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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. 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: **Mar. 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: **Mar. 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: **Mar. 19th**

**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
(Lobby area)
Free parking
Next Meeting: **Mar. 13th**

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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”

You will love Brenda E/Perry’s story! A former hairdresser who did not just brush-off a colon cancer diagnosis...or allow it to prevent her from living life to the fullest. In fact, she parlayed her experiences into a second career as creative comedienne, motivational speaker and author 20+ years later. She is a consummate colostomate courageous cancer survivor consumed with “living and laughing”...now, “Gutsy,” Linda’s 10.3 year old ileostomy stoma KNOWS YOU are in a hurry [to read their story]...so, don’t worry!...but, do check out her website: www.livingandlaughing.com Brenda@livingandlaughing.com ...and, enjoy Brenda/Perry’s story, as shared with Gutsy, reprinted with their permission... Origin of Perry: named for Saint Peregrine, patron saint of cancer

BRENDA/PERRY’S STORY: “gory to glory

One thing I love about Linda is that she is out there with the optimistic attitude of gratitude for her ostomy and celebrates it too. I’m all about that and have been since the beginning of my ostomy experience. Thanks Linda for asking me to write a little bit about myself and my grateful journey through colorectal cancer at age 39, and what’s happened in the 20 years since that 2nd day in October 1995 when I was diagnosed with cancer of the rectum. Hey, I’m writing about it so you already know it had a happy ending!

I was a mother of 2 children, ages 3, and 5 and my husband and I had been married only 6 years. I was the owner of a successful large hair salon located near the Mall of America in Minnesota. I was a hard worker, with a busy life, and suddenly had an awful pain in my tush that wouldn’t relent. The next week I went to the doctor expecting the news that I would need a hemorrhoidectomy and instead being told my whole rectum would have to be removed. I had 10 different doctors look me over with 10 different vaginal and rectal exams. I had photos of places taken I didn’t think were possible. And at the time I had an outstanding butt. It was so outstanding, if I was standing in the kitchen, it was outstanding in the living room! Three weeks later I had 7 hour surgery that would end in a colostomy, vaginal reconstruction and complete hysterectomy.

Here’s the weird thing that happened along the way, I found tumor humor. It was embarrassing at first trying to talk about what kind of cancer I had, but eventually I found my way through using humor. Besides, I had to stop crying and be able to function. I didn’t want my kids seeing me like that and I still had to run a business. I was never ashamed or

shy about talking about the ostomy, I knew it was saving my life every day. You have to be able to poop or you die. End of story. I had to get over it, and deal with it. Why be bitter, I got time with my kids. When the doctor told me initially if the cancer had spread to my lungs or liver, they wouldn’t bother with the operation, I said, “Oh, no, you have to make me well, I intend to dance at my children’s weddings. And last year my son married a beautiful woman and I celebrated by dancing all night long.

I was never one to say I’m grateful for getting cancer, but I am blessed with the opportunity that cancer presented to me to see what I was made of. I found out I am not a quitter, I’ve got spunk and talents I never dreamed of. So I had my rectum removed, and found there was more room for creativity!

Two bucket list items I had were to become a comedian and to go to college. Both I did, within 3 years of my diagnosis. I still haven’t graduated yet, but my aunt is 86 and a sophomore in college. I am following in her footsteps! I was honored to win the title, The Twin cities Funniest Person in 1996. I conquered all the rounds finally beating 150 young, thin, punks, that were amateurs like me...a matronly 40 year old, and didn’t need to swear either! I won \$1000 with that contest and so I split it with my husband, I gave him \$50.

After that I went to college, scored high in the writing assessments which was a surprise and was awarded any choice of class. I took the one called, “How to Write a Major Project” and out of that class, my first book, If the Battle is Over, Why Am I Still in Uniform was born. It has sold over 25,000 copies to our niche market of the ostomy world. After that, I couldn’t stop writing and 4 more books, I’d Like to Buy a Bowel Please!, Bedpan Banter, It’s in the Bag and Under the Covers, (anthologies, all with a sense of humor and hope) came along with my most recent last October called, Your Glasses Are On Top of Your Head. It’s about looking at aging with humor.

I sold my salon 11 years ago and became a professional speaker and writer. I have been speaking about colon screening and its importance for 18 years now and it’s still a hot topic! I became the president of the MN chapter of the National Speaker’s Association, a teacher in the speaker’s academy, beginner and advanced and last year I was the conference chair for the Association of Applied and Therapeutic Humor held in Arizona. I earned my CHP (Certified Humor Professional) certificate after a three year

program. So you see, having the cancer, provided many opportunities to make the most of it. I write and speak honestly in a conversational manner, with no feelings of inadequacy or embarrassment of having an ostomy. I am truly grateful for the opportunity to meet many fantastic people dealing with bowels or bladders gone berserk around North America. I feel truly blessed to have had all these years with my children and I am looking forward to the next segment of my life. I hope you'll be curious about me enough to order my books or visit my website at www.livingandlaughing.com. I kind of live by a sign with a saying that hangs in my office: (anonymous), Blessed are they who can laugh at themselves, for they shall never ceased to be amused!"



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The Ostomy Files: The Evolution and Innovation of Ostomy Products

Gwen B. Turnbull, RN, BS May 2003

Ostomy surgery (sic) was considered by many to be an unmitigated disaster, a measure of last resort to be undertaken only in patients in extremis because of the inability to control the unpredictable fluid excreta. --- Professor Brian Brooke¹

Most of us who have been in the field of enterostomal therapy for some time are familiar with an etching that appears in a 1750 surgical textbook.² A middle-aged woman is peering down at her abdomen — the rags she had wrapped around her midsection removed to expose her stoma. Amazingly, this woman (who had the first colostomy of record) lived for many years with nothing more than rags or tree moss to absorb and manage her output.

As late as 1900, no manufactured appliances were available, and patients had no other recourse but to invent their own collection devices — inner tubes, tuna fish cans, and bread bags. Concoctions of vanilla and peppermint

extracts, aspirin tablets, mouthwash, perfume, parsley, and bicarbonate of soda utterly failed to control odor. Omnipresent peristomal skin problems were treated ineffectually with cornstarch, talcum powder, and aluminum paste.³ Most ostomy patients were relegated to their homes as social outcasts, afraid to venture out into society because of odor, a lack of security, and the fear of embarrassment. Due to the resulting decrease in the quality of life for the patient, ostomy surgery remained the “secret surgery” of last resort for many years.

It was not until the early- to mid-1950s that a cycle of innovation of ostomy pouching systems appeared in the medical device marketplace, literally transforming the life of the ostomy patient. Bulky, heavy rubber products yielded to aesthetically pleasing odor-proof plastics and other modern materials that quickly found their way to ostomy manufacturers' research benches. At about the same time, peristomal skin care made a quantum leap forward with the introduction of karaya. The “skin barrier” was born.

Over the next few years, skin barriers became the impetus for startling advances, not only in ostomy care but also for incontinence and wound care. However, it was not long before karaya's limitations became evident. Watery or copious output washed karaya away. It was thermally unstable, had poor adhesion, and many patients developed allergic dermatitis or complained of burning when it was used on broken skin.

In 1965, in conjunction with recommendations by noted colorectal surgeons of the day, a material used to treat oral ulcers (Orahesive® Paste and Orahesive® Powder, developed by J.L. Chen of E. R. Squibb and Sons, Princeton, NJ) was launched in the UK for peristomal skin care. Eight years later, Stomahesive® wafers were introduced by E.R. Squibb and gained rapid acceptance by clinicians and patients due to a decrease in allergic reactions, increased thermal stability, low moisture absorption, increased wear time, and fewer skin problems. These wafers were sandwiched between the skin and a commercially available pouching system to prevent peristomal skin breakdown.

A decade later, ostomy management took another leap forward when ConvaTec, a Bristol-Myers Squibb Company, introduced a two-piece pouching system with a low-profile body-side Stomahesive® wafer incorporating a snap-lock flange. This system afforded the patient the freedom, security, and ability to remove the pouch, empty or rinse it, and reapply it without removing the body-side wafer from the skin. With this freedom and autonomy, people with a stoma gained a sense of security and were able to live more normal lives. Since that time, many versions of the flanged coupling system on two-piece pouching systems have been developed by a variety of manufacturers.

Innovative research firmly grounded in feedback from people who live with an ostomy has prompted investigation into different versions of two-piece coupling systems that take the divergent lifestyle needs of the wearer as well as discretion, flexibility, low profile, differences in manual dexterity, and comfort into consideration. The technology of

repositional adhesives has found its way into ostomy care in the form of adhesive couplings on two-piece pouching systems. By replacing plastic flanges with an adhesive coupling, the profile of two-piece flanged systems can be lowered, giving patients the option of removing and applying pouches to body side wafers multiple times without removing the body side wafer. The ability to customize a pouch type to the time of day, the character of stomal output, particular clothing, or even the activity in which a patient is engaged could provide a new sense of independence and freedom, increasing self-esteem, and improving quality of life.

The variety of quality of products available today has come a long way since the first recorded colostomy 253 years ago. The past 53 years have been a time of incredible innovation and shared dedication to the ostomy patient by researchers, clinicians, and manufacturers. Each step forward in technology, as well as advances in the operating room, has furthered the quality of life for a person with an ostomy to a higher level that could never have been imagined many years ago. It has taken an enormous investment of time, research dollars, and dedication. If past decades are a model for medical innovation, people with an ostomy can eagerly anticipate future technological advances that will positively impact the quality of their daily lives.

The Ostomy Files is made possible through the support of ConvaTec, A Bristol-Myers Squibb Company, Princeton, NJ.

References:

1. Brooke BN. Historical perspectives. In: Dozois RR, ed. *Alternatives to Conventional Ileostomy*. Chicago Ill: Year Book Medical Publishers, Inc.;1985:21.
2. Cheselden W. *The Anatomy of the Human Body*. London, UK: Hitch and Dodsley; 1750:324.
3. Turnbull RW, Turnbull GB. The history and current status of paramedical support for the ostomy patient. *Seminars in Colon & Rectal Surgery*. 1991;2(2):131-140.

Summertime...and the Living is Easy

by Bobbie Brewer, Greater Atlanta Ostomy Association, July 2011

Summertime fun may include many outdoor activities and travel, but may also lead to some concerns about ostomy management. Let's review:

Swimming is an excellent exercise and activity you can enjoy with family and friends. So, why are so many of us afraid to get back into the water? Check out these tips:

- Don't go swimming immediately after you have put on a new pouching system.
- Make sure your pouch is empty and has a secure seal.

- Picture framing your wafer with water-proof tape isn't necessary, but may give you the extra confidence you need.
- Take precautions against sunburn. Besides being bad for your skin; a bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes.
- When sitting and soaking up the sun, protect/shade your pouching system by placing some covering across the outside area (e.g., hat, towel, magazine).
- Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, consult an ostomy nurse.

Fluids and More Fluids are needed during the hot summer months. Review the following:

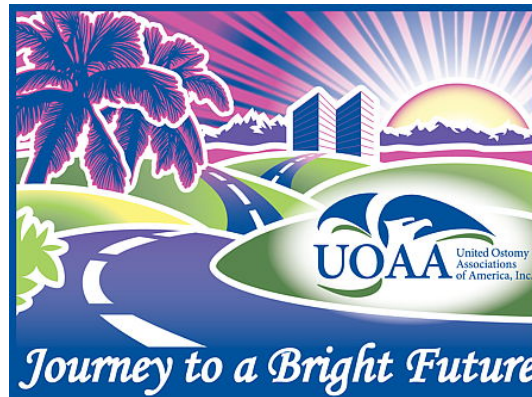
- Water is an essential nutrient needed by each and every body cell. Up to 75% of the body's mass is made up of water. Water controls body temperature, serves as building material and solvent, and transports nutrients. Thirst is a signal that the body needs fluids. Daily losses must be replaced. Encourage fluid intake of eight to ten (8 oz) glasses of liquids each day.
- Any liquid containing water (soda, milk, juice, etc.) helps to meet your daily requirement. You can also get water from the food you eat (e.g., tomatoes have a total of 94% water content). [North Central OK Ed. note: And don't worry if liquids contain some caffeine. It's a myth that caffeinated drinks are dehydrating.]
- Water is an excellent natural beverage; however, over-consumption of water can wash away electrolytes in the body. Drink a combination of water and electrolyte beverages. The glucose ingredient in electrolyte drinks aids in the absorption of electrolytes. [North Central OK Ed. note: To emphasize this point, runners in marathon races have collapsed, and sometimes even died, due to hyponatremia—low blood sodium caused by drinking too much plain water.

Summer Diets

- Remember the fiber content of those fresh fruits and vegetables—enjoy but chew, chew [ileostomates, especially].
- Add only one new food at a time to determine the effect (if any) on your output.

Tips for Traveling with Medications and/or Ostomy Supplies

- Keep your medicines (and emergency pouches) with you—not in the checked luggage.
- Bring more than enough medicine and/or ostomy supplies for your trip.
- Keep a list of all your medicines and/or ostomy supplies with you.
- Do not store ostomy supplies in your car, especially under the hot summer sun.



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