

UOASL 2014 MEETING SCHEDULE

www.uoaastl.org (Notice the dash is gone!)

July 7: St. Luke's– Peristomal Skin Care: Troubleshooting and Treatment

July 7-12, Youth Rally, San Diego, California

August 4: St. Luke's Hospital – TBA

***September 8:** St. Luke's Hospital –

Summer Wrap-up: Dinner and Breakout Groups

****October 6:** Christian Hospital

November 3: St. Luke's– Leonard Naeger Lectureship

December 1: Annual Banquet

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

Publication Deadline August 25, 2014

Send articles to: Mary Beth Akers

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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.

FOR THOSE WHO USE FACEBOOK AND TWITTER

The National UOAA is on both!

To find us on Facebook, go to Facebook.com/UOAAinc.

To follow us on Twitter, go to 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

Summer 2014

President's Message

To All Members and Friends of UOASL,

Well, the summer is upon us. In the last issue I wrote that spring was in sight. I think we saw it for a few days between the winter and summer days. Check out the articles for summer hints to make the next few months easier for you.

We had a great product fair with many in attendance. We had many of our regular members as well as some first time attendees. Whether members came to find out the latest products or to hear our speaker, Joe Zimecki, they did not go home disappointed. Make sure to read the recap Sheila wrote.

As I write this, I am very busy with the Youth Rally. Our local chapter will have five campers and five counselors representing the Greater St. Louis Area! It has been quite a while since we had so many from the area. Watch for our recap of the Rally in the next issue of the Live and Learn. Each of them/us will share our thoughts.

I am so grateful to Sheila Reddick who has been working with me on this newsletter for a year now. She has been reading the old issues of the magazine back to the 80s and 90s. You will see a couple articles, sort of a “throwback” to times gone by. It is amazing to see that the more things change, the more they stay the same.

As “The Old One” said in her message, if she had come to a meeting, she would have learned some new ways to deal with her ostomy a lot sooner. Some of you reading this will recognize Pennye Pollard, a name that brings back memories. If it has been awhile since you attended a meeting, consider coming again. I would highly recommend the September Summer wrap up with breakout groups, but any meeting is sure to give you information and support.

I hope to see **you** at our meetings, and if you have questions please do not hesitate to call or e-mail me (636) 916 3201, marybethakers@excite.com

Mary Beth Akers,

President, UOA St. Louis

PRODUCT FAIR RECAP Thanks to Sheila Reddick

Coloplast enabled the UOAASTL to bring Joe Zimecki to St. Louis in order to give a dynamic talk, Pursue Your Dreams No Matter the Obstacle. Joe described his sudden onset of severe UC more than 10 years ago at the age of 30 during his first year of marriage. He described his struggles because his doctors could not diagnosis his condition. Joe went through what seemed like endless pain, weight loss and suffering along with the heavy treatments of the usual drugs including Prednisone which failed to impact his disease. After a year-long ordeal it was finally determined that ileostomy was the only way back to health. Since the surgery Joe has worked in the field of IT but he has been involved in fitness. He finally decided to heed the encouragement of his clients and test the waters in the area of body building. We saw slides of Joe's transformation into his amazing physique. A year ago he entered a body building competition with his ostomy pouch in full view above the waist of his shorts.

Joe credits his wife with the courage and tenacity to help him get to the right doctors. She has been through everything with him and even changed his ostomy appliances in the early weeks of recovery. These days he manages his ostomy care without even a second thought. Because of his intense interest in good health he has not had any significant issues except for consuming some problematic foods that he knew were risky, all in the name of testing his own boundaries. Joe and his wife have two children who explain that 'Dad does number3' unlike the rest of the family! Joe is clearly a fine example of how patients with UC can return to health and live full and satisfying lives with ostomies.

Here are the links Joe offered us during his talk:

- Muscle & Strength: <http://www.muscleandstrength.com/transformations/joe-zimecki>
- SupplementSuperSource.com Sponsored Athlete: www.supplementsupersource.com
- All American EFX Supplements: <http://www.aafx.com/index.php/inspiration/natural-freak-spotlight/211-joe-zimecki>
- Facebook: <https://www.facebook.com/Over40FitnessPics>
- Fitness Writer: <http://www.illpumpyouup.com/articles/writers/joe-zimecki.htm>
- Bodybuilding.com: <http://www.bodybuilding.com/fun/over40t.htm>

**LIVE, LEARN,
SHARE**



THE UNITED OSTOMY ASSOCIATIONS OF AMERICA (UOAA) is declaring that on October 4, 2014, UOAA is acknowledging ostomy and continent diversion surgery. The day will be recognized as **Ostomy Awareness Day 2014 - Live, Learn, Share**. Our mission by celebrating this special day is an effort to help patients LIVE a normal life following surgery, to help the medical community LEARN about the needs of ostomy patients, and to SHARE our stories to raise awareness about ostomies throughout the United States.

The UOAA is a patient support services, volunteered-based organization, whose mission is to educate and build awareness to patients and to the public. UOAA has many services that assist the new patient and their caregivers before and after surgery, helping in the transition to their new life with an ostomy. UOAA and our over 350 Affiliated Support Groups (ASGs) across the country support our members and welcome new patients every day. But on this day, we are asking that ASGs, our Management Board of Directors, the Affiliated Support Group Advisory Board and our partner, Wound Ostomy Continence Nurses (WOCN) Society, to spread the word about ostomy surgery and how this surgery can make a positive difference in the lives of our patients and members.

We will be using our Social Media, our website www.ostomy.org and our monthly updates to give suggestions on how to celebrate Ostomy Awareness Day and how you can show your support for this event. We will be providing a press release that you may distribute to your local area, a proclamation that you can personalize and send to your local or state governments to ask them to recognize Ostomy Awareness Day, and many other documents to help you plan for this important day.

Thank you for your continued support.

Warmest regards,

Susan Burns

President, UOAA

Push the Skin-Don't Pull the Tape!!

UOAA UPDATE April 2014

Damaging the skin around a stoma (or anywhere else), is asking for infection. Don't peel your pouch away from your body. Hold the edge of the adhesive sections or tape, and PUSH THE SKIN AWAY FROM THE TAPE.

Take a good look at what is happening when you pull tape. The tape is pulled upwards, dragging the skin with it until it is pulling hard enough to break loose. It even looks painful. (Sometimes the skin breaks before the tape comes loose.)

Now look at what happens when you push the skin away from the tape. It doesn't hurt, the tape is separated from the skin gently and the outer layer of skin remains intact. People who think yanking it fast is best ought to take a good look at the skin afterwards. It is usually red and irritated.

If you have a leak, digestive enzymes in the discharge will excoriate your damaged skin quicker and deeper than if your skin is okay or protected with some sort of skin preparation. The farther away from the rectal area the stoma is in your intestines, the stronger the digestive enzymes in the discharge (leak), and the sooner your skin can become excoriated. Pulling the tape off the skin can do great damage. It is extremely difficult to keep a pouch on an oozing surface. Learn to treat skin gently.

In a nutshell, when removing tape, push the skin away from the tape, do not pull.

EXPERIENCE IS THE BEST TEACHER!

By Ellice Feweson, via Metro Maryland & S. Brevard (FL) OSTOMY NEWSLETTER Reprinted from "Live and Learn" Volume 1 #4 1995-1996

Having an ileostomy does require some patience, I'm afraid. Even though as a person with an ostomy, I have 100% better quality of life than I did when I had ulcerative colitis, there are of course some minor drawbacks. One of which are pouch leaks, infrequent but unpredictable. The best approach to these situations is to be calm and relaxed as best one can. I have had several accidents (pouch leaks) in the past three years, and have dealt with them in various ways. In the beginning, I would get frantic and anxious and thought that this was the ultimate in disasters. I really did not have the coping skills to deal with a half full or full pouch coming off or leaking. Almost always, it was due to my not completely clicking the two pieces together or not closing the end of the pouch completely.

My first reaction was horror—"now what can I do?" Of course, the answer was obvious. I clean myself up, throw out the pouch that leaked or fell off, put on a new one and go about my business. However, in the early months after surgery, I was very apprehensive that an "accident" was going to occur and I really was not prepared as to how to deal with one.

By now, I have experienced occasional leaks and know what to do. These are my suggestions:

- Never wait too long to empty your pouch.
- Always carry an extra set of clothing and appliances with you, either in your drawer at work, in a tote bag, or in your car, anywhere accessible to you.
- Always take your time when an accident occurs.
- If you rush when changing your pouch, you will become more anxious and accident prone.
- Always stay calm, with each mishap you will become more experienced in changing the pouch and less apprehensive when another leak occurs.
- Last of all, remember most likely you and you alone know that a leak occurred, nobody else has any idea!

Reprinted from "Live & Learn".....Spring 1991

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.

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Hollister Incorporated	(888) 740-8999
Marlen Manufacturing	(216) 292-7060
Nu Hope Laboratories	(800) 899-5017
Ostaway x-Bag	(800) 774-6097
Ostomy Secrets	(800) 518-8515
Torbot	(800) 545-4254

WHEN TO CALL A DOCTOR OR WOC NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after several emptying.
4. If you have a strong odor lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.

Ileostomy group discussion at UOASL

April 7, 2014 Notes: Sheila Reddick

Two nurses from Christian Hospital, Retta Sutterfield RN, WOCN and Dena Muscarella RN, WOCN attended the ileostomy break out group. They work with patients who are hospitalized after ostomy surgery. Retta asked the group to share ‘wear time’ for ostomy appliances. The group of a dozen patients have experienced on average 3 to 4 days wear time with some able to extend wear time up to 7 or even 8 days.

A new ileostomy patient shared that her surgery was the result of familial adenomatous polyposis. We had a discussion of this condition which is a disease that runs in families and causes multiple cancerous tumors of the colon to develop.

Several in the group use pouch covers, Mary Beth showed the group her homemade version. Pouch covers are useful to prevent skin irritations due to sweating/chaffing under the pouch area. Mary Beth also led the discussion about hernia belts. One member of the group finds the belt helpful but is not able to wear it for extended periods. Some folks have been told that hernia belts are not covered by Medicare, but others disputed that claim. Nu Hope is the manufacturer of hernia belts which can be purchased locally or directly from the company.

There was a discussion of products helpful in holding appliances in place. There was some agreement that ‘sheer strip’ works better than ‘pink tape’.

Mary Beth explained to the group that Devrom from Parthenon works well for odor control, while others suggested that Na’Scent works well in the pouch to control odor.

Simethicone or GasEX works well preventing gas from inflating the pouch. (Mi-Acid from Medicine Shoppe Pharmacies can be purchased for under \$5 for 100 tablets. Order #220-4899, sometimes must be ordered, not on shelf.)

Finally there was a discussion of issues with air travel security agents. Many group members have traveled with no issues. However several people explained that some TSA agents have been rude and caused trouble for travelers because of ostomies. The pouches of course have liquid contents which are problematic for security purposes. People have been asked to use their own hands to rub over the pouch then their hands have been wiped to check for dangerous chemicals. Mary Beth shared the idea that if possible a pouch should be emptied before going through a security check.

Medicare Patients: Watch Out for "Under Observation" Status

Compiled from Internet sources - OK Ostomy Outlook

UOAA UPDATE April 2014

If you're under Medicare and get hospitalized, be aware whether you've been classified as an "inpatient" or are just "under observation." The distinction may seem subtle, as you may receive the same care both ways. However, the difference may cost you thousands of dollars.

The difference in cost may occur two ways: First, if you're only under observation, you may need to pay somewhat more for the hospital care itself. When you're an inpatient, the costs are covered by Medicare A, which usually pays the full cost after a deductible is met. If you're only under observation, the costs are covered by Medicare B, which pays only 80% of the cost. The really big consequences occur if you require care in a skilled nursing facility after your hospital stay. Medicare pays for the nursing costs only if you were in the hospital as an inpatient for at least 3 days. If you were only under observation, Medicare pays nothing for the nursing care, so you must pay that whole cost yourself.

Hospitals have been using under observation status increasingly in recent years, due to pressure from Medicare to reduce costs to Medicare by reducing improper inpatient admissions.

What can you do as a patient? First, make sure you know whether you're an inpatient or just under observation (the hospital may not always tell you). If you're only under observation, but think you should be an inpatient, ask your regular doctor to speak with the doctor in charge of your hospital care, and try to get your status changed. If that doesn't work, you can appeal Medicare denial of payment decisions. This can be a long and difficult process, but has a reasonable chance of success if you go through with it.

The following links contain more information on this topic. The first is a story aired by NBC News on Jan 9, 2014. The third contains detailed advice for patients:

www.nbcnews.com/video/nightly-news

www.medicareadvocacy.org/medicare-info/observation-status/

www.medicareadvocacy.org/sef-help-packet-for-medicare-observation-status/

YOUR URINARY OSTOMY

By Edith Lenneberg, ET Via: Evansville, Indiana Re-Route, Town Karaya, Ostogram & Hemet-San Jacinto, CA (Reprinted from L&L 2009)

The urinary ostomy requires three kinds of preventative attention: care of the stoma, care of the skin around it, and care of the kidneys. Your routine care of kidney functions includes:

1. Drinking at the very least, one quart of liquid daily like tea, coffee, juice, soup, colas, water, beer, etc. These should be decaffeinated, preferably.
2. Getting your urine tested (urinalysis) every six months.
3. Having an X-ray taken (IVP-intravenous pyelogram) of the kidneys once every two years.

Observations to be made:

1. Stoma - changes in size. After initial healing is complete (about six months), measure with paper measuring gauge every six months; change to equipment with correct opening. Appearance of stoma: Does it appear different than usual, (color, shape, little white or red spots, etc.)? Look for this at each change of appliance, show to surgeon or clinic.
2. Skin - signs of irritation: Are there pink spots, tiny pimples, reaction to adhesive, etc? Look for this at each change of appliance. Learn methods of dealing with routine minor irritations, soreness or raw or infected area: Do not delay, see (your doctor immediately; white deposits or whitish appearance around the base of the stoma. Look for this at each change of appliance; drink at least 8 oz. of cranberry juice daily. Soak the appliance in water/vinegar solution (3 parts water to 1 part vinegar). If there is no improvement in two weeks, call your urologist or GU Clinic.
3. Kidneys - nature or urine: Look at it every day. Is it dark? Drink more liquids. Is it gritty? Tell your urologist. Is there mucus? This is normal. Is there a persistent unpleasant odor? This is a sign of infection and must be treated by your urologist.

TIPS FOR TRAVELING WITH MEDICATIONS

02/2014 UOAA UPDATE

KEEP your medicine with you-not in checked luggage.

BRING more than enough medicine for your trip.

REVIEW your dosage schedule with your doctor or pharmacist before you leave and discuss whether you should make allowances for changes in time zones.

KEEP a list of all your medicines and dietary supplements.

Internet/Newspaper Gleanings Via The Pouch in N Virginia

□ **Stomach gas may be sign of healthy gut bacteria, doctor says** — Having gas may be linked to a healthy gut microbiome because vegetables and foods with fiber, which can cause gas, deliver nutrients to microbes, says gastroenterologist Puma Kashyap at the Mayo Clinic in Rochester, MN. He says it can be normal for a person to have flatulence up to 18 times a day. “Undigested carbohydrates allow the whole ecosystem to thrive and flourish,” Kashyap said. National Public Radio/The Salt blog (4/28) *Digestive Health SmartBrief*

□ **Reaching out to others with ulcerative colitis** — “I look at myself differently like I’m not normal, and I’m not good enough because I’m sick. But I know I am. I’m stronger than I ever thought possible...And for everyone out there battling with this, you can do it. You’re perfect and beautiful. And people do understand. There are more people like you. You aren’t alone.” — blog post from Tricia on GirlsWithGuts.org. *Digestive Health SmartBrief*

□ **Probiotics in Greek yogurt may aid digestion, nutritionist says** — One of the biggest benefits of Greek yogurt may be its probiotics that aid digestion and promote a healthy gut, says dietitian Toby Amidor. “Study data also show it may help with lactose intolerance, bone health, weight management, and blood pressure control,” she says. U. S. News & World Report/Eat + Run blog (5/5) *Digestive Health SmartBrief*

□ **The importance of testing for celiac disease** — “Patients with irritable bowel syndrome (IBS) may experience improvements in bloating, abdominal pain, and diarrhea with a gluten-free diet. These patients may be misdiagnosed as having celiac disease. Without confirmation of celiac disease by small intestine biopsy, they may be unnecessarily committed to lifelong gluten restriction” WebMD *Digestive Health SmartBrief*

□ **A better life after ostomy** — “Yes, sometimes I miss having a colon. Yes, I still get upset at times when I look at my stoma. Yes, I sometimes try to remember what it’s like to be ‘normal’ (even though I can’t really do so). And YES, it has all been worth it. I am now living with a lot less stress and worry and pain than I used to. I wouldn’t go back to the life I had for anything. My ostomy has changed me. And while I may not like every single thing that has changed along with it, it has given me back some of the hope I had lost in living a beautiful life.” — blog post from Stephanie on StolenColon.com. *Digestive Health SmartBrief*

TRAVEL, FUN AND THE SUN

UOAA UPDATE 1/20/14 by Patti Burke, RN, CWOCN, ET

Preparing for Travel

1. Change your pouch 24 hours before departure to assure complete adherence.
2. Make a list of all supplies you use with their stock numbers. Take photocopies of the catalog that shows the products you use.
3. Call your manufacturer to get a list of suppliers in the area where you will be traveling.
4. Obtain a referral list of doctors and medical centers in the area where you will be traveling.
5. Check with your doctor about taking an antidiarrheal medication to treat any diarrhea that may occur.

Packing your Carry-on Bag

1. Change of clothes.
2. Bring pre-cut wafers/pouches that were prepared at home.
3. Rounded tip scissors can be packed in your carry-on bag. (Check with your airline to be sure.)
4. Pack supplies in carry-on and checked luggage.
5. Take twice your normal amount of supplies. (Remember Murphy's Law.)
6. Pack baggies or plastic bags to dispose of used pouches.
7. Obtain a statement from your doctor about your need for ostomy supplies.
8. Urostomates need large plastic bags that zip closed for bedside overnight drainage. Attach the bag with a clothespin to a wastebasket and zip closed close to the drain tube.
9. Colostomates who irrigate should do so only with drinking water.
10. Take an insulated bag to store your supplies in extreme temperatures.

Swimming with an ostomy

1. Empty your pouch before swimming.
2. Swim when the bowel is less active, usually in the morning. Use pink tape to frame your wafer for security.
3. Women should choose a patterned suit with a liner for a smoother profile.
4. Men can wear a tank shirt and trunks if the stoma is above the belt line.

PERISTOMAL SKIN PROBLEMS AND TREATMENTS

Edited by B. Brewer, UOAA UPDATE May 2012

The most common problem occurs when effluent, stool or urine, comes in contact with the skin or when adhesives are used incorrectly. This can begin as skin irritation which can lead to future break-down. The appearance is red, weepy, sometimes denuded skin, with occasional bleeding present. The treatment is to wash and pat dry the area. Then apply a skin barrier powder, such as stomahesive powder and seal the powder in with a skin prep, preferably a no-sting prep or one without alcohol to avoid burning of the skin.

Another common problem can be caused by the removal of hair from the follicle, or either by incorrect pouch removal or by aggressive adhesives resulting in irritation or infection of the hair follicle called folliculitis, evident by the reddened areas at the base of the hair follicle. Treatment consists of clipping the hair with a scissors or shaving of the area with an electric razor and then following the treatment used for skin irritations.

A third problem is a fungus or yeast rash caused by persistent skin moisture or from antibiotics resulting in fungal overgrowth. Its appearance is a red rash with itching present and several satellite lesions, this is called macular popular rash. The treatment consists of keeping the skin clean and dry and applying an antifungal powder, with a prep sealant over the powder before pouch application. Repeated treatment is necessary until condition clears.

Lastly, an allergic reaction which can be attributed to any product can also create a problem. A patch test will be needed to determine the allergen to be eliminated. It may be necessary to see your WOC Nurse (ostomy nurse) or physician. Also, a corticosteroid agent may be needed to control the itching.

Preventing skin problems is better than treating them and some basic steps that can help minimize these problems are:

1. Begin with proper pouch removal, which means gently peeling the pouch away from the skin, while pressing down on the skin, thus preventing a shearing or friction injury of the skin.
2. Proper cleansing and rinsing of the skin after using solvents of any kind and the use of proper skin protection products, such as preps, powder and paste.

3. Proper cleansing consists of using warm water and if soap is used, rinsing thoroughly to re-move residue to prevent dermatitis. Also, allowing the skin to dry adequately before applying pouch.

4. Shaving should be done routinely if the personal skin is hairy to prevent folliculitis. Shave from the stoma out and cover the area that the pouch rests on.

5. When routine care warrants using a powder whether it be stomahesive powder or an antifungal powder, it is to be applied sparingly and the excess powder brushed off and blotted with a skin prep.

6. Readjustment of the size of the wafer/barrier opening may be necessary to prevent leakage of stool or pooling of urine. (Change in stoma size or weight gain or weight loss)

Remember!

- √ **Change pouch regularly**
- √ **Correctly size the opening**
- √ **Gently remove pouch**
- √ **Clean and prepare skin properly**



The St. Louis Chapter is not going to have a team at the Southwest event as we have in the past but you are welcome to sign up to walk the survivors lap and join them for dinner. Brenda Schulte is involved in the one in **Lincoln County, August 1-2, 2014, 6:00 PM – 2:00 AM, Clonts**

Field, Hwy 47 Troy, MO. If you would like information about the relay, to join us, to donate money, buy luminarias, or would like directions to Clont Field. Please contact Brenda Schulte who is a Team Captain. UOASL aschulte@centurytel.net 636.661.5607

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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PLEASE CONSULT YOUR DOCTOR OR WOCN (ET) FOR
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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 _____

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