

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





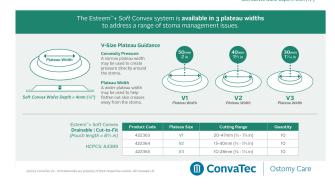
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#### Jacksonville Contact Information:

Patti Langenbach (800) 741-0110

(904) 733-8500 <u>patti@ostomymcp.com</u> Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street Next Meeting: July 21st

### 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: **July 7th** 

### 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: **Sept 8th** 

### **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 **July 21st** 

#### 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: July 8th



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

"Tomorrow I get my large intestine removed. My complicated homage...



The Littlest Ones

"Promise me you'll always remember your are braver than you believe, stronger than you seem, smarter than you think, and loved more than you know." - Christopher Robin

My ostomy Percy and I have been together since 2011, and so my life was saved. From the day of Percy's creation forward, I have lived in gratitude, dedicating my passion and energy to ostomy awareness, advocacy, and support, as my expression of appreciation.

Through the readership of my published adult ostomy books, website, THE OSTOMY FACTOR blog, and volunteer work with the Ostomy Canada Society, Medical Advisory Committee (MAC), in the capacity of "Ostomy Lifestyle Expert", I receive many requests for pediatric ostomy information and recommendations for young children. Although there are excellent instructional publications I have been able to recommend, there is scant resources/publications that young ostomates can relate to individually, nor how they and their families live with an ostomy, (lifestyle). And so, during the past few months I have shifted my focus to pediatric ostomy awareness, advocacy, and support for the purpose of shinning a light on the important and often invisible topic of Pediatric Ostomy. It has been through this journey that I've had remarkable experiences with the littlest ones and their families.

Two of the amazing young people I have met, (through interview), are Mallory, (4 years old), and Delia, (13 years old). Mallory's health and ostomy journey began Day 2 of her life. Delia's at 8 years of age. The messages the girls and their parents share are many. Delia and her family want everyone to know; "Having an ostomy doesn't change who you are. You can love yourself well, embracing whatever challenges you have. Don't look at limitations, but follow your heart and you will do whatever you want in life." Delia lives pure self love, (self love can be very challenging for most of us). Her message is universal, with or without and ostomy, our lives are enriched.

Mallory's parents are working with her to shape her fearless spirit. They embrace their medical parent role, and are often asked; how do you do it? Mallory's parents' response is profound. "We are full time professionals and parents of Mallory (medical miracle), and Collin (healthy 7 year old). The answer is simple, it's just love. Any parent could be a medical mom/ dad because it's just love."

A common concern the parents and children shared with me is their concern with regard to the lack of books and toys designed specifically for children with an ostomy. As mentioned, there is scant resources/publications the young ostomates can relate to individually. Recognizing this concern in the summer of 2018, I wrote and illustrated, "Why Buttercup Wears a BAG!"

Published January 2019, (available on Amazon), this book was written with the desire to inspire children and the people in their lives, to know that although we are faced with challenges, we are not alone and we can live a quality of life in spite of it all.



#### July 2019

The littlest ones and their families are extraordinary, ordinary people. Sometimes in life, moving forward takes bravery. Ostomates of all ages can attest to that. We do our best to run towards, not away from the challenges. We muster up the courage to stand up and face our realities. Having a life saving ostomy sure has a way of testing us, as we experience a 2<sup>nd</sup> chance at life's reward too, rewards that we never imagined. Pediatric ostomates are the future and they march steadily towards it. They inspire us by their true life stories, their journey, their messages, and all the while as they enrich their own lives and the lives of their families, they enrich ours.

*"The things that make me different are the things that me" - Piglet EOL. Poopology [advanced degree!]: <u>www.jo-annltremblay.com</u>* 



Several smiling faces of Jo-Ann L. Tremblay jo-ann@potentialsmanagement.com

### **Returning to Work with an Ostomy**

From industrial jobs to the classroom, from long shifts at the hospital to dancers – and all workplaces in between – people living with an ostomy are successfully returning to work following ostomy surgery. These tips from the me+<sup>™</sup> Team may help you return to the workplace with more confidence and less anxiety.

• Be prepared. Pack a bag with the items you need for a full change of pouching system and a change of clothes. You may not need your "emergency kit" at all, but it can offer peace of mind knowing that it is at the ready.

• Pack your water bottle and stay hydrated. Drinking water is one of the simplest ways to improve your health and well-being. Learn more about hydration with an ostomy.

• Initially, you may be self-conscious about emptying your pouch in public due to odor or sound. Create a buffer with a layer of toilet paper in the toilet bowl to avoid splashing when emptying your pouch. Some people also include toilet deodorizing products in their ostomy supply kits.

• Dress comfortably. Do not worry that others will notice the pouching system through your clothes. Having an ostomy may seem very noticeable to you, but in reality it is rarely noticed by others. Ostomysecrets® apparel keeps your ostomy pouch supported & flat against your stomach allowing you to wear tailored clothing.

• Consider starting back to work on a Thursday, allowing you to ease back in with a short work week. You will be able to rest over the weekend before taking on a full week of work.

• Think about what facilities are available in your work restroom and plan accordingly. If no paper towels are available, have pre-moistened paper towels in zip lock plastic bags or moisturizer-free wipes. Try to think of how to accomplish a pouch change in that setting if needed.

• Take breaks. It is easy to get wrapped up in the task at hand, but allow yourself time to empty your pouch.

• Don't try out new products or foods right before going back to work. Save testing new products or diet changes for the comfort of home.

• Most likely, your co-workers will not realize you have an ostomy unless you tell them. It is a personal choice whether or not to tell your employer about your ostomy. Although it may help to tell your manager or trusted co-worker(s) if you require frequent breaks or accommodations.

• You have legal rights under the American Disabilities Act prohibiting employment-based discrimination. UOAA can be a helpful resource if you encounter workplace discrimination.

Consult your physician or healthcare professional before returning to work. If you have other questions about returning to work following ostomy surgery, contact the me+ Team at 1-800-422-8811 or cic@convatec.com.

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.



### **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.

# UOAA Discussion Board

https://www.uoaa.org/forum/index.php



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# **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

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To: