

UOASL 2018 MEETING SCHEDULE

www.uoaastl.org

See enclosed flyer-Hang it on your fridge

Any articles welcome for consideration:

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

Publication Deadline February 25, 2018

Send articles to: Mary Beth Akers
949 Chestnut Oak Dr.
St. Charles, MO 63303
636/916-3201
marybethakers@excite.com

LIVE & LEARN By Email

Are you interested in getting this publication by email? Send an email to Mary Beth at marybethakers@excite.com and let her know that.

Mailing Information Update

Please let Brenda Schulte know if your info changes.

Her address is: 115 Pine St., Old Monroe, MO 63369.

Her phone number is: 636-661-5607.

Please let us know if you have any change in home address, email address, company address or contact person.

We would really 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 that, too.

FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!

To find us on Facebook, go to [Facebook.com/UOAA](https://www.facebook.com/UOAA) Inc.

To follow us on Twitter, go to [Twitter.com/UOAA](https://twitter.com/UOAA),
or while logged in, search for @UOAA.

UOAA also has a Social Blog! You can find our blog at
blog.ostomy.org.



LIVE AND LEARN

Winter 2018

President's Message

To All Members and Friends of UOASL,

We have once again come to the end of another year! How did it happen so fast? We celebrated a wonderful dinner and banquet at Syberg's. We had over 70 people in attendance! What a great turnout! Thanks to all those who helped make it wonderful. Special thanks to Marge and Dave Blomenkamp who gave us all a gift of homemade salsa and chips. They have donated the favors for many years. Thanks also to Bill and Jackie Kriete, who once again made trays of cookies for attendance prizes. More than 15 prizes were given away. I am already looking forward to next year's party!

Hopefully you had the chance to read Karen Kroger's article in the last issue about the National Conference. As it is every two years, there is not one in 2018 but plans are already in the works for 2019 in Philadelphia. We will also let you know of any regional conferences that are within driving distance. You can always go on the UOAA website to find ones to travel farther to. They are always fun and informational.

We will be having a couple new board members joining us in the new year. Carol DeBoard and Rachel Basler, both nurses, will come on board. I want to take a moment to recognize a wonderful board member who will be stepping down. Betsy Naeger has been on the board for MANY years and has done so much to help our group stay so active! She will still be involved in the group and will be at meetings. I know we will continue to benefit from her knowledge!

At our last board meeting, we voted to send a donation to the national UOAA to help with the mailing of the NEW PATIENT GUIDES. We all know how vital it is to send new ostomates home with something to read more once they are no longer on pain meds and adjusting to their new normal. If you are looking to make end of year donations, I know it will be used in the best way possible. Please read Susan's article on the next page.

Please do not hesitate to call or e-mail me (636) 916-3201 or marybethakers@excite.com with any questions.

Mary Beth Akers, President, UOA St. Louis

Why would I donate to the United Ostomy Associations of America?

By Susan Burns, President of UOAA

I have been asked this question many times, so I thought I would put my thought into words.

UOAA is a patient support group which means many things to many people, but I think we can agree that it does do one thing – UOAA advocates for people that have or will have ostomy or continent diversion surgery. Your donation makes it possible for the national team to coordinate with multiple resources to distribute our information, and spread awareness of these types of surgeries. We know that more education of our health care professionals make our quality of life better. Your gift supports our website, www.ostomy.org as well a great discussion board for those who cannot attend a support group.

We are expanding our reach into the home health care industry, which is where many people receive their care right out of the hospital. We are committed to strengthen our relationships with Wound Ostomy Continence Nurses Society and Ostomy Management Specialist. These nurse professionals are an intricate part of our recovery. We exhibit at many conferences dealing with ostomy surgery, so these professionals know we exist to help with their patient's overall quality of life.

We publish a New Patient Guide magazine which is free of charge to nurses so when a patient leaves the hospital, they have information about their specific surgery, explanation of varying types of appliances, inspirational stories and resources they may need in the future.

The national organization does one more very important task, and that is making sure our government legislators know we need our appliances and need them to be covered by insurance.

UOAA works with many volunteers who give their time to pay it forward. UOAA helped me when I had my surgery, and the St. Louis group is a part of UOAA national. When I think of the people who have attended our monthly meetings, and the distribution of the supplies that we have been given, it warms my heart to know I am part of a group that truly does help people live life after this surgery.

I hope you will consider donating to the UOAA, by going to our Website www.ostomy.org or by sending a check to in care of:

UOAA, NC.

P. O. Box 525

Kennebunk, ME 04043

Best Regards,

Susan Burns, Vice President, UOASL, President, UOAA

YOUTH RALLY 2018

As you know, we are always looking for youths, 11-17, to send. This year will be in Boulder, CO in July.

Please share this information with any youth who has any issue with the bowel or bladder. St. Louis Chapter UOAA pays first year scholarships (Tuition and airfare minus \$75 Registration Deposit).

If you know of an interested youth, have them contact Mary Beth at 636-916-3201 or marybethakers13@gmail.com for more info or log on to www.youthrally.org



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

Common Ostomy Problems and Possible Solutions

Excerpted from an article in the Huntsville, Alabama “Re-Route”

Food blockages. Symptoms may include no output from the stoma for more than 4 hours, cramping in the abdomen, nausea or vomiting and high watery output. Solution: Drink hot tea and increase your fluid input. Take a warm bath or shower and massage your abdomen. Have a glass of wine. This will help relax your abdominal muscles. Get down on all fours with your backside in the air. An undignified position, but it does help some people move a blockage. If the blockage persists for more than a few hours, seek medical advice from your nearest hospital. **Mucous and bleeding from the rectum.** Solution: This is completely normal if your rectum is still intact, although annoying, since the mucosal lining of the rectum is still working. Try wearing a sanitary napkin to save soiling your underwear. If the bleeding is profuse, see your doctor. **Odor.** Solution: Simple solutions that work for some ostomates are to place mint tic tacs or mint mouthwash into your bag. Deodorants, either taken orally or placed in your bag, are available from your ostomy supplier. DO NOT place aspirin in your bag in an attempt to eliminate odor—doing so can cause damage to your stoma. **Bleeding.** Solution: First, determine if the bleeding is coming from the surface of the stoma or from internally. If it is internally, then it's wise to seek medical advice. If the bleeding is from the surface of the stoma, it should stop quite quickly. Stomas are made from the same type of skin as the inside of your cheeks and you know how easily they bleed. Even the slightest little nick can cause it to bleed. If bleeding is profuse or doesn't stop quickly, seek medical help. Cuts to the stoma can also be caused by the wafer riding off center. Try "picture framing" the wafer with some tape to stop it from moving. **Phantom rectal pain.** i.e., you get the urge to go to the toilet in the—old wayl, even though you know you can't. Solution: This pain is because your body needs time to adjust to its new plumbing and still thinks it needs to go to the toilet in the old way. Try going and sitting on the toilet anyway, even though you know it's pointless. A lot of people find this alleviates the pain. The good news is that over time, phantom rectal pains become less frequent and eventually disappear altogether. **Stoma is placed on or above the beltline.** Solution: This is more common in men than women for some reason. DO NOT let them site your stoma on or above the belt line if at all possible. Belts will stop the stool from flowing into the pouch so try wearing trousers a size bigger than you would normally wear and wear braces or suspenders to keep them up rather than a belt. **Stoma shows through a tight dress.** Solution: Try wearing bike pants or similar lycra pants under your outfit that will smooth out the line of the bag. Empty frequently.



WALKING

Via Metro Maryland and *The New Outlook*, Ostomy Association of Greater Chicago

We are built for walking. Sitting contributes to back end spread and puts strain on the wrong places. Standing is exhausting and can be bad for the circulation.

Walking moves everything correctly and helps out body function. Walking is endorsed by medical and health authorities for an astonishing variety of benefits. Physical fitness experts say it is one of the best exercises. Cardiologists say it is a preventive for heart problems.

According to obesity experts, walking is a first-rate weight controller. Walking is an aid to digestion, elimination and sleep. Walking is an antidote for tension. In fact, walking and breathing freely helps the circulation that every part of the body benefits.

A one hour walk can reduce blood pressure to a safe level. Maintaining a steady pace while walking keeps the circulation flowing freely, the lungs breathing, and the eyes taking in sights they never noticed or appreciated before. In twenty minutes, you can comfortably do a mile and smile.

Factors That Affect Ostomy Function

Via Middle Georgia Ostomy Rumble

Ostomy function may be changed by a variety of medications and medical treatments. The following are examples: Antibiotics—These often cause diarrhea, even in patients without an ostomy. Make sure your doctor knows about your ostomy, and inform him/her of problems as they occur. Drink plenty of liquids and drinks that will help maintain your electrolyte balance if diarrhea strikes. Pain Medications—These are often constipating. Extra irrigations or laxatives or stool softeners might be required for colostomates to combat the side effects of pain medications. Perhaps the dosage of pain reliever may be reduced to eliminate the situation. Again, be sure to drink plenty of liquids. Chemotherapy—Many cancer patients have follow-up chemotherapy after surgery or as an alternative to surgery. That often produces nausea and/or vomiting. You need to drink fluids that help you maintain your body chemistry balance. Radiation Therapy—This often produces the same effects as chemotherapy. Travel—Travel may cause constipation in some people and diarrhea in others. Be aware that these are possibilities. Altered diet when traveling accounts for some of this, plus the

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excitement of new surroundings. Allow sufficient time for irrigations and take along an antidiarrhea medication. Antacids—Some types of antacids may cause diarrhea—usually those with magnesium. There are many fine new products on the market. Find out which is best for you. Drink plenty of liquids. You need to maintain your electrolyte balance in case of diarrhea. Tea, orange juice and even sodas/cokes are sources of potassium. Bouillon cubes mixed in hot water are a source of sodium. Some of the signs of electrolyte imbalance are irritability, nausea and drowsiness.

THE FLU AND WHAT TO DO

UOAA Update 7/13 Via Pittsburgh Triangle

The flu brings with it headaches, upset stomach, diarrhea, muscle aches and pains!!!! The advice: plenty of fluids and rest in bed - this remains sound medical advice for your general attack of the virus. But if your case of the flu includes diarrhea, you may find the following hints helpful. For those with a colostomy it is usually wise not to irrigate during this time. Your intestine is really washing itself out. After diarrhea, you have a sluggish colon for a few days, so “leave it alone.” Start irrigation again when your colon has had a chance to return to normal. For the ileostomate diarrhea is a greater hazard. Along with the excess water discharge, there is a loss of electrolytes and vitamins that are necessary in maintaining good health. And this loss usually causes dehydration. Therefore, it is important to restore electrolyte balance. First, eliminate all solid food. Second, obtain potassium and sodium from drink or food sources. Fourth, drink a lot of water. For urostomates be sure to keep electrolytes in balance by following the general instructions for colostomies and ileostomies. Vomiting also brings the threat of dehydration. If it is severe and continuing, your doctor should be notified or you should go to the ER. You should also know that diarrhea may be symptomatic of a partial obstruction or an acute attack of gastroenteritis. Since the treatment of these two entities is entirely different, a proper diagnosis should be made by a physician as rapidly as possible. If you are unsure, check it out with your doctor. No ostomate should take medicine for pain or a laxative without a physician’s order. Do not use antibiotics for colds or flu unless the doctor orders it. In colostomy patients, drugs or certain foods can cause constipation. This can be prevented by drinking plenty of liquids. Increased water intake for the ileostomate results in increased urine output rather than increased water discharge through the appliance. When returning to a normal diet, use fiber-free foods at first, then gradually increase to regular, normal diet.

Individuals with Urostomies: Fluid Management and Infection

By Juliana Eldridge, ET/WOC Nurse Via UOAA UPDATE

People with urinary diversions no longer have a storage area, a 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 even after an hour, it is of serious 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. Since kidney infection can occur rapidly and be devastating, prevention is essential. Wearing clean pouches and frequent emptying are vital. Equally important is adequate fluid intake, particularly fluids that acidify the urine and decrease problems of odor. In warm weather, with increased activity, or with a fever, fluids should be increased to make up for the 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

*Cloudy, bloody urine

*Decreased urine output

All ileal conduits normally produce mucus in the urine, which gives it a cloudy appearance. Blood in the urine is a danger signal. Thirst is a good index of fluid needs.

Important: If urine is collected for urinalysis, either routine, microscopic (R&M) or for culture and sensitivity (C&S), or if you are asked to give a sterile urine specimen, be sure your doctor and nurse know a sterile specimen must be taken directly from your stoma and not from the pouch. Bacteria build up in the pouch constantly. You will always get a false positive test result.

If they are not sure how to do this, do the following:

- 1.) Remove your pouch
- 2.) Clean your stoma
- 3.) Bend over
- 4.) Catch the urine in a sterile cup

[Editor: It is also recommended in some articles to have the stoma catheterized for a sample.]

Ileostomies and the Immune System

By David Beck, MD, Ochsner Clinic, New Orleans Thanks to Ostomy Outlook, North Central, OK, via Rosebud Review, Eau Claire, WI

In response to a query about the possible side effects of ileostomy surgery on the immune system, Dr. Beck noted that the surgery, by itself, should have no long-term effect on the immune system. Although there is some transient reduction in a patient's immune system response right after major surgery, this usually returns to normal in a couple of days. However, the diseases that cause patients to need a stoma (such as inflammatory bowel disease), the medications used to treat the diseases (such as steroids), or malnutrition associated with the disease may all affect the immune system. If you are concerned, there are several tests a doctor can perform to test your immune system. One of these involves placing chemicals or allergens into the skin to see how the body responds. Others involve blood tests. We are continually learning more about the human immune system from our experience with HIV infections. Most efforts are directed toward identifying and then treating the cause of the immune dysfunction. Although good nutrition and some supplements (such as vitamins) are necessary for the immune system to work, little has been proven to improve immune function.

POWDER YOUR STOMA? Via UOAA UPDATE

Powder is normally not required during the routine maintenance of a stoma. As a matter of fact, most modern disposable barriers are designed to adhere to the skin by themselves. Powder is used to treat irritated skin or a fungal infection. Yeast (fungus, Candida) infections are very common, especially during the summer or when one perspires during regular exercise. Micro granulated anti-fungal powder is used only when there are signs of a yeast infection: i.e., an itchy rash and raised red bumps. Use the powder until the infection clears, then discontinue. Pectin based powders such as Hollister Adapt Stoma Powder or Convatec's Stomahesive Powder are used to treat irritated skin. To apply any kind of powder, clean the peristomal skin well with plain water and then dry before applying the powder. The skin should be completely dry. Dust the skin with the powder, gently rub it around and then brush off the excess. If one wears a standard regular barrier, dissolve the powder by gently dabbing the area with skin barrier wipes. Be careful. Skin sealants and barriers are generally not recommended for use with the newer extended wear wafers. Try the powder, if you think you need it, without applying the skin barrier. The skin barrier chemicals may impede adhesion of some of the extended wear appliances.

Stoma Shape and Leakage

Via Green Bay Area Ostomy Support Group

Are you aware that stomas sometimes change shape? This can happen when you change from a standing to a sitting position. Mirrors are handy gadgets—take a look! The stoma that is round when you are lying down or standing may be oval when you sit down. This may be a source of a leaking problem and merits thought. Remember, the stoma is a portion of the intestines brought to the surface of the abdomen. The healthy red color of the stoma means there is a good blood supply. The natural lubricant of the intestines is mucus. No adhesive will stick to the stoma because of the mucous lining. Therefore, any part of the faceplate/ wafer that comes in contact with the mucus on the stoma will automatically refuse to stick. Thus the seal around the stoma does not change even though the stoma shape changes. This means that if the stoma is oval in a sitting position, perhaps the opening on the faceplate should be oval. This particularly applies to people who are sedentary most of the day. This is not an absolute rule, but a consideration if you find leakage a problem.

What Your Pharmacist Should Know About You

U.S. Food and Drug Administration Via Green Bay Area Ostomy Group

“Help your pharmacist to know you and understand any limitations to your care,” says the U.S. Food and Drug Administration's Mary E. Kremzner, Pharm.D., M.P.H. “Pharmacists really want to help people get the maximum benefit from what's prescribed with the least amount of risk.” For example, some large pills are hard to swallow. “The pharmacist will know the drug's makeup and whether you can crush it without altering its effectiveness or release rate,” Kremzner says. Another risk is interactions—food-drug or drug-drug. “For example, if you take a certain blood thinner, don't eat too many dark leafy greens, because the vitamin K can decrease the drug's effect,” says the FDA's Lindsay Wagner, Pharm.D. “The interaction can depend on the patient, the drug or how often you eat certain foods.”

Your pharmacist should know: Everything you take for your health: all medications, dietary supplements, herbal supplements and vitamins; Your medical history and experience with medications, including allergic reactions and side effects; If you are pregnant or breastfeeding; If you have trouble swallowing pills, opening bottles, reading labels or remembering when to take your medicine.

A Visit from St. Ostomy

by Marjorie Kaufman, Los Angeles (CA) Los Ostomy News;

'Twas the night before Christmas and all through the flat,
There was general confusion including the cat.
The bathroom was strewn with the ostomy ware,
That I had abandoned in utter despair.

The courage I'd had in the hospital bed,
To follow instructions, had suddenly fled.
It all looked so strange, and uncommonly new;
I swore I would never know quite what to do.

Now which goes to which, and what sticks to what?
I fumbled each step, with my nerves overwrought.
And then in my anguish, I went to my room,
To settle my brains for a night full of gloom.

With a household a-flutter in holiday matter,
I shut out the sounds of excitement and chatter.
When out in the hallway I heard from below,
The sound of a voice with a jolly "Hello."

As I peeked through the door, up the stairway she came;
And she smiled when she saw me, and called me by name.
And I, in my wonder, just couldn't believe,
That ostomy visits were made Christmas Eve.

And then in a twinkling she put me at ease,
And said she could lessen my anxieties.
She was dressed all in white, in a form-fitting sheath,
With nary a sign of what lay underneath.

So trim and well-groomed, a delight to behold,
No one would suspect, unless they'd been told.
That standing before me so calm and serene,
Was the very first ostomate I'd ever seen.

Her manner so friendly, with faith and good cheer,
Soon gave me to know I had nothing to fear.
My questions, like leaves in a hurricane flew;
And with each knowing answer, my confidence grew.

Then under her guidance each part fell in place,
As I conquered the problem I'd just failed to face.
And all of a sudden I knew I was free,
To live just as normal and happy as she.

For only an ostomate is really akin,
To the fears and frustrations that lie deep within.
Her time and her friendship so willing to give,
Will keep me remembering as long as I live.

And my family was grateful for what she had done,
For once more the evening was festive and fun.
Now each time I meet her, more clearly I see
The "Saint" who came calling with blessings for me.

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.

Stomal Prolapse: Via Middle Georgia Ostomy Rumble

Prolapse is a relatively frequent stomal complication (affects up to 14 percent of all ostomates), defined as the excessive protruding of the bowel out of the abdomen. The piece of bowel that protrudes may often be as long as six inches in length, up to three inches wide easily. If your stoma prolapses, you should remove your pouch, so that the bowel has space without being constricted. Apply a cool compress. If this is the first time you have prolapsed, call your physician or WOC(ET) nurse immediately. If you cannot get in touch with an ostomy nurse and especially if your drainage has stopped, it would be wise to go to the emergency room at your local hospital. If your stoma has prolapsed before, you may have been taught by your physician how to "reduce" your stoma.

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

SPONSOR
AMERICAN CANCER SOCIETY
4207 Lindell Blvd.
St. Louis, MO 63108
1-800-ACS-2345 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: Would like to help on Phone Committee

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: Brenda Schulte U.O.A.S.L.
 115 Pine Street
 Old Monroe, MO 63369
 Phone: 636-661-5607

(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

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If you don't like something, change it.
If you can't change it, change your attitude.

Maya Angelou

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LIVE AND LEARN – Winter 2018



Officers and Board of Directors

- President:** Mary Beth Akers 636-916-3201
- Vice President:** Susan Burns 636-926-2737
- Secretary:** Linda Geurin, RN, CWOCCN
- Treasurer:** Shanan Rodgers

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