

# UOASL 2021 MEETING SCHEDULE

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

All meetings on zoom until further notice

April 5, May 3, June 7, July 5

Meetings at 7pm at Zoom.com Meeting ID: 911 5889 5347 Passcode: 554205 You can also call in at 1-312-626-6799 and enter the meeting ID and Passcode listed above.

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## Any articles welcome for consideration:

**personal experiences, health, obituaries, tested tips, etc.**

Publication Deadline May 25, 2021

Send articles to: Mary Beth Akers

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## LIVE & LEARN by Email

Are you interested in getting this publication by email only?

Send an email to Mary Beth at the email above to let her know and we will save the postage and printing cost.

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Please email Rick at [rickhaley61@hotmail.com](mailto:rickhaley61@hotmail.com) or call him at 636-375-6871

if you have any change in home address,

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We would like for you to keep getting the L&L's and postcards.

If you do not receive any of our information, please let us know.

## FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!

To find us on Facebook, go to Facebook.com/UOAA Inc.

To follow us on Twitter, go to Twitter.com/UOAA,

or while logged in, search for @UOAA.

You can find our social blog at [blog.ostomy.org](http://blog.ostomy.org).

## From UOAA National Office

"Eating with an Ostomy" Nutrition Journal is newly updated and available on the UOAA website ... <https://www.ostomy.org/diet-nutrition/>. Feel free to download it or print it out for your own reference.



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# LIVE AND LEARN Spring 2020

## President's Message

To All Members and Friends of UOASL,

Spring seems to be right around the corner! I am looking out the window at a few kids riding their bikes in the park. Not as many as I would have seen last year as some families are still keeping separate as much as possible. We continue to meet by Zoom as hospitals are not opening their meeting rooms just yet and our board is not ready to push it by looking elsewhere for meeting spaces. I am truly looking forward to seeing our members together in one place again but for now, we continue to make the best of it and hope you are reaching out to others by phone, text, email, etc.

We will not be having our product fair in May but our Zoom meeting May 3<sup>rd</sup> will have the look of what we have done the past couple years. We will have a number of nurses and will use the Breakout Room feature to allow you to ask questions about topics you are interested in such as basic ileostomy, colostomy, urostomy, hernia, diet and nutrition, etc. Send me a message if you have something you would like us to include.

We have also been missing the opportunity to help folks with their ostomy supplies by having the table of offerings out at every meeting. We are having an Ostomy Pop-up Shop on March 24<sup>th</sup> at St. Luke's, our normal meeting spot, but we will be in the lower level of the parking garage so we are outside but under cover. We will be there from 6-7pm. Stop by and see what we have. You are welcome to anything we have for free, if you are underinsured, if you are uninsured, or if you are fully insured but you are looking to try out something new. If you have things to donate, you can drop them off then as well.

Thanks to all those individuals who provide support to our group through contributing ostomy supplies, volunteering in so many ways, or donations.

I look forward to seeing you at a meeting and please do not hesitate to reach out by e-mail me at [marybethakers@excite.com](mailto:marybethakers@excite.com) or call 636-916-3201.

Mary Beth Akers, President UOASL

## THE LEGENDARY PHOENIX via Tucson, The Courier

As the symbol of the constant renewal of spiritual values, of the flames of love and compassion, of the seasonal spring of life, may the Phoenix serve as a glowing, vibrant sign for each of us.

## EMPATHY

This guy's walking down the street when he falls in a hole. The walls are so steep he can't get out.

"A doctor passes by and the guy shouts up, 'Hey you. Can you help me out?' The doctor writes a prescription, throws it down in the hole and moves on.

"Then a priest comes along and the guy shouts up, 'Father, I'm down in this hole can you help me out?' The priest writes out a prayer, throws it down in the hole and moves on.

"Then a friend walks by, 'Hey, Joe, it's me can you help me out?' And the friend jumps in the hole. Our guy says, 'Are you stupid? Now we're both down here.' The friend says, 'Yeah, but I've been down here before and I know the way out.'"

*This story Shanan Rodgers shared on one of our zoom meetings truly illustrates how important our group is. We have all been in our own little holes but we know the way out and can share that with others.*

# Get Ostomy Answers!

*The Phoenix* is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.

Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.



**The Phoenix**



One-year subscription \$29.95    Two-years for \$49.95

Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

## Wash Those Hands

Via The POUCH, Ostomy Support Group of Northern Virginia

We were taught that infectious agents (bacteria, viruses, etc.) were primarily carried through the air. We know that direct contact with infected materials, particularly with our hands, is a major transmitter. The hand that covers a sneeze, removes a soaked bandage or scrubs a bathroom, carries microorganisms on its surface and in skin crevices, including the fingernails. If this same hand, unwashed, goes on to handle food, dress a baby or bandage a cut, touch the eyes, nose or mouth, or change an ostomate's pouch, it can spread "bugs" most effectively. Hand washing is the most important activity we can perform to prevent infections to others and ourselves. But thorough washing requires effort beyond a mere quick rinse: at least 20 seconds of vigorous friction with soap is the minimum. As this relates to ostomy care, it means washing hands before and after emptying. AND as we now know—Wearing a mask is also just as critical. Be sure to wear yours!!!!

## Did I Read That Sign Right?

Via The POUCH, Ostomy Support Group of Northern Virginia

• In an office building rest room door: "Toilet out of order, please use floor below." • In a Laundromat: "Automatic washing machines: please remove all your clothes when the light goes out." • In a London department store: "Bargain basement upstairs." • In an office: "Would the person who took the step ladder yesterday, please bring it back or further steps will be taken." • In another office: "After tea break, staff should empty the teapot and stand upside down on the draining board." • Outside an second-hand shop: "We exchange anything—bicycles, washing machines, etc. Why not bring your wife along and get a wonderful bargain!" • Notice in a health food shop: "Closed due to illness." • Spotted in a safari park: "Elephants, please stay in your car." • Seen during a conference: "For anyone who has children and doesn't know it, there is a day care on the first floor." • Notice in a farmer's field: "The farmer allows walkers to cross the field for free, but the bull charges." • Message on a leaflet: "If you cannot read, this leaflet will tell you how to get lessons." • On a repair shop door: "We can repair anything. Please knock hard on the door—the bell doesn't work." • "Man kills self before shooting wife and daughter" ... This one I caught in the SGV Tribune the other day and called the Editorial Room and asked who wrote this. It took two or three readings before the editor realized that what he was reading was impossible. They put in a correction the next day.

• 'Panda mating fails, Veterinarian takes over.' • "Hospitals are Sued by 7 Foot Doctors"

## Is This Normal, Even If It Is Different?

Via The POUCH, Ostomy Support Group of Northern Virginia

Whether you are new to having an ostomy or you have had one for a long period of time, you may sometimes wonder if what is happening is normal. Figuring out your new normal can take some time and even over many years, changes can take place. This is a recurring issue that may cause you to wonder, “Is this normal even if it is different?” With everything that is happening in our world right now, fear, worry and anxiety are running rampant. Social distancing, lack of everyday groceries, reduced income, or no income and avoiding the COVID-19 virus doesn’t give us our usual outlets. Certain life altering situations, such as a death in the family, divorce, certain diagnoses or even upcoming health care tests can also cause anxiety. If you have a urostomy, you may notice more mucus around the stoma or in the urostomy pouch. If you have a colostomy or ileostomy, you may notice more noise and/or gas coming from the stoma and more mucus on the stoma. This is different because it is not your usual normal, but it is normal if you are going through traumatic circumstances. These changes happen when you are anxious because the lining of the intestine produces more mucus and the intestinal muscles are more active than usual. Remember that with a urostomy, the stoma is created with a piece of the intestine. These changes should improve as your world calms down. See your physician if you have changes that do not resolve.

## POSITIVE ASPECTS OF OSTOMIES

*At our December zoom meeting for the St. Louis area when we would normally be gathering for our annual banquet, we decided we wanted to stay upbeat so we each shared the top three positive things about our ostomy.*

\*I feel a lot freer and in control. \*I have the courage to try new things. \*I have learned to laugh and not take things so seriously. \*The inspiration of others. \*Self-defense - I can throw a bag of poo at an attacker!! ;-)\*I am able to spread the word about ostomies.\*Teachable moments for my children. \*My support system-my spouse \*I don't need to find the bathroom so urgently!! \*Less stress! \*I can sleep more. \*No more diapers. \*Independence. \*The members of the group have become like a family! \*I have my health back. I was sick of being sick. \*The knowledge gained. \*It makes me grateful for what I have. \*The medical advances. \*Resilience. \*I feel worthwhile! \*Thankful for the nurses! \*Better quality of life! \*Gave me a good attitude. \*It set an example of reaching an endpoint.

## Hospitalization Guidelines for Ostomy Patients

by Dr. Lindsay Bard via North Central Oklahoma Ostomy Outlook

It is important for a person with an ostomy to know how he/she should be handled differently than someone without an ostomy when you need to be hospitalized. Here are some rules to help you cover the details:

Rule 1 – The Cardinal Rule! If you feel something is being done or going to be done to you that might be harmful, refuse the procedure. Then explain why to the medical personnel, especially your physician. They will then decide with you if the procedure will actually be in your best interests.

Rule 2 – Supplies Bring your own supplies to the hospital. Never assume the hospital will have the exact pouching system or irrigation system you use. Most hospitals have some supplies available. These are used for emergency situations.

Rule 3 – Laxatives & Irrigations Follow the points below concerning laxatives or irrigation practices, according to which type of ostomy you have. Medical personnel often assume all stomas are colostomies. But, of course, practices vary among the various types of ostomies. A transverse colostomy cannot be managed by daily irrigations. The only colostomy that can be managed by irrigations is the descending or sigmoid colostomy. However, sigmoid or low colostomies do not have to be irrigated in order for them to function; many people with sigmoid colostomies prefer letting the stoma work as nature dictates. If you do not irrigate your colostomy, let the fact be known to your caregivers. If your physician orders your bowel cleared, irrigate your own colostomy; do not rely on others. There is a strong possibility that those caring for you will not know how to irrigate your colostomy. Bring your own irrigation set to the hospital. If you have an ileostomy or urinary diversion ostomy, never allow a stomal irrigation as a surgical or x-ray preparation. Remember that laxatives or cathartics by mouth can be troublesome for people with colostomies. For people with ileostomies, they can be disastrous—people with ileostomies should always refuse them. A person with an ileostomy will have diarrhea, may become dehydrated and go into electrolyte imbalance. The only prep needed is to stop eating and drinking by midnight the night before surgery. An IV should be started the night before surgery to prevent dehydration.

Rule 4 – X-rays X-rays present special problems for people with ostomies, again, differently managed according to ostomy type: A person with a **colostomy** must never allow radiology technicians to introduce barium into your stoma with a rectal tube. It is too large and rigid. Take your irrigation set with you to x-ray and explain to the technicians that a soft rubber or plastic catheter F#26 or 28 should be used to enter the stoma. Put a transparent pouch on before going to x-ray. Have the technician or yourself place the rubber or plastic catheter into your stoma through the clear plastic pouch. When enough barium is in your large bowel for the x-ray, the rubber or plastic catheter can be

withdrawn and the open end of the pouch closed. The pouch will then collect the barium as it is expelled and can be emptied neatly after the procedure. Once the x-rays are completed, irrigate normally to clean the remaining barium from your colon. This will prevent having to take laxatives by mouth after the procedure. A person with an **ileostomy** may drink barium for an x-ray procedure, but never allow anyone to put barium into your stoma. A person with a **urostomy** can have normal GI x-rays without any problems. Never allow anyone to put barium in your stoma. At times, dye may be injected through a soft plastic catheter into a urostomy for retrograde ureter and renal studies, often called an ileo-loop study. The same study may be performed on a **urostomy patient with a Kock pouch**. The dye will be injected via a large syringe; this can be a very painful procedure if the dye is not injected very slowly. Even 50 mL will create a great deal of pressure in the ureters and kidneys, if injected rapidly. Remember to request that the injection be done slowly. For anyone who wears a two-piece pouching system: you may remove the pouch just prior to the insertion of the catheter, and replace the pouch after the procedure is completed. If you wear a one-piece pouching system, bring another with you to the x-ray department to replace the one removed for the procedure. In the event you are incapacitated, and cannot use your hands to replace your pouching system, request that a WOC nurse in the hospital be available to assist you. The WOC nurse will be able to replace the skin barrier and pouch for you before you leave the xray department.

Rule 5 – Instructions Bring with you to the hospital two copies of instructions for changing your pouching system and/or irrigating your colostomy. Provide one to your nurse for your chart and keep one with your supplies at bedside. If you bring supplies that are not disposable, mark them “do not discard.” Otherwise, you may lose them.

Rule 6 – Communicate! Again, let me stress that you must communicate with the hospital personnel who take care of you. You will have a better hospital stay, and they will have an easier time treating you.

## New Ostomates Take Note: Walking the Walk

via UOAA UPDATE

Posture Matters! When you return from hospital you will be feeling sore and uncomfortable. You may be anxious about the front of your body getting bumped, or self conscious about the stoma which can lead to a habit of hunching over to “guard” that area. Try to focus on keeping your head up and your back straight. Walking Works! Don’t lie or sit all day. Walking helps restore lost muscle tone, gets your circulation going and just generally perks you up. Get up and walk several times a day.

## Urostomy Questions & Answers

by Juliane Eldridge, RN, CETN; via TriState OA, Iowa; Metro Maryland; and North Central OK Ostomy Outlook

*Q: Why do urostomates occasionally notice blue discoloration in a urostomy pouch or overnight drainage bag?* A: Be assured there is nothing wrong with the appliance. In recent laboratory tests conducted by ConvaTec, the blue colour was found to be the result of normal bacteria decomposition of an essential amino acid called tryptophan. There is not clinical evidence, according to an article in the American Journal of Nursing, to indicate that the production of indigo blue is harmful or that dietary tryptophan should be limited. If you are concerned, please talk with your doctor. Tryptophan is part of the regular intake of dietary protein. As it passes through your system, it changes to a blue colour when it finally oxidizes in the urostomy pouch.

*Q: Why are fluids so important for the urostomate?* A: People with a urinary diversion no longer have a storage area (bladder) for urine. Therefore, urine should flow from the stoma as fast as the kidneys can make it. In fact, if your urinary stoma has no drainage for even an hour during the day, it is time for concern. The distance from the stoma to the kidney is markedly reduced after urinary diversion surgery. Any external bacteria have a short route to the kidney. As kidney infections can occur rapidly, and be devastating, prevention is essential. Wearing clean appliances and frequent bag emptying are vital. Equally important is adequate fluid intake, particularly fluids that acidify the urine and decrease problems of odour. In warm weather, with increased activity or with a fever, fluids should be increased even more to make up for body losses due to perspiration and increased metabolism. It is important that you be aware of the symptoms of a kidney infection: elevated temperature; chills; low back pain; decreased urine output; and cloudy, bloody urine. Ileal conduits normally produce mucous threads in urine, which give a cloudy appearance but bloody urine is a danger sign. Thirst is a great index of fluid needs. If you are thirsty, drink up! Also, develop the habit of sampling every time you see a water fountain. Better still, make a habit of carrying a bottle of water with you at all times!□

### VISITING SERVICES

Upon request from you, a Doctor, a Nurse, or an Enterostomal Therapist (Wound Ostomy Continence Nurse): A **VISITOR**, who has been specially trained will be sent to visit an Ostomy patient, either Pre- Op or Post-Op. The visitor will be chosen according to the patient’s age, sex and type of Ostomy. There is **NO CHARGE** for this service and **WE DO NOT GIVE ANY TYPE OF MEDICAL ADVICE**. We only show the patient that his/her operation is not the end of the world, but a **NEW** pain free beginning to life again. Call Mary Beth at 636/916-3201.

## **In this winter season ... Walk like a penguin?**

Source: Niagara Ostomy Association,

via Regina and District Ostomy News and Winnipeg

Ideally, people will shovel snow from walkways and mop water from floors. But if they don't, how can people stay safe and avoid slipping? I saw one interesting suggestion on Twitter for the Dublin Fire Brigade: "Do the penguin walk! Walking like a penguin in compacted snow and ice will help prevent slips, trips and falls." • Bend slightly and walk flat footed • Point your feet out slightly like a penguin • Keep your centre of gravity over your feet as much as possible • Watch where you are stepping • Take shorter, shuffle-like steps • Keep your arms at your sides (not in your pockets) • Concentrate on keeping your balance • Go S-L-O-W-L-Y Following in the foot-steps of these experienced—and adorable—ice walkers is a great idea any time you're on slippery ground.

## **WHAT YOUR URINE COLOUR SAYS ABOUT YOU**

Source: Cleveland Clinic—The Colour of Pee: Via Ottawa Ostomy News, Niagara Ostomy Association, Regina & District Ostomy News and Winnipeg

Human urine has been a useful diagnostic tool since the earliest days of medicine. The colour, density, and smell of urine can reveal much about the state of our health. Here is a quick look at some of the things you can tell from the hue of your liquid excreta. **NO COLOUR, TRANSPARENT:** You're drinking a lot of water. You may want to cut back. **PALE STRAW COLOUR:** You're normal, healthy and well-hydrated. **DARK YELLOW:** Normal, but drink some water soon. **AMBER or HONEY:** Your body isn't getting enough water. Drink some now. **SYRUP or BROWN ALE:** You could have liver disease, or severe dehydration. Drink water and see your doctor if it persists. **PINK to REDDISH:** Have you eaten beets, blueberries or rhubarb recently? If not, you may have blood in your urine. It could be nothing, or it could be a sign of kidney disease, tumors, urinary tract infections, prostate problems or something else. Contact your doctor. **Outside Influences:** Stuff you take can change the colour of your urine. For instance, some medications, laxatives, chemotherapy drugs and dyes doctors give to you to diagnose urinary tract infections can make your urine darker than normal. **FINAL WORD:** The Invisible World of Urine: You can tell a lot from looking at your urine. But you can tell a lot more from the kind of urinalysis you should be getting along with a regular physical exam by your doctor. Blood in the urine, a serious sign, is often invisible to the naked eye. The level of sugars in your urine may indicate a risk for diabetes. When you're at your doctor's office, don't be afraid to pee in the cup. It's one of the best things you can do for your health.

## **Ostomates and COVID-19: What lessons can we share?**

By Tim Kist via Winnipeg Ostomy Association

Ostomates are...Resilient and Adaptive. We hear so much about needing to adapt to a "new normal" because of COVID-19. Yet, we long for some of the pre-COVID freedom that we have enjoyed throughout our lives. I get a bit frustrated personally at this talk about "new normal" because Ostomates have already adapted to this concept. And quickly, too. Despite the restrictions put in place during COVID-19, most people are largely able to go on with their lives in a normal manner. As Ostomates, we were not given that opportunity. I am not bemoaning my urinary diversion surgery because I am on this side of the ground. I had to adapt to a few new things, and to do some things in a new way. There was trial and error – yes, there were a couple of wardrobe malfunctions. There was some innovation that helped stall the wardrobe malfunction until I could change my urostomy appliance. There is a silicon tape that you can buy from Diamond Medical Supply that is easy on the skin and is reusable. If I got a small leak, I put this tape on and it held until a change could be completed. I still play hockey and basketball. Not that well because I am older and slower, but I can compete. Nobody took my competitiveness away from me. Most days I forget I have the ostomy bag on because I am focused on my life. I suppose this is why I am tired of the "new normal" being thrust upon everyone because of COVID. Sure, we have adapted many aspects of business into a virtual world. In my experience from the work I do as a certified management consultant there have been some good outcomes and some not so good. It certainly makes me think deeper and search for options when assisting a client. Yes, this has forced me to adapt and that is a good thing for my clients. And when we open our province again, people want to get together. We long for theatre, concerts, sports, and all the other things in our life that gave us such satisfaction pre-COVID. We want to do the things we like to do, safely of course. We do not want to be stuck inside like a hermit, either. We are gregarious by nature. Every WOA meeting is fun to attend because you can see the smiling faces and connect with friends. While we can "see the smile" on a zoom meeting, we cannot always "feel the smile" on zoom that you can when in person. Every ostomate I know is different. Not because you are ostomates, but because you are different as a person. You adapted and demonstrated resilience after your surgery. You kept up with your life, even if there were some added challenges. You didn't give up. And this is what the rest of our fellow citizens need to accept. You have a choice in any situation. If COVID means "X" then you decide accordingly. You may have to adapt. And you darn well will demonstrate resilience because you will continue to move forward. I believe that the way ostomates have adapted to their new normal, well before the phrase was applied to life during COVID, can be a model for everyone else. Ostomates bring personal strength and conviction that can elevate anyone out of the personal doldrums. We can, and we will, continue to

demonstrate our adaptability and resilience for everyone to see. Even when we have a rough day we draw upon our inner strength, or strength from family and friends, to increase our resilience and help us to have a better day. The Stoics always looked for a way over, through, and around obstacles. Ostomates bring this stoic effort to the fore every day of our lives. Message for society – Ostomates know what living in a new normal is all about and it is actually pretty good! Editor's Note: Tim Kist is a member and certified visitor of WOA as well as a certified management consultant in his professional life. Tim's ostomy story "That's Not What I Expected—Cancer, Chemo and Surgery" can be found on our website at [www.ostomy-winnipeg.ca](http://www.ostomy-winnipeg.ca).

### **YOUTH RALLY 2021**

As so many things, including our monthly meetings, are on zoom these days, it will likely not be a great surprise that Youth Rally will be virtual again this year. The campers will participate online July 14-17<sup>th</sup> in the afternoon/early evening and the cost is \$100. We are looking for youths, 11-17, to attend. Anyone with any bowel or bladder issue is invited to apply. This could mean an ostomy, self cathing, bowel management program and so many more. If you know of an interested youth, have them contact Mary Beth for more info at 636-916-3201, log onto [www.youthrally.org](http://www.youthrally.org) or email [marybethakers13@gmail.com](mailto:marybethakers13@gmail.com).

### **A TIP FROM A NURSE USING PASTE AS A WATERPROOF FILLER**

From The Pouch, Northern Virginia

Hi, All — When I had my recent surgery in March, I talked with an ostomy nurse about reducing leakage. My ileostomy was created on a (MACE) scar so the skin dips deeply on both sides of the wafer adhering to my abdomen. I use seals (sometimes rolled, but not always), Stomahesive strips, and even the material itself when I cut out stoma holes on my wafer to buttress the skin on my abdomen and try to make the area flat.

The nurse suggested PASTE and I'd used that before around the hole for the stoma. But this was a new use. If you put a small amount of paste (any kind, I think) and press it down and add a small amount of water to it and press it in place, it acts like a horizontal or vertical (or other shape) kind of material to fill in gaps on your abdomen. Give it a try with a few droplets of water — and let it dry.

### **A Loving Wife Speaks Out**

*by Sandie Storer, Warner Robins, GA via North Central OK Ostomy Outlook*

Family members experience a period of adjustment to ostomies just as ostomates do. I would like to share the process of adjustment I've undergone as a spouse, in order to encourage others. I hope other spouses or loved ones can benefit from knowing the process of change I have experienced concerning my husband Gene's ileostomy, and that they will realize any guilt or pain will pass to brighter days. The change in our lives seems so much smaller than it did a year and a half ago when my husband had ileostomy surgery. Looking back on the process of acceptance, I can see different stages much as one experiences in bereavement: **DENIAL**: For the year prior to Gene's surgery, we both denied its necessity. I tended to slip back and forth between denial and anger. I was angry that he was denying the inevitable--then I would deny it. When he actually had the operation, I tried to act like nothing had happened. I refused to look at his stoma and wanted nothing to do with the United Ostomy Associations of America. This was a mistake. Now I see there were avenues of emotional support the Association had to offer; but I was pretty stubborn. **ANGER**: I had little support here in our home community as we were fairly new in the area and I got into some pretty traumatic emotional problems. I became very angry and withdrawn and had to rely on professional help to bring me around to the bargaining stage. **BARGAINING**: I was angry with Gene for something he had no control over. Once I admitted that, I was willing to talk with him about compensating for his stoma. I was expecting him to somehow be a better husband to make up for "what he was putting ME through." When I could have been a staunch support for him, I was expecting HIM to consider ME. Thank goodness he had his WOCNurse, the doctors, and the UOAA to help him. **DEPRESSION**: I finally reached the depression state and spent a lot of time sleeping. It was difficult to do housework. I started to feel guilty about not giving him more support and for being so upset with the procedure that would put an end to the dreaded ulcerative colitis he had suffered for ten years, a procedure which would probably save his life. **ACCEPTANCE**: Now I am more accepting of his ileostomy. I will someday make some fancy pouch covers -- maybe a Santa Claus! Seeing how well other ostomates get along in the world has been encouraging to me. What has happened is not something terrible, but something life giving and wonderful.

**TIP OF THE MONTH** Via Tulsa OK newsletter

Those car keys that you casually place in their designated handy spot are actually one of your best emergency alert systems.

- Fall down and can't get up? Just press that little red button and your car horn will sound until the battery goes dead.
- Hear an intruder in the middle of the night? Keep your keys on your nightstand. No burglar wants to stick around with your car alarm blaring. Just make your neighbors aware that if your car alarm continues to sound, you need help

## HEALING SKIN AFTER LEAKAGE

From [www.myostomy.com](http://www.myostomy.com) via The Austi-Mate Journal, Austin, Texas

Leakage happens from time to time, like forgetting where you put your keys, or putting your shirt on back-wards. It should not happen regularly. If leakage is a regular occurrence, you may need to review your pouching system with your Nurse Specialized in Wound, Ostomy & Continence (NSWOC) or WOC nurse. Leakage can irritate skin. It can feel like a burn and it can itch.

**Urostomy:** The moisture of urine, and the waste products that make it urine, can cause irritation of the skin. The skin around the stoma may turn whitish grey.

**Colostomy:** The moisture content of the stool on the skin can cause irritation. The higher up in the bowel the stoma is located, the more moisture there will be in the stool.

**Ileostomy:** The moisture content of the stool is quite high, and this can damage the skin. Ileostomy output also contains digestive enzymes, chemicals our body makes to help breakdown food. These enzymes also work on the skin, and cause damage.

Damaged skin can be red, itchy or burning, and some-times is weepy or oozing. This weepiness is moisture coming to the surface of the skin to help heal the damaged areas. If your skin was uncovered, this would make a scab.

Your pouching system sits on top of this damaged area. The moisture your body is sending to heal this area will break down your seal more quickly. This leads to leak-age on tissue that is trying to heal. Damaged skin will start to heal as soon as the cause (leakage) is removed. To help the skin heal and become dry again, you will need to change your pouch more often until your skin is healed.

Creating a Dry Surface Over Damaged Skin Some people use crusting to absorb some of the extra moisture. "Crusting" refers to the use of ostomy powder and a skin barrier film to create a dry surface over top of damaged skin around a stoma. It is done in the case of skin breakdown where there is a small amount of moisture present. Crusting allows the affected area of skin around the stoma to become dry in order to stick the flange/barrier and remain stuck, thus providing a more secure seal.

Crusting is a tool you can use when you have weepy skin. If you have red, dry skin and the powder doesn't stick, you don't need crusting, so stop. If you need to use crusting with every change, you may need to see your ET nurse to re-evaluate the fit of your entire pouching system.

Leakage behind the flange causing skin damage should be a once-in-a-while event, like putting your shirt on backwards. If you're having weepy, irritated skin every time you change, something isn't right. Perhaps your flange is cut too small, or too large, or maybe you are waiting too long in between changes. Barrier rings are also helpful for absorbing some of the extra moisture coming from your skin as it heals. Most manufacturers will send out free supplies. Trial and error is usually what's needed to find out what works best for you.

Change BEFORE the Next Leakage Happens

Changing your pouch before stool or urine gets on your skin again is the most important factor in helping skin heal. Sometimes this means changing daily or every second day until your skin is healthy. Once the skin around your stoma is healing and dry, you can return to your regular change schedule.

## \*MARCH IS COLON CANCER AWARENESS MONTH\*

### Foods Rich in Magnesium May Cut Colon Cancer Risk

Thanks to Pittsburgh Ostomy Society & MetroMaryland MSU Senior Wellness Newsletter Research done at the University of Minnesota has found that eating a diet rich in magnesium may reduce the risk of developing colon cancer. In the study, those with the highest intake of magnesium from food sources and not from supplements (more than 351 milligrams per day) had a 23% lower risk of colon cancer compared to those with the lowest intake of magnesium (less than 245 milligrams per day). Good sources of magnesium include artichokes, avocados, cashews, spinach, wheat germ, bran cereal, lentils and dark chocolate.

### About Sticky Stuff

Source: Ottawa Ostomy Support via Regina & District Ostomy News

Ostomy barriers come in a variety of adhesive types; most common are those that have tape included around the perimeter. Tape that comes unstuck is usually not the fault of the tape itself. Here are some common reasons for failure of the tape to stay on. **Moisture on the skin.** No adhesive is going to work properly if your skin isn't completely dry. If you are having trouble getting your skin completely dry, use a hairdryer on low setting. It won't hurt your stoma. **Residue left on skin.** It goes without saying that you should not use creams, lotions, or moisturizing soaps on the peristomal skin. Even the plainest soap can leave a slight residue if not fully rinsed off. Rinse, rinse, rinse! **Insufficient application pressure.** In order to stick, the tape has to be firmly pressed down, particularly at the edges. **Touching the tape before applying.** Sometimes we inadvertently touch the adhesive before it gets applied to our skin—too much pre-handling of this material will undermine its ability to stick. Try your best not to touch the tape when you peel off the backing. **Too much powder on the skin.** If you use powder, take it easy with how much you're putting on. Just a very light dusting is enough. **Stretching the skin under the tape.** If you always get a leak in the same spot, your body movements may be pulling or stretching the skin in that spot so that the tape can't adhere properly. Make sure you are sitting or standing straight when applying the barrier so that the skin is as flat as possible. If this doesn't work, you might consider adding more tape around the edges. Ask for skin-friendly 'pink tape' at your drugstore or speak with your ostomy nurse who can recommend specific brands. **Damaged skin.** Skin that is denuded, irritated, extremely itchy or broken can cause tape failure. Take care that you are removing your barrier gently by holding the skin down as you pull the tape off. If leakage is accompanied by chronic itchiness, redness, or spots you should see your ostomy nurse to check for allergies or yeast infections. It might be necessary to switch to a different type of tape. **Lastly, DO NOT apply a second coating of adhesive.** It re-wets the first coat and can give unpredictable results. Paper tape can be made more waterproof by covering it with Skin Prep after it is in place.

## UOAA ADVOCACY REPORT FROM 2020

2020 will certainly be a year for the history books and living through a pandemic is a challenge none of us expected a year ago! However, I am reminded daily by our logo's Phoenix that the characteristic trait of resilience comes second nature to many ostomates, and we will rise again.

For fifteen years UOAA has been the leading organization advocating for people living with an ostomy or continent diversion. We remain steadfast in realizing our mission and achieving our goals.. People don't always "see" advocacy efforts. I'd like to end the year by putting a spotlight on strides made in advocating for the ostomy community in 2020. In no particular order, and not an all-inclusive list, below you will get a glimpse into what we tackled this year. This does not include monitoring COVID-19 legislative activities and all of the coalition letters we signed onto to show our support.

✔ 2020 was the 10th Anniversary of Ostomy Awareness Day! On October 3rd thousands of people shined a positive light on this life-saving surgery. (5,820 people visited our dedicated webpage for this special day.)

✔ To smash stigma in the public eye we created a Mythbusters infographic for the ostomy community to share.

✔ Under the auspice of the University of Oklahoma, we are very excited to announce that UOAA completed its first-ever research project and submitted the results for publication consideration in the Journal of Wound Ostomy Continence of Nursing. The manuscript is entitled United Ostomy Associations of America's Ostomy and Continent Diversion Patient Bill of Rights: An Examination as Best-in Practice Care for Ostomy Patients.

✔ We made progress in advocacy efforts regarding access to ostomy care and ostomy supplies. You can learn more in our position statements and/or letters of support for the following:

- We are in the process of working with the Centers for Medicare and Medicaid Services (CMS) to get coverage of disposable irrigation sleeves with proper reimbursement and quantities for daily irrigation. Current coverage is only for reusable sleeves with a maximum monthly allotment of four.
- In a joint effort with the WOCN Society, we are advocating to get coverage of fistula supplies under Medicare/Medicaid.
- In efforts with the DDNC we are educating decision makers regarding our opposition on non-medical switching of ostomy supplies.
- We submitted public comments to CMS regarding ensuring Medicare beneficiaries have access to the latest innovative technology that could save lives as well as those devices that could improve ostomy patient health outcomes.
- Collaboration efforts with the WOCN Society continue towards making improvements in Community Care (i.e., admittance and retention of residents with an ostomy in assisted living facilities). We produced joint FAQs to educate decision-makers and facilities on the care required for residents with an ostomy.

✔ We continue to foster existing relationships, build new alliances and increase ostomy care education. This year we

- gave a webinar to CMS nurses on staff who review claims and perform audits to educate them on urostomy products and their clinical indications.
- recorded a podcast for the Wound Ostomy Continence Nurses Certification

Board to inspire more nurses to get certified in ostomy care.

- presented ways to get involved in UOAA's advocacy program at a meeting for 11 Health's Gutsy Gathering online support group.
- were invited by the American Society of Colon and Rectal Surgeons (ASCRS) to participate in a webinar on a multi-disciplinary approach to comprehensive care for the patient living with an ostomy. We presented on quality ostomy care and the importance of UOAA resources and support groups. You can listen here. (UOAA comes on at minute 55.)
- partnered with the Health Advocacy Summit in a Twitter Chat for adolescents and young adults on dealing with the holidays with a medical condition.
- published six articles in UOAA's Upfront with Ostomies column for the Wound Management Prevention Journal to educate medical clinicians from the patient perspective.

✔ We continue to expand on our Patient Bill of Rights (PBOR) Initiative to ensure quality ostomy care:

- Since we started the initiative over 50,000 people have received the wallet card from UOAA (increase of over 15,000 in 2020).
- In 2020 there were 948 downloads of the PBOR and 1,514 people visited the PBOR webpage.
- We formed a powerhouse task force with representatives from ASCRS, American College of Surgeons, WOCN Society, American Urological Association, National Alliance of Wound Care and Ostomy, Hollister and Convatec. These stakeholders are in the process of writing a White Paper validating the PBOR with evidence-based research. This will be used when UOAA launches a National Quality Ostomy Care campaign in 2021.

✔ We have 3 active Federal legislation campaigns including the Safe Step Act and Disability Integration Act with hundreds having contacted their elected officials. All three saw an increase in co-sponsors for bipartisan support in the 116th Congress. On December 9th, the Removing Barriers to Colorectal Cancer Screening Act passed the full House and we are optimistic it could pass by year-end. You can learn about these efforts and still take action here.

✔ By the numbers in 2020:

- Over 1100 people have now joined UOAA's Advocacy Network! Want to join forces with us? Sign-up here.
- 2,861 people were curious about our advocacy program and visited the advocacy home page.
- Even during the pandemic people were traveling or planning future trips when times are safer. There were 1,210 downloads of our TSA Communications card!
- UOAA Office Staff included various advocacy resources such as our checklists, advocacy calendar and patient bill of rights in over 1000 mailings plus included a few in the start-up boxes for 12 new Affiliated Support Group!

I am grateful for everyone that took the time to get involved in our advocacy program this year, and most especially the volunteers on our Advocacy Committee (Co-Chairs Joanna Burgess-Stocks and Sue Mueller; Anita Prinz and Keagan Lynggard-Hysell) who help make all of this happen!

Looking forward to better days and greater achievements in 2021!

Yours in advocacy, Jeanine Gleba

# UNITED OSTOMY ASSOCIATION OF GREATER ST. LOUIS

**Our mission at UOASL is:**

- To offer the opportunity to persons who have had colostomies, ileostomies, urostomies, or alternate procedures to meet with others who share similar challenges of adjustment and for sharing of ideas and knowledge.
- To aid the ostomate in recovery and rehabilitation.
- To provide educational opportunities to medical, nursing, and lay groups through lectures, demonstrations, and exhibits regarding care of the Ostomy patient.
- To provide the ostomate with volunteer services and social activities.
- To provide hospital visits to the patient, before and / or after surgery, at the request of the patient's physician.
- To maintain close contact with appliance manufacturers, also local pharmacies.
- To provide information about the availability of products to ostomates and the medical profession.

**ARTICLES AND INFORMATION PRINTED IN THIS NEWSLETTER ARE NOT NECESSARILY ENDORSED BY THE UOASL AND MAY NOT BE APPLICABLE FOR EVERYBODY. PLEASE CONSULT YOUR DOCTOR OR WOCN (ET) FOR THE ADVICE THAT IS BEST FOR YOU.**



**AFFILIATION**  
UNITED OSTOMY ASSOCIATIONS  
OF AMERICA  
1-800-826-0826 [www.ostomy.org](http://www.ostomy.org)



AMERICAN CANCER SOCIETY  
4207 Lindell Blvd.  
St. Louis, MO 63108  
1-800-ACS-2345 [www.cancer.org](http://www.cancer.org)

## Membership Benefits:

Education                      Mutual Support from Fellow Ostomates  
Visitation Program          Conferences Country-Wide  
Product Information        Local Meetings and Programs  
Ostomy Guide Books and Informative Literature  
**“Live and Learn” Our Own Publication**

### CHAPTER MEMBERSHIP APPLICATION FORM

NAME: \_\_\_\_\_  
SPOUSE'S NAME: \_\_\_\_\_  
ADDRESS: \_\_\_\_\_  
CITY: \_\_\_\_\_  
STATE: \_\_\_\_\_ ZIP CODE: \_\_\_\_\_ - \_\_\_\_\_  
PHONE: HOME: (\_\_\_\_) \_\_\_\_\_ OFFICE (\_\_\_\_) \_\_\_\_\_  
OCCUPATION \_\_\_\_\_ e-mail \_\_\_\_\_  
YEAR OF SURGERY: \_\_\_\_\_ DATE OF BIRTH: \_\_\_\_/\_\_\_\_/\_\_\_\_

**Please check all applicable information**

Type of ostomy:             Colostomy    Ileostomy    Urostomy  
    Continent Ileo    Continent Uros  
    Other (Specify): \_\_\_\_\_

Meetings:  Send meeting notices             Don't send meeting notices

Help:  Other Activities \_\_\_\_\_

Assistance             Request *Complimentary Membership*

Medical Profession  Doctor     RN,WOCN    Other \_\_\_\_\_

UOASL Chapter Membership Dues: (Effective Jul 2006)  
\$12.00 annual

Make check payable to U.O.A.S.L.  
SEND CHECK TO: Rick Haley  
907 Pevely Pointe Dr. Apt. 106  
Pevely MO 63070

(ANY CONTRIBUTIONS OVER \$12.00 ARE TAX-DEDUCTIBLE  
AS WE ARE A NON-PROFIT ORGANIZATION)



949 Chestnut Oak Drive  
St. Charles, MO 63303



Local website is [www.uoaastl.org](http://www.uoaastl.org)

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You can't go back and change the beginning but you can start where you are and change the ending. *C.S. Lewis*

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**LIVE AND LEARN – Spring 2021**

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Michele Harris      Mollie Tinnin  
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