



# INSIGHTS

The Newsletter of the  
**OSTOMY ASSOCIATION  
OF SOUTHERN NEW JERSEY**

[www.ostomygroupsnj.org](http://www.ostomygroupsnj.org)

SERVING OSTOMATES IN SOUTH JERSEY SINCE 1977

JANUARY 2017

## **WELCOME!**

The **Ostomy Association of Southern New Jersey (OASNJ)** is dedicated to providing information, advocacy and peer support to our members, their family and caregivers, and to the area's intestinal and urinary diversion community at large.

We meet regularly to share experiences, provide mutual support and learn about the latest products and information for colostomy, ileostomy, urostomy and continent diversions.

Meetings are held at the **Virtua-Memorial Hospital Burlington County**, located at 175 Madison Avenue, Mt. Holly, NJ 08060 in the 1st floor Conference Center. We meet on the **3rd Monday of each month with the exception of July and August**. The June meeting is traditionally held in an area restaurant. Meetings begin at **7:00 pm and adjourn by 9:00 pm**. Families and friends of ostomy patients are always welcome to attend. There is no fee to attend and refreshments are served.

For more information about the OASNJ, contact us at our NEW website... [www.ostomygroupsnj.org](http://www.ostomygroupsnj.org)

### **AFFILIATION:**

OASNJ is an affiliate of UOAA, the **United Ostomy Associations of America**. It has IRS 501(c)(3) Charity Status and 360 affiliates nationwide. Contact UOAA at **800-826-0826** or [www.ostomy.org](http://www.ostomy.org). For more info sign on to **Twitter.com/UOAA** or **Facebook.com/UOAAinc**.

## **MEETING SCHEDULE**

*Happy New Year ... Welcome 2017*

**JANUARY, TUESDAY the 17th THIS MEETING WILL BE HELD in the VIRTUA HEALTH WELLNESS CENTER 401 Young Avenue, Moorestown, NJ, 7:00 PM We will have an open discussion of ostomy issues**

**FEBRUARY 20, 2017** Our ConvaTec representative, Kristina Klein, will "show and tell" about the company's new products.

**MARCH 20, 2017** Program TBA at later date.

### **OASNJ Satellite Support Group**

**Where:** Virtua Health Wellness Center, 401 Young Avenue, Moorestown, NJ

**When:** The 1st Wednesday of the month, from **Noon to 2:00 PM** .. **The next meeting is January 4th.** For meeting information contact: Lois Moskowitz, at **609-707-4368** or e-mail her at: [Strongcoffee1@verizon.net](mailto:Strongcoffee1@verizon.net).

**Attention Gloucester County Ostomates** and anyone else that is interested! The Woodbury Ostomy Support Group meets the 3rd Wednesday of each month at the Inspira Medical Center Woodbury, Medical Arts Building, Suite #14 **Next meeting January 18th at 6:00pm**. Contact Kathy Pflieger at [pfliegerk@ihn.org](mailto:pfliegerk@ihn.org) for details.

**Attention Cumberland County Ostomates** and anyone else that is interested! The **Cumberland County Ostomy Support Group** meets the 4th Wednesday at the Inspira Medical Center Vineland. **Next meeting January 25th at 6:00pm**.

Contact: Jeanne Spencer 856-327-6505 for information.

**VISITING PROGRAM:** If you, or someone you know is in need of a trained ostomy patient visitor, call **Sandy Ritter** at **856-983-1433** to arrange for an in-person or telephone visit.

*Production and distribution of this INSIGHTS newsletter is made possible thanks to the generosity of the:*

**AMERICAN CANCER SOCIETY.**

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**DISCLAIMER :** No suggestions made, or any products named in any article or advertisement in this newsletter, at our meetings or recommended by a member of our organization is to be considered as an endorsement by the Ostomy Association of Southern New Jersey or the United Ostomy Associations of America, Inc.. Always consult your doctor and/or WOCNurse before using any products of ostomy management procedures published in this newsletter.

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American Ostomy Supply .... (800) 858-5858  
Bruce Medical Supply ..... (800) 225-8446  
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Marlen Manufacturing .... (216) 292-7060  
New Hope Laboratories ... (800) 899-5017  
Ostaway x-Bag ..... (800) 774-6097  
Ostomy Secrets ..... (800) 518-8515  
Schena Ostomy Technologies 239-263-9957  
Torbot ..... (800) 545-4254  
Trio Ostomy Care USA (844)-331-8746

### • WOUND, OSTOMY and CONTINENCE NURSES SOCIETY ... [www.wocn.org](http://www.wocn.org)

#### Area WOCNurses:

Arlene Peahota (856) 764-6634  
Kathy Pflieger (856) 845-0100 x 3725

Diane Wagner (215) 707-3092  
Gillian Reeve (856) 566-2059

Nancy Fonte, WOCN ... (609)-484-7300 ext 185 ... [Nancy.Fonte@atlanticare.org](mailto:Nancy.Fonte@atlanticare.org)

**Ostomy Support Group meets 2nd Wed of each month at 4:00 PM at the Atlanticare Center,  
2500 English Creek Avenue, Bldg 400, Egg Harbor Township, NJ**

### • WHEN TO CALL A DOCTOR OR WOC NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after several emptying.
4. If you have a strong odor lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.

# Maintaining Healthy Peristomal Skin

via ConvaTec *me+* Answers

## Preventative Care

Keeping the skin around your stoma (peristomal skin) healthy is important. You can steer clear of many complications by following these simple suggestions:

### Bath and shower tips

You can bathe and shower just as you did before surgery, with your pouch on or off—the choice is yours.

Because soap residue can cause your skin barrier to lift, avoid oil-based and moisturizing soaps.

Soap and water will not flow into the stoma and cannot damage it.

### Choose a well-fitting skin barrier

To help keep the skin around your stoma healthy, it is important that your skin barrier fits properly. Choose a well-fitting pouching system to help prevent irritating stoma contents from coming into contact with your skin.

Your ostomy nurse can teach you how to use a measuring guide to determine the size of your stoma and select a cut-to-fit, pre-cut or moldable barrier. Your stoma size will change up to 10 weeks after surgery, so you will need to measure it periodically. Changes to the abdomen caused by pregnancy, exercise, weight gain or loss, hernia or other medical conditions may also require a new pouching system and/or size.

### Tips for pouching system changes

Make an easy-to-follow schedule for your pouching system. This will ensure your skin barrier is changed before the adhesive has eroded, reducing the chance of urine or feces coming into contact with your skin. Your schedule should be personalized based on your system type and the advice of your doctor or ostomy nurse.

At each skin barrier and pouch change, make a habit of looking at the skin around your stoma. Redness, swelling or a rash are signs of irritation. If you see any of these, or other signs of irritation, notify your healthcare provider.

Never rip or tear off your skin barrier. Instead, remove the skin barrier gently by beginning with one corner of the barrier and slowly pulling off the remaining adhesive. Adhesive releaser spray and remover wipes can make pouch changes easier and ensure clean skin, ready for your next skin barrier.

Make sure your peristomal skin is completely dry before replacing your pouch and skin barrier. Dry skin ensures a good adhesive seal and helps reduce the risk of fungal infection.

A skin care routine including skin barrier foam, spray or wipes can help ensure healthy, comfortable peristomal skin for years to come.

In hot, humid locations, consider using a pouch with a fabric backing. This will keep the pouch from sticking to your skin and causing skin irritation.

## Meghan Tierney Hultman ... Great Comebacks® Award Recipient - 2012

Via ConvaTec me+ Community



At 23, Meghan started to notice unusual pain and bleeding when she went to the bathroom, but tried to ignore her embarrassing symptoms.

Soon her pain escalated rapidly and left Meghan paralyzed one night. She was rushed to the emergency room and a test revealed she might have a polyp in her colon.

But during outpatient surgery to remove the polyp, the colorectal specialist discovered that what Meghan really had was a significant tumor. The tumor had extended through her intestinal wall and had invaded the adjacent muscle tissue, causing the excessive pain. Meghan woke from surgery to find out she had stage 3 rectal cancer.

“I had worried that something was very wrong, but my worrying did not prepare me to hear the actual news. I had...cancer? Everything I thought I knew about life was torn to pieces in the matter of an instant,” she said.

Meghan’s PET scan showed that her cancer had already spread to a few lymph nodes nearby. She feared for her future. The next day the surgeon told her that her cancer was too low in her digestive tract – the only method of treatment he could try was a permanent colostomy.

“This was even harder to hear than the cancer diagnosis itself. Would I still be able to do the things I like to do? Wear the same clothes? What about food? Exercise? Intimacy? I had so many questions, and I couldn’t find much comfort in any of the answers,” she said.

Meghan soon started a six-week chemotherapy and radiation therapy treatment program to shrink the tumor before her rectal resection and colostomy surgery. Then, she went back to chemotherapy treatment for six months, which left her incredibly sick. On top of her sickness, Meghan struggled to accept her colostomy and find ostomy information for young adults. But a strong support system of friends and family and a great healthcare team helped her to get through the many appointments and her new way of living. In November 2008, she finished treatment, cancer free.

“I experienced an overwhelming number of losses due to my cancer, but I have also experienced some gains, including learning what I truly want from life. I also developed a new dream: to embrace love and pursue healing in all areas of my life and to use my experience for the benefit of others,” said Meghan.

Instead of celebrating, Meghan soon returned to the hospital as a volunteer to help other people living with cancer. She was also inspired to pursue a master’s degree in nursing and since August 2011 has been working as an oncology nurse. “The most difficult part for me was feeling like no one could really understand what I was going through. I have received so much energy from connecting with other cancer survivors and I hope that by putting my story out there, I can bring a sense of fellowship to others and show them that there ARE healthy, active, happy young adults living with an ostomy,” she said.

Meghan, now 28, lives with her new husband Matt in Eagan, Minnesota. She enjoys running as a source of relaxation and recently completed a half marathon. Meghan says she has grown to appreciate her colostomy as a small scar from all that she went through to be here today.

# Having An Ostomy Helped Me Find A New Sense Of Purpose

Jo's vlog via November 18 OstomyConnection

What does it mean to have a stoma?

You might get a hundred different answers to that question. What it means to me is being part of something that is bigger and more important, rather than I am alone.

## **Being diagnosed with rectal cancer at age 38 is a bit of a mind-bender.**

The first equation I had to figure out was:

Mental health + cancer = ?

As if that wasn't hard enough to reconcile in my mind, the news that I would have to have a colostomy bag was unthinkable! At first it was a coin flip as to whether I'd need a temporary or permanent stoma. But after intense radiation failed to shrink the tumor as much as was hoped, I was told there was no chance of a reversal if I wanted the best chance of survival.

## **There are so many emotions in the run up to ostomy surgery.**

The main one being Terror, with a **capital T**.

My mum said she'd get a colostomy bag with me. Suffice to say that has yet to happen!

My fiancé Jay told me he'd be right there with me every step of the way and we were gonna make it through, together.

The most memorable moment was when my sister-in-law Lesley told me I'd own it, that I would face it head on like I have every other challenge in my life, and that I was going to be more than OK.

Through the tears I nodded in agreement and murmured she was probably right. I was a really good liar it seemed! Inside I laughed and thought no way was that going to happen. How did she know that? It was me facing this life changing surgery, not her.

## **I seriously considered not having the surgery.**

Sure, I'd take my chances with the cancer, anything was better than pooing out of my belly!

And that was the stark reality. As much as I hated innards and liked everything inside where it was supposed to be, the fact was that my intestine (what?!) was going to poke out of me (What?!) and I was going to poo from my belly (WHAT?!?!). This was not going to go well, no way, nuh uh...

So here I am, 9 months later, a pro at my own stoma care, loving the amazing sense of community and camaraderie I get from being an ostomate. I bloomin' love it! I also love little ButtFace, as I unaffectionately called my stoma. That name was meant as an insult, now it's a term of endearment and a seemingly infinite source of giggling-pleasure for me and my young niece and nephew. Lesley was spot-on (once again – ain't those kind of people annoying?! ) I do "Own It."

## **Lately I've found myself feeling more and more grateful for my new little extra appendage.**

Without it I wouldn't be writing this now, I wouldn't have created a [vlog on YouTube](#) to offer advice and support to other ostomates who are in the situation I was nine months ago.

I think I may have reconciled that original equation. Yes, there's an incurable cancer diagnosis, but with the new sense of purpose having a stoma (and a loud voice) has afforded me, so I think I'm going to cope okay. If I have helped even just one person on their ostomy journey, I'm satisfied. I've made something of my life and at last, there's meaning.

If you fancy having a laugh at mine and ButtFace's expense, pop on over to my [vlogostomy](#).







## Advocacy News

By Jeanine Gleba, Advocacy Manager  
and Jay Pacitti, Executive Director

### **UOAA Opposes Budget Proposal to Include Ostomy & Urological Supplies in Medicare Competitive Bidding.**

United Ostomy Associations of America is working with a coalition of patient organizations, health care clinicians, and technology manufacturers to address concerns over the President's FY 17 budget provision to expand Medicare's competitive bidding program to ostomy and urological supplies.

Because it is a medical necessity that individuals have access to a properly fitted pouching system, the one-size-fits-all policy that could result from competitive bidding is unacceptable. UOAA has long opposed the inclusion of ostomy supplies in competitive bidding proposals, and will continue to do so in the future.

The coalition's plan to oppose this proposal is on a positive track. It is important that the ostomy and continent diversion community present a united front in addressing this issue with lawmakers. We ask that you connect with us and follow our updates on the progression of this proposal before taking any advocacy action.

Your personal stories highlighting the necessity of specific fittings of ostomy and urological supplies will be an especially powerful tool in convincing lawmakers of the folly of this proposal now and in the future. We will ensure that your voices are heard on this matter, and will call for your support and action at the most opportune time in this process. Send your story to Jeanine Gleba, [advocacy@ostomy.org](mailto:advocacy@ostomy.org)

### **Progress in New York State**

On a more local level, you may remember that in 2015 a state health mandate required all commercial health insurance policies in New York State to cover ostomy supplies. There remains only one health insurance plan in NY that does not cover ostomy supplies: Child Health Plus (CHP). Although the majority of the plans participating in CHP have volunteered to include ostomy supplies, they are not required to do so.

Earlier this year, Senator Kemp Hannon and Assemblyman Kevin Cahill introduced legislation (S01400/A01038) to ensure coverage of ostomy supplies in NY CHP program. Both UOAA and the WOCN Society have written letters supporting this legislation. Please help us to close the last gap in coverage in New York State. If you know of a child with an ostomy who is covered by NY CHP, it would be a great help for their parents to contact Advocacy Manager Jeanine Gleba . One of the best ways to convince legislators to close this gap is to share real examples of the need for coverage. Meanwhile, we will continue to work with the WOCN Society and legislative staff on this issue in the coming months.

### **A New Year**

Following the presidential election, we are carefully monitoring the transition team's plans and statements as they relate to health care coverage and costs. There is a good deal of uncertainty, and we will remain vigilant so that we can respond to issues that may arise.

# California Dreamin'

*You're invited to UOAA's National Conference!*



**6<sup>th</sup> National Conference**  
Tues.–Sat., Aug. 22–26, 2017, Hotel Irvine, Irvine, California

*Plan now to attend.  
It is a great experience  
you won't soon forget*

**August 22-26, 2017  
At the Hotel Irvine  
in Irvine, California**



**Irvine** is in the heart of Orange County in coastal Southern California. The fabulous “lifestyle hotel” the Hotel Irvine will be the home of the conference and is a perfect base of operations for area attractions. You’ll find amazing shopping at the Irvine Spectrum Center (pictured left) and other premiere areas near Irvine. Pacific beaches and Newport Harbor is accessible and nearby, as is golf, hiking and family attractions such as as Knott's Berry Farm and of course Disneyland! Southern California has many airport options but if you fly into nearby John Wayne International Airport a free airport shuttle will take you straight to the hotel that is both affordable and packed with amenities.

## **Conference-Related Information**

Please go to [www.ostomy.org](http://www.ostomy.org), the UOAA website, to register and view the educational programming that is planned for you. Information regarding conference registration will be posted on the UOAA website when available and will be published in the March 2017 issue of *The Phoenix* magazine







# Get Ostomy Answers!

The Phoenix magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations of America.

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ASG052016

~~~~ ✂ ~~~~~ **TO BECOME A MEMBER OF THE** ~~~~~ ✂ ~~~~~  
**OSTOMY ASSOCIATION OF SOUTHERN NEW JERSEY**

Membership in the Ostomy Association of Southern New Jersey is open to all persons interested in ostomy rehabilitation. Membership dues are only **\$10.00 per year**.

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**Date(s) of Ostomy Surgery:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

**Make check payable to "OASNJ" and mail to:  
 Ken Aukett, P.O. Box 318, Collingswood, NJ 08108**