

The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala



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UOAA Discussion Board https://www.uoaa.org/forum/index.php

## Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt\_homepage\_panel

#### 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: May 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 Lodge2121 SW 16th St Gainesville, FL Next meeting: May 5th

#### Ocala Support Contact info:

Lynn Parsons 252 337-5097 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: **May 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 **May 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 ParkwayJacksonville, FL 32218 (Meeting Room 3-4) Free parking Next Meeting: **May 13th** 





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

#### Life's a Polyp: "Meet Jenny

I'm Jenny and I was diagnosed with Familial Adenomatous Polyposis (FAP) at age 8. FAP is a hereditary rare disease that causes the development of hundreds to thousands of polyps throughout the gastrointestinal tract. An individual with FAP is guaranteed to develop cancer at some point in their lifetime, which is why preventative treatment is crucial. However, cancer is able to develop anywhere in the GI tract as well as other parts of the body with FAP. Due to surgeries to remove my colon and part of my small intestine, I was diagnosed with another rare disease: Short Bowel Syndrome (SBS). I have also been diagnosed with Acquired Polycystic Kidney Disease and am at greater risk of cysts and tumors due to FAP.



My mother, grandfather, and countless great aunts and uncles also had FAP and GI cancers. My mother and I are the last survivors in our family with FAP and I hope to be the one to end FAP in my family.

At age 9, my polyps were starting to turn cancerous and removal of my colon with a temporary ileostomy was decided necessary. I experienced many complications and near death experiences the following year resulting in 4 more surgeries and I was left with an ileostomy for 6 years. After a routine scope and consultation with another surgeon, it was decided a straight pull-thru may be an option. At age 15, I had the straight pull-thru surgery and experienced life threatening complications from adhesions that resulted in another surgery for adhesions removal. My health slowly stabilized over the next 5 years. I was able to graduate with a Masters degree, I have maintained full time employment, and am enjoying life as well as discovering new challenges for myself every day.

This is my journey with FAP and SBS: recounting memories and experiences, coping with life changes, tackling new challenges, and doing my best to continue to survive. When I was a child, I didn't know anyone else with FAP outside of my family. I hope you'll join me and together we can fight this disease."

#### <u>"Ostomy Connection" articles</u>: [Hollister newsletter]

Why I've Only Told a Few People about My Ostomy

What a Bad Day Feels Like with Short Bowel Syndrome

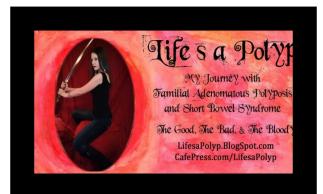
Not Everyone Copes the Same Way with Having an Ostomy

What I've Learned about Managing a Chronic Illness at Work

Why I Need B-12 and Iron Supplements for Short Bowel Syndrome

Email: lifesapolyp@yahoo.com Blog Website: http://lifesapolyp.blogspot.com/p/ about-

Jenny's "My About" page on blog: http://lifesapolyp.blogspot.com/p/absout-me.html





## **Intimate Moments**

By Ellyn Mantell, The Union County Ostomy Support Group of New Jersey

As an advocate and UOAA Affiliated Support Group Leader, I make it very clear that there is no question or concern that is offtopic for me, and I truly believe that since this is our "new normal" it is very important to be open about all aspects of our lives. The question that seems to most concern new ostomates is about their sexual interactions, and how their partner or future partners will react to their unique anatomy. Since I feel that our anatomy is so beautifully functional (as it may not have been for a long time) I encourage ostomates to look at their ostomy in the most positive of lights. Additionally, it is always my belief that intimacy begins and dwells in the mind, rather than the body.

UOAA President Susan Burns had ileostomy surgery at 36 and knows how important being open about intimacy concerns is. "This is a topic that needs to be discussed but is not addressed enough by health care professionals so it is important to read our guide, find peer-support, or a support group member that is comfortable discussing it," Susan says.

I believe that intimacy is a beautiful gift one gives to another, and sex is only one meaningful part of the intimate moments people share. I also believe that being intimate with another is a means of communication, a sharing, of thoughts and feelings. This positive reflection of our emotions and adoration for our partner is what bolsters a relationship.

For over two decades, my body was in turmoil, and although I wasn't faced with a pouch on my abdomen, feeling "sexy" was a transient and very much undependable feeling. Bowel obstructions, bloating, worry all interfered with a positive outlook for intimacy. Couple that with a busy life struggling to be productive in between the medical episodes, and my intestine certainly held me hostage.

My 23rd abdominal surgery, my ileostomy, helped me to begin to have a more predictable life. I am comforted in the knowledge that I function differently, but it is dependable. No longer expecting to be hospitalized on a regular basis, I am free to be productive in so many ways...support groups, motivational speaking, my writing, seeing my family and friends.

The key, however, to the conversations I have with ostomates regarding their own intimacy is to be totally candid with them. Here is what I say...if you are blessed to love and adore your partner, who loves and adores you, then you will travel the road to a joyful connection, enjoying the closeness that you share because you are able to do so. You have the ability to dance together and move together as never before, all the while knowing that your bond is even stronger than you ever thought possible. You are amongst those of us who know that intimacy, that beautiful gift we give each other begins in the mind, and the body just follows along.



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## Ostomy Myths vs. Reality The Truth About Living with an Ostomy

After ostomy surgery, you may find helpful tips and tricks from other people living with an ostomy in online communities, support groups, forums and more. Weeding through the fact and fiction can be difficult. Our me+ team of certified ostomy nurses and product specialists have outlined some of the most common myths they hear to provide you with the truth about living with an ostomy.

**Myth:** Only use the ostomy pouching system that you were fitted with in the hospital or doctor's office. You should not explore new products on your own.

**Fact:** In the weeks and months following ostomy surgery, you may find your stoma and body changing. In the first few weeks and months post-surgery, your ostomy pouching system may need to be changed also. Contact our me+ team today to be fitted with ostomy samples designed to fit your lifestyle and body.

Myth: All ostomy products are the same. It doesn't matter what type of pouching system you wear.

Fact: There are a large variety of ostomy products available to fit the needs of each person living with an ostomy.

Myth: Your stoma should not change size after a few months after surgery

Fact: In the weeks and months following ostomy surgery, your stoma may change in size and appearance.

**Myth:** Having skin irritation is a normal way of life with an ostomy.

**Fact:** If the skin around your stoma becomes damaged, it could be painful and lead to infection. It also becomes more difficult for the skin barrier of your pouching system to adhere to your skin. Prevention is the key to maintaining both healthy peristomal skin and your comfort.

Myth: If you have an ostomy, your significant other will not love you the same way.

**Fact:** It is common to have anxiety about relationships following ostomy surgery. Whether you're looking for a partner, have been dating a few months, or married 25 years, ostomy surgery will have an impact on you and your relationships.

Myth: Odor is a part of life when you have an ostomy.

Fact: You will become more comfortable with your ostomy pouch over time, and will gain confidence in its ability to retain odors.

Myth: People living with an ostomy cannot fly, because the cabin pressure can cause the pouch to fail.

**Fact:** People living with an ostomy can fly, ride in a car, take a train and use all the same modes of transportation they utilized pre-surgery.

**Myth:** I can't get my pouch or wafer wet, which means I can't enjoy water activities or bathe with my pouching system in place.

**Fact:** You can shower, go swimming, or even get in the hot tub with your pouching system in place. If using a pouch with a filter, cover the filter with the covers provided. If you are unable to enjoy water activities with your current system, contact the me+ team to learn more about products that may help, 1-800-422-8811 or cic@convatec.com.

Do you need help debunking an ostomy myth? Contact the me+ team of ostomy product specialists and ostomy nurses today, cic@convatec.com or 1-800-422-8811.

Editor's note: This educational article is from a UOAA digital sponsor, ConvaTec. Sponsor support helps to maintain our website www.ostomy.org and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.



# **Philadelphia Freedom**

Celebrate Your Independence at UOAA's National Conference



**August 6-10, 2019** Philadelphia is home to the 7th UOAA National Conference. It's a not to be missed event for the ostomy community and your chance to connect and learn from medical experts and people living with an ostomy from all around the country. Gather at Philadelphia 201 Hotel, a great vacation destination right in the heart of this historic city (Special UOAA rate available).

Please join us and prepare to make new life-long friends, to laugh, shed a tear, celebrate, and learn. You've earned it.

# **Conference Highlights**

Free Stoma Clinic with WOC Nurses

Ostomy Product Exhibit Hall

Sessions for New and Experienced Ostomates

The Active Lifestyle Panel Discussion with ostomates of all ages will feature a race car driver, runner, an active grandmother and young professionals

Caregivers Track - Caring for Female and Male Ostomates and Caregiver Stress

**Pediatrics Track** 

Young Adults Track with a number of networking opportunities

Medicinal Marijuana, Pain Management and Alternative Practices Visit www.ostomy.org for more information



\*Keynote addresses by Dr. Richard L. Rood and Dr. Judith Trudel

# Social Events

Fashion Show Saturday Night Roaring 20's Casino Night Free Improv Comedy Show 21+ Meetups City Excursions Available ASG Leader Networking

Medical Care Products, Inc PO Box 10239 Jacksonville, FL 32247-0239

To: