported back to my urologist for a consultation. The diagnosis was that the cells of my bladder wall exhibited characteristics for a pre-cancerous condition. I don’t believe he said they actually found “dyed in the wool” cancer cells and apparently, it was just a matter of time before they would, indeed, become cancer. Many men have exhibited similar symptoms, also including or only involving the prostate. The usual procedure then would involve chemo and/or radiation treatments. The type of cancer involved usually progresses so slowly that many of them die of other, natural causes before this cancer becomes fatal.

However, due to my age, 56 at the time, there was a good chance I could live long enough for the cancer, despite treatments, to become an issue. He recommended surgery to remove the bladder and create an ostomy opening in my abdominal wall to allow urination. He then explained what I needed to know about how to live with such an arrangement.

I went home and discussed the situation with my wife. I did value her input but ultimately, it was my decision to make. I don’t know why, but the thought of having surgery and an ostomy didn’t really get to me. Yes, there was a good chance of beating the cancer and that seemed to matter most to me...” *more to come!*

Bill is the first to “regale us with ostomy tales”...Who will be next?...Be a “lamb” and: Email stoma names/stories with publication permission to: [Patti@ostomymcp.com](mailto:Patti@ostomymcp.com) or

Linda: [blumbergl@duvalschools.org](mailto:blumbergl@duvalschools.org)...”Gutsy’s Gab-about:” CAN’T WAIT TO KNOW Y-O-U BETTER!!!...

### UOAA 2015 Conference Photos

<http://uoaa.smugmug.com/Other/St-Louis-2015/>

## My Change of Life(style): What Happened When I Stopped Irrigating

by Judy Lippold, Editor, Chippewa Valley (WI) *Rosebud Review*

Most women go through their "change of life" gradually, over a period of years. I experienced that transition also, but the change I'm describing now was quite different from the one programmed by Mother Nature. This change in my lifestyle occurred almost overnight, because I stopped irrigating my colostomy.

Thirty years ago I had surgery for rectal cancer resulting in a sigmoid colostomy. Before I left the hospital, I was taught to irrigate my colostomy. "You'll want to do this daily or every other day," the ET nurse said, and I did as I was told. Over the years, I managed my altered elimination process as best I could, trying new techniques now and then, acquiring improved equipment occasionally, adjusting my diet as needed, and always learning, learning, learning--especially learning how to communicate with and listen to my body. I made good use of one of the most common methods of learning anything: trial and error. Sometimes I mused about what it might be like to not irrigate, but a small voice within cautioned me against tampering with success, so I continued with my usual colostomy management procedures.

Enter calcium. During an annual physical examination, it was determined that I had rather severe osteoporosis, the weak-bone disorder. I always had been conscious of needing calcium in my diet, but every time I attempted to increase the amount, for example by taking calcium tablets or Tums daily, I experienced constipation extreme enough to put me in a bind (literally!) and make my irrigations miserably ineffective. My simple (and simple minded) solution was to discontinue the added calcium.

With my new diagnosis of osteoporosis came the doctor's strict orders to, among other recommendations, ingest 1500 mg of calcium per day. I decided to do this by consuming calcium-rich orange juice, soy milk, skim milk, plus soft calcium "chews" that successfully imitate delicious candy, hoping to skirt the constipation problem by avoiding the more obvious calcium supplements I had tried previously.

Well, as we've been told, "You can't fool Mother Nature," and so it was I could not fool my body. "Calcium is calcium," my body said, "and I'll react the way I've always reacted to an increased intake of that mineral." This time, the doctor's order and a mental image of my bones crumbling led me to a different plan of action. After a week-long struggle with futile irrigations, I did not quit taking calcium as I had done before; I quit irrigating my colostomy.

Suddenly I, a 25-year "expert" in my personal colostomy management, became an insecure novice needing help, advice and encouragement from ET nurses and fellow colostomates. My learning began anew, and I heard my body's message loud and clear: "Now listen up and pay attention to my needs, address my problems sensibly, and we'll get along fine."

As I adjusted to the physical and management changes I was experiencing, I realized my thoughts and attitudes were changing too. I no longer had "mono-bathroom phobia," a term coined years ago by a newspaper columnist who said she was reluctant to stay in homes where there was only one bathroom--and **she** didn't even have an ostomy!

Since I no longer had to spend two hours or more in the bathroom while irrigating, I felt differently about early morning appointments or late night meetings. Why, I could be out and about at 7 a.m. without having to arise at 4 a.m. to do so. (I had learned early-on during my irrigating years that not only could you not fool Mother Nature, you couldn't hurry her either. Even a covert wish for the process to go faster would usually shut down the irrigation completely--an impressive demonstration of the mind-body connection!) Having company in my home no longer posed a problem for me. Although I have more than one bathroom available, it had been awkward when I, the hostess, would disappear for hours at a time. Long-distance train travel, a favorite mode of transportation for me and my spouse, became much more pleasant to contemplate--no more need to spend hours jostling around in that teeny tiny Amtrak restroom. Another travel plus: less ostomy gear to carry on.

Additional issues that are no longer issues: sharing a bathroom in a Bed and Breakfast or in a college dormitory or an Elderhostel is not problematic any more, and the thought of visiting a country with questionably pure water is not so worrisome.

There were advantages to irrigating, of course. Once a day and that was that. I greatly appreciated the clean-pouch condition that I experienced for many years.

As I move along this new path in my ostomy life, I sometimes speculate whether I would choose to resume irrigating if I could do so successfully. I'd have to weigh seriously the pros and cons and listen to advice from my body. I wonder what I would decide!

## **Incidentally...**

by Marjorie Kaufman, *Los Ilcos News*, Los Angeles; via Northern Virginia *The Pouch*

No one can tell me at a glance that I have an ostomy. Only those close to me know it for sure. Perhaps that is why it is difficult for me to recognize a curious fact; some people do not realize it's a BLESSING, not a DOOM! One wonders whether this knowledge might have some value to the human race—at least that part of the human race that tends to look upon an ostomy as a disaster.

Acceptance is part of being happy. People need happiness as much as they need food; without it they're devoured by restlessness and discontent.

How many people who think they resent an ostomy would, if they were truthful, recognize it as the thing they most needed to enjoy life again? How many could, with a simple change in mental outlook, admit it's a BLESSING?

Many people never learn; they never achieve the peace of mind and contentment this knowledge brings. They spend their lives in a prison where an ostomy is the eternal punishment. An ostomy is not DOOM—that's a mental attitude.

Nothing is a joy or a burden; only thinking makes it so. How can we avoid that feeling of compulsion that makes an ostomy a burden? We don't disclaim it. There's no use kidding ourselves about that.

Nevertheless, there are things we can do to take the edge off the feeling of compulsion and make things more pleasant. We need to expend our mental and physical energies.

If these energies are not expended in a constructive fashion, they turn inward and poison our minds and bodies with resentment and dissatisfaction. We need that warm sense of accomplishment, to be needed, wanted and useful. We need it to give balance to our lives.

Contentment depends not so much on the BLESSING as on the attitude of the person who has it.

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## **UROLITHIASIS**

by A. Trudeh, RNET, Lexington; via Worcester (MA) *New Diversions*

Urostomates, ileostomates and transverse colostomates have one thing in common: continuous output with a loss of fluids. If the liquid intake does not exceed the output, these ostomates may be dehydrating their bodies, making themselves prone to a condition called "urolithiasis," which refers to the presence of stones in the urinary system.

These stones may be found anywhere from the kidney to the bladder. They vary in size from mere granular deposits, called sand or gravel, to bladder stones the size of an orange. In the majority of stones, 90% are composed of calcium, with 5-8% uric acid and 1-3% cystine accounting for the rest.

Conditions which predispose to stone formation are: (1) infection, (2) periods of immobility, (3) concentrated urine, (4) abnormally high concentration of calcium in the blood, (5) heredity and (6) dehydration.

If you were to develop urolithiasis, the symptoms you may experience are: (1) low back pain and/or severe, sharp pain in the lower back radiating to the groin; (2) chills, fever; (3) difficulty or burning with urination; (4) blood in the urine; (5) nausea, vomiting and diarrhea. See your physician as soon as possible if any of the above symptoms appear.

Measures to prevent stone formation are: drink 2 to 3 liters (quarts) of fluid daily--preferably water and juices. Include acidic juices such as cranberry to maintain acid urine which helps prevent infection. Urinate during the night if necessary. Exercise daily. Use caution with foods containing calcium. Since a certain level of calcium is required for good health, restrict your diet only with the advice of a physician.

## Cranberries - For and Against for Urostomates

via Lawton-Fort Sill (OK) *Great Plains Ostomy News*

**FOR** -- The secret ingredient in cranberries that is pivotal in preventing urinary tract infections (UTIs) is concentrated tannins, called proanthocyanidins, in the juice. In a Boston study published in the Journal of the AMA, cranberry juice was found to be effective in reducing the incidence of UTIs and the need for antibiotic treatments.

This has important implications for persons with ostomies and continent diversions. Recurrent UTIs can be common in persons who catheterize frequently. They can be more evident if proper hand washing and cleaning of catheters is not done routinely. In addition, a large proportion of women over age 65 will experience at least one UTI per year.

How does this special ingredient in cranberry juice work? The tannins from cranberries prevent E-coli bacteria, the main culprit in urinary infections, from adhering to cells that line the walls of the bladder and kidneys. The bacteria thus will "wash out" before infection can develop.

Scientists in the Boston study believe that the routine addition of cranberry juice to dietary regimes in circumstances where UTIs have a high incidence would be sensible.

**AGAINST** -- An article from the Mayo Clinic says drinking cranberry juice to prevent recurring bladder or urinary infections is an "old folk" remedy. Does it work? Maybe--but don't count on it.

A key to preventing a bladder infection is blocking the growth of the bacteria that cause the infection. Researchers have two theories about how cranberry juice may help:

(1) By making the urine more acidic, discouraging the growth of bacteria. But scientists don't know whether a realistic amount of cranberry juice can produce enough change in urine acidity to affect bacteria.

(2) By keeping bacteria from "sticking" to the bladder wall where they multiply and cause infections. This theory was confirmed in the laboratory and in mice, but results vary in humans.

We do know that taking 500 mg of vitamin C (ascorbic acid) twice a day along with cranberry juice can increase urine acidity. Still, if you think you have a bladder infection, don't try home remedies. See your doctor. The usual treatment is antibiotics and lots of liquids.



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