



From the Advocacy Manager at the United Ostomy Association of America (see the letter in this issue of the MailBag):

Thank you for your organization's support of our Presidential Proclamation request letter for National Ostomy Awareness Day. In total, 46 organizations joined our effort this year.

**President Joseph R. Biden Jr. The White House
1600 Pennsylvania Ave, NW Washington, DC 20500**

May 15, 2023
Dear Mr. President:

Each year the ostomy community unites to celebrate National Ostomy Awareness Day on the first Saturday of October. The aim of National Ostomy Awareness Day is to work toward a society where people with ostomies and intestinal or urinary diversions are universally accepted and supported socially, economically, medically and psychologically.

There are between 725,000 to one million Americans living with an ostomy or continent diversion, and over 100,000 new life-saving ostomy surgeries occur in the United States each year.

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https://www.facebook.com/JaxUOAA?ref=aymt_homepage_panel
Find all the past issues of the MailBag at <http://ostomymcp.com/id6.html>

**UOAA NATIONAL CONFERENCE HOUSTON TX
August 10-13, 2023**

<https://www.ostomy.org/event/uoa-8th-national-conference/>

**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: **June 18th**

Also join us by Zoom

<https://us06web.zoom.us/j/94640600811>

Meeting ID: 946 4060 0811
or call +1 301 715 8592 US

**Gainesville Support Group
Contact info:**

JoAnne Bell at 352-284-4214

Meets the 1st Sunday of each month (except Holidays)

at Hope Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: **TBA**

Ocala Support Contact info:

Karen Franco 352-304-1309

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: **TBA**

**Citrus County Support Group
Has Disbanded**

To find a support group in your area visit:

<https://www.ostomy.org/support-group-finder/>

**Amelia Island Area
Ostomy Support Group**

(904) 310-9054

Meets second Monday of each month at 6:30pm

Next Meeting: **TBA**

The Villages Ostomy Support

We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August)

Linda Manson

tvostomy@gmail.com

865-335-6330

Next meeting **June 13th @ 6 pm**
Saddlebrook Rec Center (near Polo Field)
Masks Required

Contact Linda tvostomy@gmail.com



The MailBag

June 2023

For the past six years Representative Donald Payne with other original co-sponsors introduced a House Resolution on the House floor officially declaring National Ostomy Awareness Day. In 2022 this was H.R.1422. In years past President Reagan and President Clinton have issued Proclamations supporting the ostomy community.

This year we are asking for your support and requesting a Presidential Proclamation recognizing October 7, 2023 as National Ostomy Awareness Day in the United States.

Ostomy surgery may be needed by people who suffer from cancer including colorectal cancer, bladder cancer, cervical and ovarian cancers; inflammatory bowel diseases such as Crohn's disease or ulcerative colitis; trauma sustained in Military service; birth defects, injury, and other intestinal or urinary or gastroenterology medical conditions. Patients have a surgically-created opening (stoma) in their abdomen for the discharge of waste and a 'pouching prosthetic system' is continuously worn over the stoma to replace the lost functions of waste storage and elimination.

This day is an opportunity to raise awareness and remove stigma about this life-saving surgery to prevent death and promote quality of life for people living with this life-altering new "normal". It's such a simple truth - ostomies are life savers and yet, we continue to hear "I would rather die, then have an ostomy." 34th President Dwight Eisenhower chose life during his Presidency with his ostomy surgery for Crohn's disease in 1956.

The undersigned organizations represent thousands of medical professionals, patients, survivors, caregivers and advocates. We will continue to carry on breaking the silence and shining a positive light on what has saved so many lives. We urge you to join us and increase national visibility of those living with ostomies with a proclamation recognizing National Ostomy Awareness Day.

Please contact Jeanine Gleba, Advocacy Manager, at United Ostomy Associations of America with any questions and response at advocacy@ostomy.org or 207-569-5724.

We lookforward to hearing from you.

Sincerely,

Alive and Kicking
American College of Surgeons
American Gastroenterological Association
American Society of Colon and Rectal Surgeons
Androscoogin Ostomy Support Group (ME)
Big Island Ostomy Group (HI)
Bladder Cancer Advocacy Network
Bluegrass Chapter of the United Ostomy Associations of America (KY) CBMC Ostomy Support Group
Cedar Rapids/Iowa City Ostomy Support Group (IA)
Corstrata
Crohn's and Colitis Foundation
Digestive Disease National Coalition
Global Colon Cancer Alliance
Greater Baltimore Ostomy Association (MD)
Fight Colorectal Cancer
Friends of Ostomates Worldwide-USA (FOW)
International Foundation for Gastrointestinal Disorders
Infirmary Health Ostomy Support Group (AL)
IU Health Jay Ostomy Support Group (IN)
Jacksonville Chapter of the United Ostomy Association of America (FL)

Legacy Health Strategies
 National Alliance of Wound Care and Ostomy
 North Sound Ostomy (WA)
 Omaha Ostomy Association (NE)
 Ostomates of Olympia (WA)
 Ostomy-211 (OK) and OstoMyFamily
 Ostomy Association of Greater Hartford (CT)
 Ostomy Association of Los Angeles (CA)
 Ostomy Association of North Central Oklahoma (OK)
 Ostomy Support Group of Central Indiana (IN)
 Ostomy Support Group of Northern Virginia (VA)
 Ostomy Association of Southern New Jersey (NJ)
 Pensacola Support Group (FL)
 Philadelphia Ostomy Association, Inc. (PA)
 Pouchtalk (Concord, NH)
 Quality Life Association
 Saginaw Tri-County Chapter (MI)
 South Palm Beach County Ostomy Support Group (FL)
 The Grateful Patient Foundation
 Union County Ostomy Support Group of New Jersey (NJ) United Ostomy Associations of America
 Wound Ostomy Continence Nurses Society
 Wound Ostomy Continence National Certification Board Youth Rally



Allergy or Fungal Infection? by **Mary Ann Brooks, CWOCN**, Singapore via OSGNV The Pouch; via The Triangle, March/April 2021, Pittsburgh Ostomy Society

Do you ever have a red itchy rash around your stoma when you remove an old wafer? The rash could be an allergic reaction. You may develop an allergy to new products or new adhesives, preservatives or artificial colors in the products. Most allergic reactions occur on the second exposure to an allergen. But people can develop a new allergy to products that never bothered them before. An allergic reaction would exactly match the area that was covered by the wafer. The skin may be dry or weepy, itchy and/or splotchy. Hives may develop. Generally, the rash would respond to the use of Benadryl if it is an allergy. You should try a different wafer and maybe some hydrocortisone cream and see if the rash resolves. But maybe the rash is really a fungal infection. Fungal infections are most common in the summer months. The symptoms are similar. The red itchy rash under the wafer may look like the allergic reaction described above.

Fungal infections are caused by the overgrowth of any number of fungal spores that are in our environment every day. If you have fungus on one part of your body for instance, it can easily be transferred to the peristomal area. Athlete's Foot is a fairly common example of a fungal infection. Ringworm is another. When fungal spores land on our skin, they usually don't harm us. But, if you give them a nice warm, dark area like under your ostomy wafer, they may start to grow and multiply. A fungal rash will generally be about the same size as the wafer, but it may grow outside the boundaries of the wafer. It may also occur under the pouch part of the appliance or extend out even further into the skin folds of the groin area. A fungal rash may have small red dots around the periphery of the central rash area. This rash will not improve with a different type of pouch or wafer. Fungal infections will not respond to Benadryl. They may improve a little with a hydrocortisone cream but won't go away entirely. What you will need is an antifungal powder. If it is a fungal rash, it should respond well to the powder. It is important to continue to use the powder after the rash is gone for a full two weeks to prevent it from coming right back. These rashes may look alike, but they have different causes and different treatment.

If you ever have a question or concern about your stoma or your peristomal skin, make an appointment to see your local WOC Nurse.

Your Ostomy is Just the Beginning By Makeda Armorer-Wade via United Ostomy Associations of America website, ostomy.org, June 22, 2021

How many times have you thought "why me?" Well, I get it.

An Ostomy is not an elective surgery. Most people who get one are having challenges with a health condition, or an accident that will require them to get one. I got my first Ostomy after a four-decade battle with Crohn's disease. I remember that day like it was yesterday. I can't remember which bowel resection I was up to. But I know that something had gone dreadfully wrong. I had the surgery and had just moved from step-down (one step below ICU, where you are kept until you become stable), to a regular room. 24 hours into that room assignment something inside began to rupture. That night I contacted my doctor who scheduled me for an intrusive test five hours later. I was in too much pain to tolerate the test, at which time they realized that I would have to have an emergency ileostomy. I was in the loneliest place in the world. I had just had a seven-and-a-half-hour surgery and I had to go back in. I did not know how my body would be able to handle it.

My family who had come to the hospital in the wee hours of the morning, were told once again, that emergency surgery would have to be done in order to save my life. Nobody was prepared for the news of an ileostomy. (An ileostomy is when they divert your intestine from the inside to the outside of your body, usually at the lower end of the small intestine called the ileum.) Neither myself or my family knew what this was, and while they explained it to me I began to ask what other options we had. Of course, the answer was "none if you want to live." I responded the way that I always

do with “ok, let’s just get this done.” I didn’t have time to express fear. Because, I saw the look on my family’s face as they began to draw on my belly in the elevator to determine the site of the surgery. I was scared, angry and worried because I had no control, so I prayed.

My ileostomy taught me a lot about life and stamina. I became even more determined to learn everything I could to make this a smooth transition. After the surgery I had my consultation with my WOC nurse and began my new journey. She was pretty amazing in how she explained everything and made sure that I understood the mechanics of taking care of my Ostomy. It was a daunting task. It was one of the longest days of my life and a big blur. My family was super supportive as I was so weak. But they didn’t have a clue what to do. They were ready to take direction from me. And while I have managed to keep a stiff upper lip through the first 14 lifesaving surgical procedures, this was different. I was grieving. I knew I had to figure it out, and my only consolation was that eventually it would be reversed (this is called a take-down). Well, I can probably tell you about that in another blog.

I became even more determined to learn everything I could to make this a smooth transition. After learning to walk 10 steps from death’s door, over the course of 18 different surgeries, I eventually learned to work my P.L.A.N.© and you can too. P.L.A.N.© stands for Prepare, Let go of Shame, Ask for help, Never Give up! I tell my clients all the time that “life will teach you some things; that which you want to learn and that which you don’t.” In life we don’t always get to pick our lessons, but I am so happy that I learned a ton of them here. It allowed me to come to the conclusion that my fellow Crohn’s Warriors and Ostomate brothers and sisters needed the same support that I did after surgery. And so I am here. I am not a doctor or a nurse, just someone who cares about you. I wrote books and created a learning platform ThePossibilitiesLifestyle, to support your experience with the books and provide The Possibilities Lifestyle Coaching. My goal is to help and support as many people as I can. Please, I want you to remember this.

Editor’s note: This educational article is from one of our digital sponsors, ConvaTec.

Visit the Peristomal Skin Assessment Guide for Consumers
<http://psag-consumer.wocn.org/#home>

UOAA COVID-19 UPDATES
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<https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/>



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