

# UOASL 2017 MEETING SCHEDULE

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

- November 6 St. Luke's – Leonard Naeger Lectureship-  
Drugs and Your Ostomy
- December 4 Annual Banquet at Syberg's (**Starts at 6:30PM**)  
Contact Mary Beth by November 7<sup>th</sup> if you would  
like to attend and haven't RSVP'd.

No January Meeting

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**Any articles welcome for consideration:  
personal experiences, health, obituaries, tested tips, etc.**

Publication Deadline December 25, 2017

Send articles to: Mary Beth Akers  
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[marybethakers@excite.com](mailto: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](mailto: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.

### **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 Betsy at 314/781-4544.



# **LIVE AND LEARN**

**Fall 2017**

## **President's Message**

To the Members and Friends of UOASL,

Fall is here! Hopefully the weather will soon feel like it. Once again we had a great Youth Rally. It was a good week for me and Herschel Austin who served as a counselor, as well as our own local campers who each had positive experiences which are reflected in their thank you letters you can find in this newsletter. I wish you could read all the thank yous from the 155 campers as well as the staff. Hopefully it gives you a little glimpse of what this week means to each one.

This summer also saw our biannual conference in Irvine, CA. Karen Kroger has written a wonderful recap that makes you feel as though you were there. Maybe it will inspire you to start making plans for 2019.

Paying dues, playing the 50/50 raffle at our meetings as well as generous donations also support our efforts locally to help fellow ostomy patients in their journey of recovery from surgery as well as learning to live comfortably post surgery. Every month, when I see new ostomates find us, I appreciate what we have. Also having several loyal Wound, Ostomy, Continence Nurses on hand at our meetings is truly a gift that we don't take for granted. On a regular basis we continue to bring speakers to our meetings who share information unique to us.

I hope the articles Sheila Reddick helps me find for the Live and Learn are helpful. If anyone of you has a need to find more answers, drop us a line. We want it to be beneficial to all our members. If I can't be of help in a pinch, I think I can direct you to some good resources that we here in St. Louis are lucky to have. I look forward to seeing you at our meetings.

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

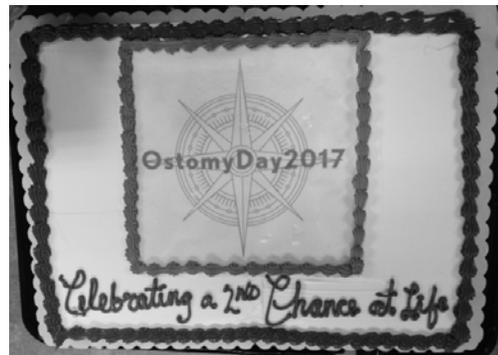
Mary Beth Akers, President, UOA St. Louis

## PROCEDURES THAT CAN BACKFIRE

Via Tulsa Ostomy Newsletter and Springfield

- **Clamp Usage:** Wrapping the drainable pouch tail around and around the clamp before closing it. This will not make the clamp work any better. All it will do is spring the clamp out of shape, which will ensure that the clamp won't work for future application and it will make releasing excess gas more difficult.
- **Releasing Gas:** Snapping the pouch off the face plate to expel gas. This doesn't do much for odor control! It's much better to hold the tail of the pouch beyond the clamp with a tissue, open the clamp and allow the gas out through the tissue with deodorant. Then use the tissue to clean out the end of the pouch and replace the clamp.
- **Normal Wear Time:** You shouldn't wear the appliance until it leaks. The object is to change the appliance before leakage occurs. This way, the skin gets the best protection and care. Three to five days is normal wear time. Some people report seven days, but manufacturers feel that this may be pushing their products to their limits.
- **Ignoring Skin Problems:** All skin problems are easier to manage if they are treated early.
- **A Full Pouch:** Letting your pouch get full before emptying it can separate a two-piece system. Try to empty your pouch when it's one-third to one-half full.
- **Seat Belts:** A well-placed and adjusted seat belt shouldn't interfere with your stoma or damage your stoma. True, in an accident your stoma may be damaged, but it's a lot easier to repair a stoma than a crushed skull.

**The cake we  
celebrated Ostomy  
Day with at our  
October Meeting at  
Christian Hospital**



## UROSTOMY ISSUES

(Elizabeth Hendrix, WOCN, Northside Hospital) Via Ostomy  
Rumble, Macon, GA

**Urinary Tract Infections (UTI)** – What are the causes of UTI? Normally, urine is sterile. It is usually free of bacteria, viruses, and fungi but does contain fluids, salts, and waste products. An infection occurs when tiny organisms, usually bacteria from the digestive tract, cling to the opening of the urethra and begin to multiply. The urethra is the tube that carries urine from the bladder to outside the body. Most infections arise from one type of bacteria, Escherichia coli (E. coli), which normally lives in the colon. Infections can also be caused by urine being forced back to the kidney through the conduit. This can happen when rolling over on a full pouch of urine and causing urine to be forced back into the stoma through the urinary tract with tremendous pressure. Invariably the urine in the pouch will be contaminated.

Treatment and Prevention include 1) Adequate hydration. You need a good flow of urine that dilutes the bacteria or germs in the urine, and helps wash them out....2 ½ quarts of liquid daily is required for the average adult. 2) Antibiotic Therapy. Antibiotics are used to fight infection, and should be prescribed by the doctor (usually prescribed for short term). 3) Unless otherwise indicated, the urine should be maintained in an acid state. To maintain an acid urine state, increase your daily fluid intake to eight or ten (8 oz) glasses of water. Drink cranberry juice in place of orange juice or other citrus juices which tend to make the urine more alkaline, take vitamin C daily (with permission from physician).

**Urinary Crystals** • Urinary Crystals on the stoma or skin are associated with alkaline urine. The crystals appear as white, gritty particles and may lead to stomal irritation and/or bleeding of the stoma. • Proper cleaning, maintaining acidic urine, and careful fitting of the stomal opening in the pouch will help prevent urinary crystals. • You may rinse out the pouch after emptying, with a solution of equal parts of water and white vinegar. Also a mix of water and vinegar compresses may be applied to the stoma when the pouch is changed.

**Can I travel at home or abroad?** Having a colostomy should not prevent you from travelling at home or abroad, whether it is for business or pleasure. The only difference is that you should plan ahead and prepare a little more than before.

**Can I go swimming?** The answer is “Yes – you certainly can go swimming”. Here are a few suggestions to help you feel more confident: • You may like to try wearing a smaller stoma bag under your swimming costume or trunks as these can be more discreet. • If you are worried about damaging your stoma whilst swimming, although this is unlikely to happen, you could try wearing a stoma shield.

**What should I eat?** By the time food reaches the colon, it has been almost completely digested, so having a colostomy does not mean you will have to change what you eat. It is not necessary to follow a special diet (unless you have been advised to do so by your doctor for another specific medical condition). Try, as far as possible, to eat a diet containing a variety of items from all the food groups (Fruit and vegetables, bread other cereals and potatoes, meat, fish and other alternative, fatty and sugary foods, milk and dairy foods). This will ensure that your body receives all the essential nutrients (protein, carbohydrate, fat, vitamins and minerals) it needs.

**Should I eat more fiber and less fat?** Bear in mind that, although current advice is to eat more fiber and less fat: • Too much fiber (e.g. bran based cereals) may cause wind or loose stools. • If you are trying to regain lost weight, it may be better to use full fat milk and cheese, rather than semi-skimmed or skimmed alternatives.

**Are there any foods colostomates should avoid?** We are all different. Some colostomates can eat anything. Others have found, by experience, that it is best to avoid certain foods. If you have persistent problems try keeping a food diary you may find it helps. If you suspect a food causes problems, try it at least three times, separated by an interval of at least a week, before eliminating it altogether. If you find you are cutting out most of the items in any one of the food groups, then it is advisable to seek individual dietary advice. Your GP can refer you to a state registered dietician.

## September 11<sup>th</sup> UOASL Breakout Meeting

**Ileostomy** breakout group discussion topics:

We talked at length about the consequences of dehydration for ileostomates. Some early signs might be a very subtle temporary memory failure. Feeling dizzy and thirsty are late developments which are sometimes too late to simply drink water. We learned that drinking milk is helpful as it remains in our system longer than water which passes through the digestive track rapidly. We learned that a children’s product, Pedialyte could be more helpful than sports drinks, Gatorade for example has more sugar. A new product was discussed, H2ORS which is an electrolyte powder to be mixed with water. It’s available on line if not at Walgreens. It could in some cases keep one from needing to get to a hospital for an IV infusion during an episode of non-acute dehydration.

**Significant Other** break-out group

Several shared reports of hospital nurses who were completely ignorant of ostomates’ situation, could not help with appliances, etc. One new ostomate was told by a nurse that he would smell of poop the rest of his life as a result of losing his colon. A Florida ER could not help with a “routine” blockage and required hospital admission and four days of tests, etc. Praise for knowledgeable suppliers: Medical West and others.

Even doctors often know little or nothing about ostomates’ needs. One exception was a surgeon who had a pouch himself and, when a patient was not getting proper care from the nursing staff, he himself cleaned up a patient and refitted him with a new device.

One spouse said her “other” was sometimes depressed, feeling his life was ruined forever because of his surgery. All participants told of how the surgery had given them back their real lives, self- confidence, energy, joyfulness. In such discussions, several described months or even years of agony their ostomates had suffered from one thing or another (or many others) before the surgery. More than one had experienced a long, slow recovery afterward, but was fine now. Several reported they would recommend to someone who could be reconnected not to do it, since many have more problems that way which were better avoided.

One participant recommended [Inspire.com](http://Inspire.com) (health and wellness website) for support group type of conversation and help.

### Colostomy breakout group

Make sure you have someone else that knows how to put your pouch on besides yourself. Irrigation can start at 6 months. Eakin seals can be great help. Parsley capsules can help with odor. When you are flying, let the TSA know you have an ostomy.

### Urostomy breakout group

Barnes has an ostomy nurse at Forest Park and Euclid. Shaving around the stoma may be necessary. Night drain bags are handy. Cranberry concentrated capsules can help prevent kidney infection. (Trader Joes has a cranberry juice and sparkling water.) Taking Vitamin C and drinking plenty of water can help keep your bags clear.

## Stoma care guides - Getting back to normal

Via Ostomy Rumble, Middle Georgia

**Do I need different clothes?** You will normally be able to wear the same clothes and underwear as you did before. However, if your colostomy is very high up on your waist this can be a problem, but help is at hand. High waisted trousers for men can be obtained at several outlets. Some men prefer to stop wearing belts and feel more comfortable wearing braces. For the ladies there is a wide choice of flattering clothes and swimwear. There are also specialist providers to whom your stoma care nurse can direct you.

**Will I be able to return to my job?** Once you have fully recovered, and providing there are no other medical implications, there is no reason why you should not return to the job you did before you had your colostomy. Your doctor will advise you when you are fit enough. If your work is strenuous and involves lifting heavy weights, or is work that puts a strain on the abdominal muscles, you should first seek advice about wearing proper support belts/girdles. It is advisable, where possible to contact your stoma care nurse to be measured. After surgery it's normal to feel tired more quickly even if you are not doing strenuous work.

**Will my driving be affected?** Once you are well enough to drive you may find the seat belt is uncomfortable across your stoma. If this is a problem try fitting a 'Klunk Klip' to the seat belt. These can be obtained from most ecr accessory stores, or on line. The Klip is attached to the inertia-reel of the seat belt preventing it from constricting your colostomy.

**Can I return to sports and exercise?** As mentioned earlier walking is excellent exercise and a good starting point after your operation. Other than physical contact sports, there are virtually no restrictions. If in doubt check with your stoma care nurse who may suggest a stoma guard if your sport is more strenuous. Thousands of colostomates are enjoying a huge range of activities such as golf, sailing, cycling, swimming, as well as more down to earth pursuits like gardening and rambling.

Continues

## 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

## YOUTH RALLY 2017 San Diego, CA

Thank you so much for the continued opportunity to participate in Youth Rally as a counselor. Every year I am more grateful and humbled than the year before to be a small part of this important outreach. Youth Rally changes kid's lives for the better and empowers them to become independent and confident young adults. I continue to learn from them each year. Thank you again for your support.  
Herschel Austin

Thank you for making it possible for me to come to Rally this year. There were 155 campers and it was the biggest Youth Rally year ever! I met this amazing girl and we became best friends really fast. She had never worn a bikini before because she did not feel confident. So when we went to the beach, we got our first bikini tops. Lots of people told us how cute we looked. I love coming to Rally because everyone is so supportive and understanding. I can't wait for next year!  
Deborah Schuster

Thank you for giving money to Youth Rally. I wouldn't be here without you because my family is tight on money. Every time I go to camp I buy my brother, sister, mom and dad something from wherever I go. I got a hat from the speaker and he even signed it. This year I made new friends. Most of my friends live far away but some live near me. I swam in the pool and went to the beach. Also 7-11 and Trader Joe's and don't forget about Starbucks. I even got a skateboard and shoes.  
Gavin Schlarmann Age 13

My name is Cassidy Thum. I am a 15 year old transgender girl who has been to rally four times. I had a great week. Monday, I had a long flight, or at least it seemed long. When I landed, I was accepted into open arms. Monday was tiring. Tuesday morning, I was so tired, I tried to work the coffee machine. How it was laid out, me being tired and clueless, I couldn't figure it out. Luckily, a counselor helped me. After breakfast, we went to our medical sessions and management. I went to groups for imperforated anus. I learned a good amount from both. After that was freetime. I went to the campus LGBT center. I could ask questions and meet other queer people. It was a great experience. Later that night was the bowling party. I am not super into bowling. I was able to hang out with friends and eat food. I had to leave early since I was so tired! I had a lot of fun. Wednesday was fitness day. My two sessions were Yoga and Rock Climbing. I have not been rock climbing since I started using a motor scooter. It was fun and I reached the top. After that was the speaker, Nick Scott. He is the world champion of both ballroom dancing and weightlifting despite being in a wheelchair. He was a real inspiration. Thursday we went to Belmont Park. I am not a

## Sitting Down

by Rosemary Watt, RN, ET, Stanford Univ.;

From Stillwater-Ponca City (OK) Ostomy Outlook September 1997: via The Ostomist and Green Bay Greater Seattle Ostomy Association,

"Sitting Down" doesn't seem like an important topic of discussion, but many ostomates have problems because their lifestyles involve "sitting down" much of the time. They may be secretaries or business executives, salesmen who spend a lot of time driving cars, and ostomates who are paraplegics who spend their waking hours in wheelchairs. Going to a movie involves sitting for several hours.

An appliance capacity may be decreased by 50% or even more when the sitting position is assumed. The pouch must be straightened out when you are seated. Men can do this by putting a hand in the trouser pocket. Women have a somewhat more difficult time, but can straighten the leg on the appliance side and adjust the pouch while they appear to be smoothing a skirt or straightening the leg of a slack suit.

An appliance belt that fits correctly may be too tight when seated, since we increase our girth when sitting. The belt may need to be loosened slightly before sitting for a long period of time.

Trouser belts may fit too tightly over an appliance when seated and prevent stool or urine from entering the pouch. The belt tightness can be tested when seated by inserting a finger under the belt or trouser.

### FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!

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

To follow us on Twitter, go to [@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](http://blog.ostomy.org).

swimming fan so I went shopping. I found a deal on a good shirt for \$3. I bought 2. One pink, and one brown. After shopping, I walked around with a counselor. When I got back to the tent, I rested in the shade. It was really fun even though I rested. I enjoyed the air. Now it's Friday. The last day of rally. Today we already learned about a counselor's trip to Honduras. Later, during freetime, I plan on going to the beauty shop and dress box. The dance is tonight and I'm really excited. During rally, I learned a lot and met more people who are similar. One thing is at rally, I can express myself much easier. At rally, I have the ability to dress as a girl and be a girl without being judged. At rally, I can get support without stress of family and immature peers. Thank you so much for sponsoring me and allowing me to have a fun, safe, judge free, educational, second home. Thank you for everything.

Cassidy Thum

#### **And from the CEO of the Youth Rally:**

When I was diagnosed with Crohn's disease at 13 years old, I would have given anything to meet others like me, but there was no Youth Rally then, Now for over 35 years, there is a CAMP FOR THAT. We support teens from the ages of 11-17 with over 50 different diagnoses of the gastrointestinal or geneto-urinary tracts.

From the bottom of my heart THANK YOU! As a volunteer counselor since 1986 and a volunteer Youth Rally Leader today, know that your generosity enables Youth Rally to continue to provide this amazing experience to so many teens who benefit from it!

Paul Hastings, Chairman & CEO Youth Rally Inc.



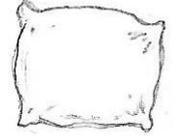
**Some of the folks  
from St. Louis and  
surrounding areas**

Bill, Cassidy, Herschel  
and Eric in the back  
row.

Deb and Gavin in the  
middle  
Mashyla in front

I recently read a little post to an ASG newsletter in California from a woman whose partner is willing to take part in the routine changing out of her pouch. Helping to gather the supplies is nice, but the best part of the story was after the pouch was in place she was able to lie down on her porch recliner with a fresh cup of tea while her partner brought her a little cloth bag of rice warmed in the microwave. I couldn't resist the idea of a warm rice bag, it's easy to make and works better than holding my hand over the pouch once it's in place...see drawing to the right.

Sheila Reddick



### **THE SWOLLEN STOMA**

It can be pretty scary to have your stoma swell for any reason and not be able to get your appliance off over it for fear of doing damage. An appliance that hugs the stoma too tightly may cause it (stoma) to swell. A fall or a hard blow or slipping appliance may cause the stoma to swell. Rather than risk further damage to the stoma by pulling the appliance off over it, try filling your pouch with ice water and letting it swirl around the stoma to decrease the swelling. Ease the appliance off carefully. Replace it with an appliance that has a larger opening until all swelling is gone. It is a good idea to keep a couple of appliances with larger openings around for such emergencies.

Reprinted from Winnipeg (MB) Ostomy Association "Inside Out" via MAOG, Memphis, Loraine Co. Chapter and Re-Route Evansville (IN); South Brevard (FL), Metro Halifax News by Greater Seattle (WA) "The Ostomist"

### **Urostomy Odor Cautions**

Via Great Plains Ostomy News

The urostomate should rinse or wipe off the spout of the pouching system with a bathroom tissue after emptying. Those few drops left in the spout after closing the pouching system can cause a urine odor under clothing. It is interesting to note that most urostomy pouching systems on the market are odor-proof, but the connecting tubing and bedside and leg bag are not. You must dispose of and replace these products when they take on urinary odors, or else your entire living quarters will smell.

## OSTOMY REVERSALS

By Joanna Burgess-Stocks, BSN, RN, CWOCN Via Cincinnati

Not everyone who has an ostomy as a result of colorectal cancer and other diseases will have the option of having their ostomy reversed. Some people will need to keep their ostomy for life. Your surgeon will determine when an ostomy will be reversed. There are many factors that determine a reversal such as the extent of the disease, a patient's overall health and treatment process (radiation and chemotherapy). Most patients with temporary ostomies will have the ostomy for about 3-6 months. Surgery for reversal of an ostomy is usually much less involved than the surgery that you had to create the ostomy. So if you are feeling nervous, keep that in mind. A typical hospital course is 3-4 days on average. For some patients, interrupting bowel function with a temporary ileostomy increases the chances that you will experience alterations in bowel function after reversal of your stoma. These symptoms can include rectal urgency, frequency, fragmentation of stool and incontinence. It is important that you notify your surgeon as soon as possible with these symptoms. Treatment includes behavioral strategies based on the symptoms and includes dietary modifications, incontinence products, skin care (use of barrier creams such as zinc oxide) and medications such as loperamide. More involved but helpful recommendations are pelvic muscle retraining (PMR) to regain sphincter strength and biofeedback. This therapy is done by a highly trained physical therapist. If the temporary ostomy is due to cancer some physical therapists recommend PMR prior to surgery or radiation to assess muscles and teach strategies for ongoing muscle strengthening that can be carried over after surgery. This helps to address any coordination or existing weakness prior to radiation due to chemo or post-operative recovery. If PMR is recommended after surgery, it is best to wait at least 6 weeks and with the surgeon's approval.

**BELTS VS TAPE** via Vancouver (BC) Ostomy HighLife; and Regina (SK) Ostomy News and North Central (OK) Ostomy Outlook

Many factors can dictate a need for further measures to ensure a worry free fit of your appliance—body shape, skin type, sports played, job demands or quantity of waste. Tape and/or ostomy belts are sometimes a solution. Each has its advantages depending on the individual. In some instances, a combination of both may be recommended. Which method might work best for you and how do you properly use them? Ostomy belts are a frequent first choice because they are reusable, washable, adjustable, and don't have to be peeled off the skin. But a belt that is too tight can cause its own problems. Wearing the belt too tight will cause the elastic to become overextended which allows the elastic to curl, forming a rope-like fit instead of a flat fit around the waist. This could get mighty uncomfortable in a hurry. You want the belt to be snug, but not so snug it's digging into you. You also want to keep the belt from 'riding up,' which will create an off-center pull on the appliance. Try to keep the belt level with your flange. Wider ostomy belts might be more comfortable if one has rolls of fat around the midsection. Most belts are about an inch wide but you could ask your supplier if a wider model is available. You might want to allow your pouch to fill up and then test how effective an ostomy belt might be under different tensions and body movements. If presented with a choice, choose cloth rather than rubber or elasticized fiber. Cloth will be cooler. Belts can provide vital support, especially if the contents of a pouch become significant. Always empty a full pouch as soon as possible, or better yet, don't let it get that full in the first place. Sometimes belts are just not practical. They may be too uncomfortable for the wearer, or spoil the look of some clothes.

Tape can be a good solution in such cases. They come in a variety of materials, paper porous tape, all plastic tape or a combination of both. Some appliances come with a tape perimeter 'built-in' but you may still need to apply another layer over top of this. Tape is relatively inexpensive so give different materials and brands a try. To properly apply tape, it should encircle the entire flange, with one half on the flange and the other half on the skin. In time you'll get skilled at applying this. A gentle pressing-on with the finger tips will ensure that it's stuck. Most problems with tape arise from poor application technique, impatient removal or allergies to the material. Prepare the skin with careful removal of the old flange and thorough cleaning and drying of the skin. When removing the tape, use the 'two hand' method—one to gently pull the tape off and the other to hold the skin down. Too frequent or rushed tape removal can cause irritation. Either or even both methods—tape or belt—can greatly increase your confidence and comfort. Give both a try if you have concerns about your appliance staying in place.

## Never Underestimate the Power of Your Story

By Karen Kroger, Member of UOASL

David and I were fortunate to be able to travel to Irvine, California for **The 6th National UOAA Conference, Journey to a Bright Future**. We arrived mid-afternoon on Wednesday, August 23rd. We checked into Hotel Irvine, signed into the Conference and were immediately met with friendly and helpful greeters that gave us a lay of the land in the Conference Area.

Our first official event was the **Ice Cream Social**, Wednesday evening, where we were lucky enough to sit down with Teri Stickel, the local UOAA President and Frances Wilson, CNS, CWOCN, CFCN, Manager of the Stoma Clinic and personally learned of all the planning and logistics that went into the Conference. At check in, I was asked if I would like to visit the Stoma Clinic and if so to please give them my name since the Stoma Clinic was almost totally booked and they were going to have to add more times. I declined, since I do not have any issues at the moment & I would rather let someone who has limited access to a WOCN use that space. We learned again that we are extremely fortunate to live in the STL area and have easy access to WOCN's. Many areas of the country do not have that luxury.

Thursday was packed full. In the morning, David and I went to the **Basic Ileostomy** but split forces for the next Session. I attended the **Ask the WOCN about Ileostomy Management** lecture with Lara Leininger, BSN, BC-RN, CWOCN and Dani Osewalt an Ostomate and Lara's Mother. They were the Cover Girls on the Spring 2017 issue of the *Phoenix Magazine*. This session was much like our breakout sessions with discussion on various topics pertinent to Ileostomates. David attended a session on **Robotic Surgery**. Did you know that a Doctor in Boston can operate on a patient in Hoboken? Simply amazing. Later, we attended **Prostate and Other Male Issues**. I attended **From Crohn's to Ostomy: Rising Above When Life Hits Below the Belt** and David attended **Fecal Microbiota Transplant**. The Exhibit Hall opened in the afternoon and we spent a lot of time talking to the various vendors. We were able to catch up with Jeff Erickson, STL's one time Hollister Rep. He is doing great, married and looking forward to building a family.

Friday was also a full day. David attended **Male Spouses or Partners Meeting for Non Ostomates**. The **Exhibit Hall** was opened and served a Box Lunch (actually it was a delicious Sack Lunch but because of the crowd, it was designated a Box Lunch). During this time, and really, all of the Conference, we socialized with UOAA Members from all over the country. For many this was their first Conference and some have attended many Conferences. We met one gentleman that has been to them all. After lunch we attended **How to: Best ASG Newsletter Ever** Lecture with

Barbara Hawes and Wendy Lueder, two woman that have been doing newsletters for a very long time. It was interesting to see the differences in Newsletters from all over the country. I will be passing on some tips to Mary Beth and Sheila. I really wanted to attend the Youth Rally Lecture but it conflicted with the Newsletter Class, but we all have first hand local experts on that. We were able to attend the **TSA Traveling-Understanding the TSA** and we both enjoyed that class tremendously. If you have any specific questions, please ask David or myself and we will try to answer your questions, or there is a Toll-Free number to the TSA for Travel Assistance and questions. 1-855-787-2227.

Saturday we attended **Advocates for a Positive Change**, which we both share a passion for and **Medicare Issues and Medicare Fraud**. Medicare recipients, you will be receiving a new Medicare Card next year, without your Social Security number on it. The mailings will be done very randomly so be on the lookout. Our last lecture was on **Pre and Probiotic Supplements and Nutrition** which was very informative. There was much discussion on hydration, which is so important for ileostomates. There are many homemade hydrating drink recipes available on line.

The Closing Ceremonies were held in the afternoon and we have to say it was an emotional and inspiring experience. Our very own Susan Burns, UOAA President, was presented with the Founders Award by Founder Ken Aukett. Frances Wilson, CNS, CWOCN, CFCN received the WOC Nurse of the Year Award. Football Star, Rolf Benirschke, was presented with an award for his continued UOAA support and advocacy. Molly McPeck and her husband Terry, treated us to a slide show of their journey to Irvine from Michigan on a motorcycle which was very inspiring, (the Harley is being shipped back to Michigan) and Joanna Burgess-Stocks, BSN, RN, CWOCN delivered a very thought provoking and emotional presentation, **Stepping Stones: Understanding the Power & Importance of Your Story**.

The last event of the Conference was an evening of entertainment with a Cook Out in the Hotel's Backyard. We were treated to a great dinner, a fabulous & fun fashion show and a DJ for our dancing pleasure. We all were scurrying around the room saying goodbye to old friends and new friends and promised to see each other in Philadelphia in 2019 to **Celebrate Your Independence**.

Both David & I gained knowledge, a deeper understanding and most of all, if we have learned anything at this conference it is: **Never Underestimate the Power of Your Story**.



**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:**    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](http://www.uoaastl.org)

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“Maybe you have to know the darkness  
before you can appreciate the light.”

Madeline L'Engle

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**LIVE AND LEARN – Fall 2017**



### Officers and Board of Directors

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