UOASL 2021 MEETING SCHEDULE

www.uoaastl.org
All meetings on zoom until further notice
June 7, July 5, Aug 2, Sept 13
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 August 25, 2021
Send articles to: Mary Beth Akers
949 Chestnut Oak Dr.
St. Charles, MO 63303
636/916-3201
marybethakers13@gmail.com

LIVE & LEARN by Email

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Please email Rick at rickhaley61@hotmail.com or call him at 636-375-6871
if you have any change in home address,
email address, company address or contact person.
We would like for you to keep getting the L&L's and postcards.
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FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!
To find us on Facebook, go to Facebook.com/UOAA Inc.
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You can find our social blog at 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.

Affiliated With United Ostomy Associations of America, Inc.

LIVE AND LEARN

Summer 2021

President's Message

To All Members and Friends of UOASL,

As Sheila and I gather virtually to put this newsletter together, we are celebrating Memorial Day weekend. While the holiday is a time set aside to honor those who have defended our country on the field of battle, I feel many of our membership have waged their own battles. While I am deeply grateful and don't want to make light of their sacrifice, I hope you can appreciate the parallels. Our health battles have brought us to where we are today. Being willing to share our stories helps those who are still struggling to find their new normal.

Again, as we honor those who have passed away on the fields of battle, we sadly recognize two wonderful men from our St. Louis ostomy family that we have lost this past quarter. Hank Thill, a member for many years, a board member and most notably, treasurer, died March 31st. Hank kept track of our finances and presented his report with an update at every meeting for many years. He always presented his report with a wink and a smile and the phrase he coined, "We've got money!" We will always be grateful for his participation in our group as well as his support of new and old ostomates.

David Kroger, the husband of board member Karen Kroger, died on April 8th after a long illness. David was active with Karen on behalf of UOA St. Louis in their endeavor to make sure that all the ostomy supplies donated to us are shared with our members as well as the FOW organization. Dave and Karen racked up many miles driving around St. Louis to collect contributions. Besides attending our meetings with Karen, he helped her sort and organize the collection of supplies. Karen will surely miss Dave the most and our condolences go out to her, but his contribution to our group can't be underestimated.

As I have always said, we are not a one-man band. We have so many dedicated volunteers in our group, and I am so proud of how we have stayed strong through all the trials of this pandemic. We have done our best to reach out to our members, whether on the zoom or by periodic phone calls. Please reach out if you are in need of any support as we look forward!

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 or call 636-916-3201.

Mary Beth Akers, President UOASL

POP UP SHOP

Our next Ostomy Pop-up Shop will be on June 28th from 6-7 PM at St. Luke's off 141, in the upper parking lot at the northeast corner. Stop by and see what we have. You are welcome to anything we have for free, whether you are underinsured, uninsured, or fully insured but looking to try out something new. If you have things to donate, you can drop them off then as well.

AUGUST MEETING IN PERSON

While we are still planning on zooming for a bit longer, we are gathering in person on August 9th. While we had hoped to be St. Luke's Hospital, they are still not allowing meetings. Therefore, we will be at the Taco Bell Pavilion at Creve Coeur Lake. Look for more information coming soon. At our board meeting at the end of the month, we will be discussing our future meeting plans.

THANK YOU

Thanks to all those individuals who provide support to our group through contributing ostomy supplies, volunteering in so many ways, or donations. One way is by sending in more than the $12 when dues are paid. The following did so in 2020, whether by rounding up to $15 or $20 or by adding any amount from $10-100 with a most generous donation of $1000 in honor of Edie Brown.

Jan Abrams, Mary Beth Akers, Nancy Barney, Maureen Bassett, Judy Beaty, JoAnne Bentrup, Marge Blomenkamp, Joseph and Betty Bordeaux, Tom Bradley, Jerry Bradley, Harvey Brown, John Brown, Susan Burns, Judy Byrd, Richard Carlson, Rebecca Chase, Sara Chasnoff, Robert Corbett, James Crump, Carol Deboard, Christine Dennise, Clyde Dickerson, Marvin Foster, Dennis Frey, Natalie Geerling, Suzanne Harris, Stephen Harris, Karen Sue Heath, John Hilpert, Charlotte Hitchcock, Kriete Hollrah, Kathleen Ives, Loretta Kaiser, Earl Kiehl, William Kriete, Shirley Leistner, Roxy Lupien, RN, Courtney Mangin, Kathy McDade, Mary McDuffie, Hermann Metz, Betty Meyer, Mary Mills, Roger Nasser, John Niese, Sallie Parker, Edward Peterein, Paulette Pierson, Leah Preston, Phil Radman, Nancy Ray, Sheila Reddick, Edward Schniedermeyer, Charles Schroeder, Brenda Schulte, Norm Stimers, Henry Thill, Janet Thompson, Elizabeth Unger, Gus Van Brokaw, Peggy Villani, Brenda Weaver, Martha Weaver, Stephanie Weber, Florence Weltin, Melody Wilson, and Gloria Zimmers.

Contributions totaled $2442 with 1261 for Youth Rally, 169 for CARES program and 1012 for the general fund to help with postage, printing, meeting costs, etc. Thanks again to all of you!

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.

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 14-17th in the afternoon/early evening. Look for a recap in our next newsletter!

HERNIA AROUND STOMA AREA

From *Ostomy Life Newsletter*, Tulsa, OK via Springfield, MO

Simply, a hernia is an abnormal protrusion, or out-pouching, of bowel through a weakened area in the abdominal wall (the abdominal wall being the muscle and fat layers). In the case of a hernia around the stoma, the weakened area is where the stoma comes through the abdominal wall. Depending upon how large that weakened area is and how much bowel protrudes through, you may notice only a slight bulge of your abdomen around your stoma, to a significant large protrusion that is noticeable even under clothes.

A hernia around the stoma (parastomal hernia) occurs in about 5-10% of people with colostomies, and about 3-10% of people with ileostomies. While it is difficult to predict who will develop a parastomal hernia, certain factors are known to predispose someone to its development.

A parastomal hernia may also change the size and shape of your stoma. You may even find that the size and shape of your stoma changes when you are standing/sitting, and again when you are lying flat. These changes may cause more frequents leaks of your appliances or may cause peristomal skin irritation. If the hernia is large, you may also find that you can no longer see your stoma to adequately care for it. If this occurs, you should contact your ET to review pouching options with you, and you should also see your surgeon to discuss options for surgical repair of the hernia.

Some people find that a parastomal hernia changes their stoma function and bowel habits. The hernia can cause the stoma to not function as often or even to cramp when it tries to function; it may cause abdominal distension (or bloating). Discussion with your surgeon should occur if you are experiencing these symptoms, as surgery may be indicated. More seriously, you may find that the hernia prevents the stoma from functioning. You must immediately seek medical attention if this occurs. People who have a colostomy and a parastomal hernia, and who manage their stoma with irrigations may need to consider stopping irrigations all together. Irrigations may worsen symptoms and cause further complications. You can consult your ET to discuss conversion to a regular pouching system.

Some people simply dislike the appearance of the hernia and want to have it surgically corrected. You should discuss with your surgeon whether repair of the hernia is an option for you. Different approaches can be taken to repair the hernia, including a local repair right at the stoma site, or resetting the stoma to the other side of the abdomen and closing the hernia. Your surgeon will be able to discuss with you if surgery is indicated, and the risks and benefits of the different types of repairs.

https://badgut.org/information-centre/ostomies/parastomal-hernias/

What are some home remedies to treat a bad itch around the stoma?

Via The Pouch

Cold applications: Because cold and itch travel along the same nerve fibers, the use of cold can "jam the circuits" and deaden itch. If the itch is directly under the wafer, remove the wafer and apply a cold cloth over the affected area. You'll need to keep reapplying the cloth to maintain its coldness, or put some ice inside the cloth. If you have an ostomy that emits waste frequently, you'll need several cold cloths. If you can handle the overall chill, standing in a shower with a cold hand spray over the affected area can help, too. If neither of these options is possible for you, try a cold pack placed overtop the appliance where the itchy spot is. (Don't overdo it -- you don't want to 'freeze' the stoma itself.) Thoroughly dry the area once done and re-apply your usual gear. A hot shower can feel good temporarily but can leave you feeling even itchier later. **Oatmeal**: If cold showers give you the shivers, soaking the stoma area with an oatmeal bag might help. It sounds a bit sticky but getting in a tub with an oatmeal bag can sooth skin all over. How do you make an oatmeal bag? Put a cup of uncooked oatmeal in a sock and tie it shut with a rubber band. Keep it in the water with you. The polysaccharides -- basically complex sugars -- in the oats leave a "gelatinous" residue in bathwater and on your skin, also combating dryness. Oatmeal proteins work to protect your skin in general. A 2010 study, published in the "Journal of Drugs in Dermatology," found substances called avenanthramides block inflammatory compounds and histamines, thus helping to soothe skin that's become itchy. **Vinegar** Mix 50% white vinegar and 50% water, wet a clean sponge in this and soak the skin for 5 to 10 minutes when changing your appliance. Be sure the skin is washed and rinsed well to remove the vinegar before applying the new appliance. **Baking soda** Mix two tablespoons of plain baking soda in water to wash around the stoma. Again, make sure the skin is completely dry before applying the water. **Over the Counter Remedies or Medications Anti-itch creams and lotions:** Look for over-the-counter (OTC) remedies with these ingredients: Camphor, Menthol, Phenol. Pramoxine Diphenhydramine, Benzocaine (or one of the other "caine" anesthetics) If the itchy area lies outside of the wafer, you can apply these products over and over, every few minutes if needed. These preparations help numb the nerve endings and stop you from a frenzy of scratching. Unfortunately, if the itchy spot is under your wafer, putting any kind of cream or lotion on that area is going to interfere with adhesion. In some cases, if you have a colostomy that doesn't emit waste very quickly, you can put a topical anti-itch product directly on the affected spot and leave your appliance off until the cream is absorbed, then re-apply your pouch. For high output ostomies, however, you really need to see an ET nurse who can assess the situation and coach you on applying different coatings of products that will a) relieve the itch and b) allow your pouch to stay on. If OTC anti-itch products aren't helping, or can't be applied, you need to see your WOC Nurse.

CAN WASTE INFECT THE STOMA?

Source: Reprinted from Colostomy Association Tidings by Great Seattle "The Ostomate" via Ottawa Ostomy News April 2021

After ostomy surgery some colostomy and ileostomy patients worry that the bacteria present in stool will infect their stoma. It won't. Just as your rectum (when you still had it, that is) never got infected from the normal discharge of stool, neither will your stoma. A stoma is only an extension of the bowel that always handled waste. It just wasn't so visible before! The stoma is accustomed to the normal bacteria in the intestine. You do want to keep the skin around the area clean and be careful of adjacent wounds. Keep the fecal drainage away from the incision. But don't worry about the ostomy becoming infected from discharge. Nature has provided well. Our bodies are accustomed to certain bacteria. The urinary ostomy patient is more likely to be susceptible to infection than the other types of ostomies. The reason for this is that the ureters through which the kidneys empty urine to the stoma can also carry bacteria back to the kidneys if one does not observe proper hygiene. Urine is normally sterile, but it is important to keep the urinary pouch very clean. On days that the pouch isn't changed, it should be rinsed with a solution of 1/3 part white vinegar to 2/3 parts tap water. This can be allowed to run over the stoma and will also prevent crystals. The vinegar produces an acid environment in your pouch. Bacteria cannot multiply as readily in an acid condition. Your night drainage pouch should be cleaned daily. White vinegar and water can be used for this too. Some individuals may use a special ostomy disinfectant or diluted Lysol solution. When the drainage bag has sediment that cannot be removed by cleaning, it should be discarded. Saving a few pennies by using it too long can cost more in the long run if you have to treat infection. Drinking plenty of liquids is important for all ostomates, but especially for the urostomy patient. Some urologists also prescribe Vitamin C to help keep the urine acid and less susceptible to infection. (Check with your doctor about this first, as some persons have reactions that would be exceptions to this.) Cranberry juice helps to keep urine acidic.

TRAVEL TIP Photocopy a page from an ostomy supply catalogue that has pictures of your appliances and some explanation of how they are used. One traveller reported a very positive result from carrying such photocopies. When an airport searcher asked about the items found during a hand search, he was able to explain their function without a long conversation that would hold up others in line. Source: Vancouver Ostomy HighLife - Mar/Apr. 2011

We Get Emails—from Friends of Ostomates Worldwide (FOW-USA)

Nigeria, June 2020 — "I want to let you know that there is nothing any one has done or can do for me that is greater or can be greater than what you guys are doing for me. I am saying a big THANK YOU to FOW-USA and I am appreciating everyone who has contributed in one way or the other to reach out to me to be able to care for my colostomy. FOW-USA gave me hope and a reason to keep living. You really turned my life around for better." — Name not provided.

Kenya, August 2020 — Monicah Ndegwa is the Founder and Executive Director for Project Afya, a non-profit in Houston, TX. Their mission is to improve public health in Kenya and across the world. She requested ostomy supplies for a teenager in Kenya, who had been separated from her conjoined twin sister, who did not survive. After receiving the supplies, the father noted in a video: "I want to urge you to continue with the spirit of giving. Do not see this as an everyday thing. I live on the far end of Meru County and things have come all the way from America and reached a place like this...Glory is doing well. She has had 6 surgeries and her health continues to be good...Glory's story has touched a lot of people…"

Solomon Tsige, Ethiopia, September 2020 — "As you know FOW-USA has been helping my mom, by sending ostomy supplies, for more than ten years. Those ten years wouldn't be easy for the whole family and especially to my mom. It really helped her to live a life to its fullest. Through the journey of my mom I have been learn a lot; all the painful and psychological difficulties related with living as ostomate. I have also recognized the impact...within the ostomates life...but...also...to families and friends around. I learn this from ostomates I visited each time to let you know that they need your help. Dear Ruth, my mom has gone (pass away) few months ago. I and my family is always remembering the help your team has done to mom. You are always remembered for this in the family. Even if my mom is gone there are a lot of ostomates in Ethiopia. Recently a doctor working in hospital told me that two youths committed suicide after they done their surgery for permanent ostomy. This is heart breaking. Now I am deciding to establish a foundation that works in helping ostomates. Till then I will continue sending the address of ostomates who are in need of your help for ostomy supply. I have strong belief that your help to others will continue as it was to my mom. I am really thankful for this."

Lubricating Deodorant Thanks to Ostomy Life Newsletter, Tulsa, OK
Ballooning happens when air from your stoma cannot escape the bag and it fills up like a balloon. Depending on the type of system you are using, you may release air from it throughout the day. If the odor is strong, consider a lubricating deodorant to help mask the smell. When applying a new pouch, simply place 6-10 drops into the pouch and spread it around by rubbing the inner sides together, avoiding the filter.

Choosing a Permanent Ostomy

by Karin Miller; via ostomyconnection.com; and Dallas (TX) Ostomatic News via North Central Oklahoma

When the surgeon and I were talking about my colectomy in the hospital, she mentioned leaving a couple inches of rectum in place [a "rectal stump"]. Partially because it was so inflamed that she wasn't comfortable operating there, but also for the possibility of having my ileostomy reversed and going the J-pouch route. I told her no J-pouch, but she didn't believe me. I'm in my 20s, so maybe the doctors didn't feel I was mature enough to make such an important decision as to removing my entire colon, especially while still taking steroids. At my follow up appointment, she told me I'd need to either get my stump (4 inches of rectum & anus they left) taken out or do the J-pouch within the next 2–3 years. I figured, great, I have time to think about it, and boo, now all of my decisions will be based upon when that surgery will be done. Boy do I not enjoy surgery. Oh wait, who does? I'm not sure how Coltrane (my stoma) feels. If he's happy seeing the world through my clothes or if he'd prefer being back inside my body. Anyway, I've made my decision. I'm going to make him a permanent part of my external body by having them take out the "stump." It was never really a question for me. My reasoning is that the couple inches they left of my rectum is still affected by the disease and it reminds me of that almost every day, multiple times a day, often with urgency. Having a J-pouch requires just a little bit of rectum to be left, but what's the point if you still get flares? Also, still having a little bit of my anus and rectum means still being a prime candidate for colon or rectal cancer – no thanks! [Editor's note: Most J-pouch surgeons leave in a few centimeters of anal mucous lining – i.e., an "anal cuff" – although some prefer to strip the anal mucous lining completely. None of the rectum is ever left in place.] "But you're so young, are you sure you don't want to give the J-pouch a try?" I can't tell you how many people questioned my certainty in a permanent ileostomy. The fact is, in addition to the logic above, I've met a number of people who have had a lot of complications with their J-pouch. If I went the J-pouch route and ended up with complications, I'd have to have a reversal surgery and worry that Coltrane #2 won't be nearly as awesome as Coltrane #1. This is just my thought process and what my gut is telling me to do, so I'm listening. I've also met a number of people who are happy and healthy with their working J-pouches. I encourage everyone to do their own research and talk to their surgeons before making a "permanent" decision.

Urostomy & UTIs

from Edgepark Medical Supplies Newsletter via OASNJ

The United Ostomy Associations of America estimates that one in 10 people with urostomies will contract a "urinary tract infection" or "UTI" at some point. Fever, strong urine odor and decreased urine output are often the first UTI symptoms an ostomate will notice. You may feel vaguely unwell and have some pain around your kidney area. If you notice amber-colored urine with white sediment, you may have an advanced infection. **What causes UTIs** The urine coming out of your stoma is actually sterile. But once it passes into a pouch, it immediately starts to grow bacteria. If urine pools in the conduit, backs up or refluxes up the ureters, it sends bacteria back through the stoma. Bacteria may also adhere to the mucus secreted by the stoma. **UTI Treatment** If you suspect a UTI, immediately increase your fluid intake and call your doctor. He or she will show you how to take a urine sample, which will be examined to determine if you do indeed have an infection. If so, you will be given antibiotics. Treatment may also include bed rest, or hospitalization for advanced infection. You may need additional tests, including blood tests, a kidney ultrasound or telescopic exam. With treatment, most UTIs begin to clear in 24 to 48 hours. **How to prevent UTIs** Drink water – The best thing you can do to prevent a urinary tract infection is to be sure you are drinking enough water — at least eight 8-oz glasses a day. This will produce a good urine flow and help flush out bacteria. This will also prevent kidney stones. Keeping your urine slightly acidic by drinking cranberry juice or taking cranberry supplement capsules may help. Be sure to talk with your doctor first as the Flavinoids in cranberries may interfere with some medications or cause gastric upset. **Find the right pouch** – A WOCNurse, medical supply company or product manufactures can help you find a well-fitting urostomy pouch. Since every stoma, and every patient, is different, you may need to try several pouches, wafers and barriers before you find the one that is best for you. The right appliance will help prevent bacteria buildup. Non-reflux pouches are available – these have an internal flap inside the pouch to prevent urine from collecting around the stoma. **Keep it clean** – You've probably been told to empty your pouch when it is one-third full. This will help keep any bacteria from making contact with your stoma. Using a bedside drainage container at night while sleeping will also help. Taking care to keep your stoma and pouch clean is important. If you have excessive mucus, regular washing of your pouch is recommended. Always wash your hands before and after changing or emptying your pouch or caring for your stoma. Pay attention to the barrier around your stoma, looking for wear that exposes your skin. Change your pouch if the barrier is becoming mushy near the edge of the wafer. Urostomy pouches with extended wear barriers are available to help prevent breakdown.

TIPS FOR HEALTHY HYDRATION WITH AN OSTOMY

From ConvaTec

Most people simply don't drink enough. Drinking more is one of the simplest ways to improve your health and well-being. You probably need to drink much more than you think. These tips can help you stay one step ahead of dehydration.

Drink little and often. Set an hourly alarm on your phone or watch to remind you to grab a glass of water.

Always take a drink when you go out. Never assume you'll be able to buy a drink. Be prepared and take one with you.

Don't wait until you're thirsty. By then you'll already be dehydrated. Stay one step ahead and keep your body hydrated and healthy.

The best indicator of your hydration status is your urine color.

- Aim for light straw-colored urine – this means you're probably drinking enough.
- If your urine is darker in color you need to drink more fluid.
- If your urine is completely clear, you may actually be drinking too much and flushing electrolytes out of your body.

IF YOU FEEL SEVERELY DEHYDRATED
OR IF YOUR URINE IS VERY DARK IN COLOR,
THEN SEEK MEDICAL ADVICE IMMEDIATELY.

How much should you drink? There are no hard and fast rules about how much you should drink. Everyone will have different needs from one day to the next. A normal healthy person is recommended to drink around 6-8 glasses of fluid per day, but some people will need more and others less. Use your urine color as the best guide.

What are the symptoms? Many people – both with and without an ileostomy – are chronically dehydrated every day. Symptoms such as headaches and tiredness can be attributed to other health conditions, but they are often due to dehydration.

Have questions on hydration? Contact the me+ team at 1-800-422-8811 or cic@convatec.com.

Managing a High Output Ostomy

Source: Hamilton Health Sciences, via Vancouver Ostomy HighLife

What is a high output ostomy? A high output ostomy is when you have more than 2 litres (8 cups) of fluid from your ostomy in a 24 hour period. The output is usually very watery and needs to be emptied 8 to 10 times or more a day. The output may also be very difficult to pouch and often leaks. A high output ostomy can increase your risk of dehydration and malnutrition.

Signs of malnutrition: • Sleepiness or tiredness • Dizziness • Losing weight without trying to • Wounds may heal more slowly • You may bruise more easily

Signs of dehydration: • Dry, sticky mouth and increased thirst • Lightheadedness or fainting • Tiredness • Irritability • Headache • Flushed skin • Dark, strong smelling urine • Muscle cramps • Fast heart rate

What can you do to manage this? Eat meals regularly. Try eating small meals every 2 to 3 hours or 6 to 8 times a day. Chew your food well. At each meal and snack try to eat a starching food and protein food. Starchy foods include bread, cereal, rice, pasta and potatoes. Protein foods include meat, fish, cheese, peanut butter and eggs. Add extra salt to your meals or include salty snacks such as crackers, chips or cheezies. You may benefit from reducing the lactose in your diet. Avoid high fibre foods with skins and membranes. Avoid foods high in sugar such as white or brown sugar, jam, honey, hard candy, molasses, juice and regular pop.

Foods that may decrease the number of stools/or diarrhea: Applesauce * Bananas * Bread * Cheese * Oat bran * Oatmeal * Pasta * Peanut Butter * Potatoes * Pretzels * Rice Pudding * White Rice * Tapioca

When you have a high output ostomy, your ability to absorb fluids is reduced. Drinking too much fluid can increase the output from your ostomy and cause you to become dehydrated, This may be opposite to what you might expect. To help you absorb fluids try changing the types of fluids you are used to drinking. There are special drinks available called oral rehydration solutions.

Commercial brands of oral rehydration solutions: • Gastrolyte * Pedialyte * Ceralyte Other fluid choices: • Diluted juice (half juice/half water) * Gatorade/Powerade * V8 Juice * Tomato juice * Clamato juice * Soup If making changes to your food and fluid consumption is not helping, you may need to see a gastroenterologist. If your gastroenterologist tract is too short to absorb enough nutrition and fluid you may need additional IV (intravenous) nutrition and fluid, in addition to making changes to your diet.

Home made oral rehydration solution recipe via Inside/Out: 1 litre (4 cups) of water 40 ml (8 tsp) sugar 5 ml (1 tsp) salt 250 ml (1 cup) orange juice Shake well and dissolve

Fertility, Pregnancy, IVF for Women with an Ostomy Men's Health: Sexual Issues and Fertility with an Ostomy

by Elaine O'Rourke, Ostomy/IBD Health Mentor;
via UOAA E-News Jan 2021 and UOAA Blog Post

(Editor's note: While the articles are very descriptive, our quarterly newsletter does not have room to include them. Rather than not share any of it, we are giving you the links to the videos and resources.)

Watch the full video on Ostomy & IBD, **Women's** Health: Fertility, Pregnancy and Sexual Function: youtu.be/7RJOAkjI3vI

Watch the full video on **Men's** Health: Sexual Function and Fertility with Ostomy or IBD: youtu.be/1w7cTXRPRaE

Other resources Blog/Vlog: Sexual Issues and Pelvic Floor

Blog/Vlog: Relationships, Sex and Intimacy with an Ostomy

UOAA sexuality guide

Make sure to grab your FREE GUIDE: '3 simple ways to eliminate fears about your ostomy' by visiting Elaine's website www.ElaineOrourke.com

Advocacy News — by Jeanine Gleba, UOAA Advocacy Manager

Safe Step Act of 2021 UOAA is one of 110 organizations supporting the Safe Step Act of 2021 (S464/HR2163). The Safe Step Act amends the Employee Retirement Income Security Act (ERISA) to require a group health plan to provide an exception process for any medication step therapy protocol. Otherwise known as a "fail first" protocol, step therapy is an insurance practice that mandates that patients try and fail medications preferred by their insurer before they can utilize treatments prescribed by their doctor. The bill will establish a clear exemption process, outlines five (5) exceptions to "fail first" protocols and requires a group health plan to respond to an exemption request within 72 hours in all circumstances, and 24 hours if the patient's life is at risk. Please encourage your federal legislators to improve patient access and address step therapy reform by supporting the Safe Step Act. Join this advocacy effort and contact the UOAA Advocacy Office. Thank You! — During WOC Nurse Week, on behalf of UOAA and the ostomy community, we want to extend our gratitude and appreciation to the outstanding WOC nurses, Joanna Burgess-Stocks and Sue Mueller who serve on our Advocacy Committee as Co-Chairs. Behind the scenes, they volunteer their time and talents with me and spend countless hours helping us achieve our advocacy goals. They exemplify being "beacons of light" for our community! —

CRANBERRIES - FOR AND AGAINST FOR UROSTOMATES

The Courier, Tucson AZ Support Group; Inside Out, Winnipeg, CA

FOR: The secret ingredient in cranberries that is pivotal in preventing urinary tract infections (UTI's) is concentrated tannins, called proanthrocyanidins, in the juice. In a Boston study published in the Journal of the AMA, cranberry juice was found to be effective in reducing the incidence of UTI's and the need for antibiotic treatments. This has important implications for persons who catheterize frequently. UTI's can be more evident if proper hand washing and cleaning of catheters is not done routinely. In addition, a large proportion of women over age 65 will experience at least one UTI per year. How does this special ingredient in cranberries work? The tannins from cranberries prevent E-coli bacteria, the main culprit in urinary infections, from adhering to cells that line the walls of the bladder and kidneys. The bacteria thus will "wash out" before infection can develop. Scientists in the Boston study believe that the routine addition of cranberry juice in dietary regimes in circumstances where UTI's have a high incidence would be sensible.

AGAINST: An article from the Mayo Clinic says drinking cranberry juice to prevent recurring bladder or urinary infections is an "old folk" remedy. Does it work? Maybe - but don't count on it. A key to preventing a bladder infection is blocking the growth of the bacteria that cause the infection. Researchers have two theories about how cranberry juice may help: - By making the urine more acidic, discouraging the growth of the bacteria. But scientists don't know whether a realistic amount of cranberry juice can produce enough change in urine acidity to affect bacteria. - By keeping bacteria from "sticking" to the bladder wall where they multiply and cause infection. This theory was confirmed in the laboratory and in mice, but results vary in humans. We do know that taking 500 mg of vitamin C (ascorbic acid) twice a day along with cranberry juice can increase urine acidity. Still, if you think you have a bladder infection, don't try home remedies. See your doctor. The usual treatment is antibiotics and plenty of liquids.

2020 Ostomy Nurse of the Year

In an ordinary year, the award would be presented at the WOCN annual banquet. Due to COVID, that did not happen. **Carol DeBoard**, second from the left, was our recipient this year. She brought 3 of her co-workers from Mercy South to help at our Ostomy Pop Up at St. Luke's where we recognized her award and thanked her for her service.

How to Measure Your Stoma: Ostomy Tips –

September 26, 2018 by VeganOstomy

A crucial skill that anyone with an ostomy should know is how to measure their stoma. Not only does it help to prevent leaks, but it can help to extend appliance wear time, and save your skin! ** If you are a new ostomate then it's very often recommended that you measure your stoma with every appliance change for at least the first month to six weeks. That's because your stoma will be shrinking during that time. Ostomates who will benefit the most from this guide are ones who have an uncomplicated, round-ish stoma that is slightly protruded. The process is very similar for ileostomates, colostomates, and urostomates who use cut-to-fit appliances. If you have a recessed, flushed, or prolapsed stoma, then you may not get perfect results by following this guide. **Things to Note** You would think that putting together a guide on how to measure a stoma would be pretty straight forward. Unfortunately, there are a few things that make this difficult: Loop vs. End Ostomy. Due to the "double-barrel" nature of a loop ostomy, it may not be possible to measure the stoma using a circular guide. If you have a loop ostomy, you may need to be creative about how you measure your stoma. One suggestion is to use a half circle, rather than the full circle of the measuring guide and measure each part (or each half) of your stoma separately. You can then trace that onto your wafer. **Every Wafer is Different** Not all wafers will act the same when they are worn. While all wafers tend to swell a bit as they come in contact with fluids or output, the degree in which they swell can differ from brand to brand. Because of this, you may need to cut your wafer slightly larger to accommodate the expansion. Doing this also helps to prevent the wafer from "strangulating" your stoma by putting too much pressure around it. Another thing about wafers is that they come in all kinds of sizes and materials. When I buy wafers, I try to get a size that allows for about 10cm of space between my stoma and the edge of the cutting lines (or up to the flange ring on my 2pc system). If you use a wafer that doesn't give you enough space, you may end up having difficulties cutting it, or worse, develop leaks. There's no harm in getting a wafer that is larger than you need, and you may be able to get more pouch support because it has more surface area to stick to. That is, of course, provided that a large wafer fits well on your skin. **Stomas Can Change** As our bodies change and so do our stomas. It's expected that your stoma will change its size (get smaller) for the first four to six weeks after surgery due to the swelling that occurs post-op. Likewise, weight loss/gain can change the size and shape of your stoma, and so can things like a prolapsed stoma or a hernia. My stoma fluctuates between 28mm and 32mm at various times, despite being over three years out from surgery. Stuff like this happens! While you won't able to control or predict these changes, you can make sure that your wafer is cut as accurately as possible. **What You'll Need** These are the supplies I like to keep on hand, but depending on the appliance you're using, some of these won't be necessary. Stoma measuring guide. If you're using a cut-to-fit wafer, these will almost always come in the box of wafers. Ostomy wafer scissors (don't use regular scissors, cuticle scissors, or anything with a sharp tip). Pen or marker for tracing. Your wafer (obviously!). Gauze (optional) to dry your stoma. I prefer gauze over toilet paper/paper towel because the latter tend to break apart when wet. Mirror (optional, but recommended). This can help to see under your stoma while measuring it. Some wafers will come with cutting lines printed on the back, while others do not. If your stoma is a consistent size, feel free to cut the wafer according to the cutting lines without the need to measure and trace the hole. Steps to Measuring Your Stoma • Gather your necessary supplies. • Empty your bag and wash your hands. • Remove your previous wafer then shave, clean, and dry the skin around your stoma. • Take your stoma measuring guide and find the approximate size of your stoma or use the previous measurement. • Place the guide over your stoma so that your stoma goes through the hole. You'll want to make sure that there's about a 1/16" – 1/8" (approx. 1.5 – 3mm) gap between your stoma and the edge of the hole. Remember, as wafers do swell, you may need to adjust this gap accordingly. If you are using a barrier ring or similar product, it's ok to cut the hole slightly larger (but not too much!). • After finding the right size, place the measuring guide on the backside of your wafer with the hole in the center of the wafer. In certain situations, like when you've got surgical wounds or skin problems, you may need to place the hole off-center. If you do this, just be sure that you are still cutting the hole within the boundaries of the "maximum cut" ring. • Trace the hole on your wafer using a pen or marker. • Cut out the hole using ostomy wafer scissors. If you are using a one-piece appliance, blow into the bag first to give some space for your scissors to move. • Test the size of the cutout by placing it over your stoma before you remove the plastic liner on the back of your wafer. Be careful as the edge of that hole may be sharp while the plastic backing is still on. • Make any adjustments if required. Complete any other skin routine, including putting on a barrier ring, ostomy paste, ostomy powder, barrier wipes, etc. •Apply your wafer. Tip: Keep the plastic liner from your wafer and use it as a template for your next appliance change. If your stoma stays consistent then it will be easier to use compared to the paper measuring guides. You can use your old release backing as a new template, but test it around your stoma to make sure it's still the ideal size.

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.

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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 _____

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Don't wait for someone to bring you flowers.
Plant your own garden
and decorate your own soul.
Luther Burbank

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