



<https://www.ncoa.org/professionals/health/center-for-healthy-aging/national-falls-prevention-resource-center/falls-prevention-awareness-week>

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Check Out The MailBag Now On FaceBook

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

**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: **September 19th**
Zoom will also be available
for those out of area or
uncomfortable to attend in person.

**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

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: **TBA**

**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

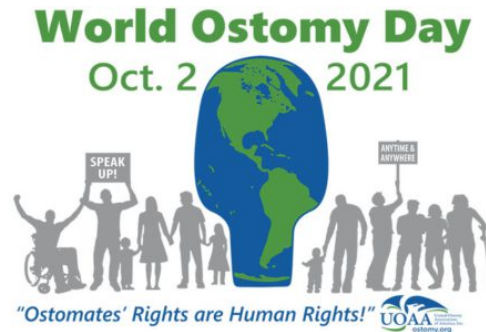
tvostomy@gmail.com

865-335-6330

Next Meeting: **via Zoom**

Contact Linda tvostomy@gmail.com

A WORLDWIDE MOVEMENT FOR OSTOMY RIGHTS!



By Jeanine Gleba UOAA Advocacy Manager

Every three years, ostomates around the world come together to celebrate [World Ostomy Day](#) on the first Saturday in October. This year it will be held on October 2, 2021 and the European Ostomy Association (EOA) has declared the motto as "Ostomates' Rights Are Human Rights – anytime and anywhere!" It is an opportunity for the world to join forces to increase public acceptance of ostomy surgery and to help people to better understand that health is a human right for everyone.

During the Covid19 pandemic the ostomy community around the world has been impacted such as ostomy nurse visits in the home being reduced and peer-to-peer support visits from an ostomy mentor in the hospital stopped. In some countries, there has been limited access to ostomy supplies due to supply chain issues and/or limited access to affordable ostomy appliances. As a result, the EOA wanted to rekindle a focus on the [Charter of Ostomates Rights](#).

In the United States an ongoing UOAA advocacy initiative is to improve the quality of ostomy health care and ensure higher standards of care in all health care settings. One strategy to drive this change has been the utilization of the ["You Matter! Know What to Expect and Know Your Rights Ostomy and Continent Diversion Patient Bill of Rights"](#) as it specifically defines what high quality care should be expected and received during the ostomy surgical experience and for continuum of care.

With the World Ostomy Day motto we will join the worldwide movement and the EOA's goal to: "underline that ostomate rights are not negotiable. They must be respected by governments, politicians, healthcare authorities, companies and suppliers, by doctors and nurses, by every human and by every society – even in uncertain times."

Quality ostomy care should be provided to all regardless of race/ethnicity, age, gender, religion, place of birth, health or other status (even having an ostomy!). This World Ostomy Day you can help us drive change in the United States. Share the newly revised patient bill of rights [poster](#) (11×17 for printing purposes) with your ostomy surgeon, GI doctor, Primary Care Physician and/or ostomy nurse. Ask them to ensure that these standards of care are utilized in their practice.

As always there will be many other fun and important ways that people can participate in this year's celebration! You can:

- Attend an Online Event. UOAA 2021 Ostomy Awareness Day Champion [Allison Rosen](#) will kick-off the day with a Facebook/Instagram Live on the morning of October 2nd and also host a candid Q&A that evening. UOAA representatives will also take part in a host of ostomy educational events with partner organizations and others leading up to and immediately after World Ostomy Day. Follow us on [Facebook](#), [Instagram](#) and TikTok for updates.
- Watch our brand-new Ostomy and Continent Diversion Patient Bill of Rights animated series (Link available in September during the weeks leading up to World Ostomy Day)
- Walk, Run, Roll or Pedal at UOAA's 2021 Virtual Run for Resilience Ostomy 5k anywhere in the world. Register [here](#) and you'll have the option to get our special World Ostomy Day t-shirt. This virtual event helps UOAA raise much-needed funds to improve quality of life for people living with an ostomy or continent diversion
- Help UOAA get a proclamation declaring World Ostomy Day from all 50 states! A sample is also available to download on our webpage noted below or you can take action at the state level [here](#).
- Upload our special "frame" for your social media profile photos that says you speak up for ostomy rights and use the hashtags: #WorldOstomyDay, #OstomyRights, #MyAccessMatters
- Submit a [letter to the editor](#) of your local newspaper or reach out to local media.
- And so much more!



Visit the World Ostomy Day [webpage](#) for further details about the special events and the full list of all the ways to get involved.

Let's make the voice of ostomates in the United States heard around the world this year!

The following is a letter to Dr. Keith Roach from one of our own... Eileen Wideman from our Amelia Chapter. She wrote a letter to the physician who writes a column for the *Times Union*, and other newspapers across the US, in response to his not reassuring a writer who was delaying getting a colonoscopy for fear the colon would be punctured and she'd have to have an ostomy. Thank you Eileen



Your Good Health: Most live unchanged lives after ostomy surgery

Dr. Keith Roach / Times Colonist
AUGUST 19, 2021 06:00 AM

Dear Dr. Roach: I am responding to a recent letter from a reader anxious about undergoing a colonoscopy. One of her concerns was a possible perforation requiring additional surgery and a temporary colostomy. You reassured her that the probability of such an occurrence was very low.

I have seen this fear often. No doubt, it comes from most people having no experience with the procedure and/or from negative portrayals in the media. Yes, it is major surgery. But it is also a lifesaver that, after an initial period of learning and adjustment, does not interfere with quality of life, work or pursuing most activities. There are cases where individuals have refused this kind of surgery and eventually died. The image of “the bag” can be that frightening.

I have an ileostomy [a connection between the small bowel (ilium) and the outside, through the skin, as opposed to a colostomy, which is a connection between the colon and the outside] as a result of years of ulcerative colitis creating precancerous, fast-growing lesions in my colon. I delayed surgery for a year, because of fear. Thankfully with education, I made a good adjustment in a matter of weeks. Today I co-lead a support group. We see a lot of new joiners, but tend to lose members after a few weeks. Why? Because by that time most say they are fine and don't need the group.

Modern medicine and space-age materials have produced appliance products that are nothing like those from earlier times. Today's are thin, deodorized and gentle to the skin. They adhere well and allow bathing, swimming, sexual activity and exercise. Most people continue with an unchanged life after recovery. Many would be surprised to learn that there are well-known celebrities, politicians, and sports figures who have had this surgery. In fact, with over 750,000 surgeries a year in the U.S. (including both bowel and bladder diversion), it's probable that everyone has come into contact with, or knows, someone who has.

I urge physicians to confront fear surrounding ostomy surgery with reassurance and education. I'm not suggesting that anyone be pushed into a major surgery if they are uncomfortable. But every important decision should be made after receiving as much education and information as possible.

E.W.

I thank E.W. for her thoughtful letter and think it's important enough to publish.

Dear Dr. Roach: My daughter-in-law tested positive for COVID-19. She agreed to do the infusion therapy. She is fine now but still part of the study. She is under the assumption she doesn't need the COVID-19 vaccine. Your thoughts?

N.H.

With many infections, such as measles, infection leads to a lifetime of immunity in virtually all people. Unfortunately, getting measles (like getting COVID-19) can cause serious complications and even death, which is why vaccination is much preferred.

Not all infections provide lifelong immunity. Although infection from COVID-19 does lead to some immunity, it appears that the immunity is often short-lived and specific to the variant a person was infected with. It is very clear that people can get COVID again fairly quickly. More importantly, they appear to be susceptible to the new variants that are spreading across the country and the world. A vaccine is absolutely indicated for people who have had a case of COVID.

Most people can get the vaccine as soon as the symptoms have resolved; however, people like your daughter who were treated with antibodies need to wait 90 days after infection to get the vaccine.

Dr. Roach regrets that he is unable to answer individual letters, but will incorporate them in the column whenever possible.

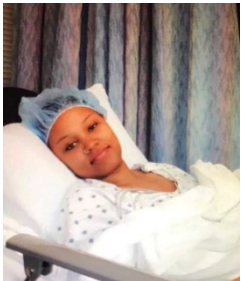
Readers may email questions to ToYourGoodHealth@med.cornell.edu

FROM UOAA AUGUST E-NEWS

A YEAR WITH AN OSTOMY PROVIDES CHALLENGES AND BLESSINGS

My name is Jasmine and I was diagnosed in 2016, at the age of 23 going on 24, with stage three colorectal cancer. I am a survivor. I went through multiple surgeries, chemo, radiation, and an ileostomy.

Many people think that having to wear an ileostomy bag would be unpleasant and very difficult. There is some truth in that at first, but I learned on the journey that it was a blessing.



Without an [ileostomy](#), I would have not have been able to have my cancer (tumor-size of a peach) taken out. Without having my cancer out, I might not be here today. There are challenges that I faced such as my bag leaking. There were some nights when I would wake up and the stool would be everywhere. It was very frustrating but I managed to get through. One day I asked myself, "is this life?" Just like anyone else I would feel down. I knew it was ok to go through the emotions but I started praying to God that things would get better. My faith, family, and friends is what got me through.

Once I explained to my treatment team about what was going on, they insisted that I have a nurse come out two-3 days out of the week to help assist with my ostomy. Thanks to Johns Hopkins in Baltimore, they gave me resources as far as where to order good quality bags that were covered by my insurance and I ordered from a supply company. They started by giving me free samples to try and then I started to order them frequently because I liked the quality and they also provided a kit that included scissors, ostomy bag holder, and barrier rings. The scissors were for me to cut the baseplate to get it to the exact size of my stoma so that it could fit properly. This was all new to me but in due time it became the norm.

The barrier rings were great because it is what protects the skin because I had issues with my stool getting on my stoma. Whenever the stool would rub on my stoma it would burn so the rings help protect the stoma and leaks.

UOAA's 8th National Conference
AUGUST 11, 2022 - AUGUST 13, 2022



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

I do not regret anything I went through though because I came out a stronger person.

The advice I'd share would be to empty your pouch on a regular schedule to avoid overflows. I ate small frequent meals because I notice when I ate a lot, my bag would fill up. Make sure you're drinking enough fluids throughout the day as well. I had to introduce foods to my diet one at a time to determine how it would feel. I always made sure that I had bags everywhere I went.

I had the ileostomy for almost a year and I was told that it did not have to be permanent unless I developed problems down the road. In April of 2017 I was able to get it [reversed](#) (taken off).

Some other challenges from the cancer were that I had a section of my rectum removed and one of my ovaries removed. I cannot have kids on my own because both of my Fallopian tubes were removed as well so I will have to go through a surrogate, knowing this, I chose to freeze my eggs.

Being that a part of my rectum was removed I have complications from time to time. I am now 29 and although I still have complications I'm so happy to still be here and share my testimony with others as well as help any others who are encountering the same illness.

My recommendation to others with an ostomy and going through this process would be to be confident in your bag. I never looked at myself as disabled, I wore my bag with pride. There were a few times when I made a design on my bag to make it my own.

One thing I went through was being able to see who my real friends were through this process. I lost some friends in the process but gained even better friends. I had trouble dating due to the fact that people were intimidated by my bag and everything I had to go through.

I do not regret anything I went through though because I came out a stronger person. Life is too short to be down, I survived cancer, I was almost at the end of the road. I was in way too deep to just give up. Do not give up, I want those who see my story to [reach out to me](#) if they need to vent. It helps to talk to someone who actually went through the same experience.

With the help of my family real friends, and God I was able to go through this process gracefully.



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

UOAA COVID-19 UPDATES
UOAA will update this blog post with any information that may affect our community.
<https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/>



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UOAA Discussion Board
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Medical Care Products, Inc
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