

UOASL 2015 MEETING SCHEDULE

www.uoaastl.org

July 6: St. Luke's - UOAA is Celebrating our 10th Anniversary-
Preview of the September Conference 2015-Susan Burns, UOAA Pres.

July 13-18, Youth Rally, Boulder, Colorado

August 3: St. Luke's Hospital

September 1-6, National Conference at Hyatt St. Louis

UOAA National Conference will be held at the Hyatt Regency St. Louis at the Arch on September 1-6, 2015.
The theme is a "Gateway to a New Life."
Plan now to "Meet us in St. Louie!"



September 14: St. Luke's Hospital –

Summer Wrap-up: Dinner and Breakout Groups

October 5: St. Luke's– Leonard Naeger Lectureship

November 2: Christian Hospital

December 7: Annual Banquet at Syberg's

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

Publication Deadline August 25, 2015

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.

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 2015

President's Message

To All Members and Friends of UOASL,

Summer has begun in earnest this past week with the temps hitting the 90s. Check out the article on dehydration and ABCs to make the next few months easier for you.

We had a great product fair with many in attendance. There were many of our regular members as well as some first time attendees, including a couple of our Youth Rally campers. Whether members came to find out the latest products or to hear our speaker, Kathryn Tristan, they did not go home disappointed. Congratulations to the winners of our raffles. Thanks to Jane Riffel who donated her gift card back to be used to buy gift cards for Youth Rally prizes.

As I write this, I am very busy with the Youth Rally. Our local chapter will have five campers plus five counselors representing the Greater St. Louis Area including UOAA President, Susan Burns and a camper from years ago! This makes two years in a row to have 10 from our 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.

The board is already beginning to work on plans for the national UOAA conference that is coming to St. Louis in September. We will be looking for volunteers to help us show off our hometown. Come to the July meeting to hear more from Susan Burns as she gives us a preview.

Susan has been very busy lately addressing the CDC commercial that many of you may have seen or heard about. We have included an article addressing it in this issue.

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

UOASL MEETING RECAPS

At our June 1, 2015 meeting at St. Anthony's Medical Center, Debbie Coleman RN, BSN, CWOCN, presented a very informative discussion of troubleshooting techniques. Some of the highlights are listed below. When cleaning the area around the stoma (peristomal area) use warm water only. Many soaps leave a residue which can prevent your appliance from adhering well.

- The best ways to prevent skin irritation are to have a correctly fitting pouch and carefully and thoroughly cleaning the peristomal skin when changing your appliance.
- If you have skin irritation you can try the crusting technique of layering no-sting spray with stoma powder.
- If you have leak issues, take off your appliance and turn it over. The back side of your appliance is a road map of the leak pattern and can tell you exactly where you need to make changes.
- Match your appliance to your abdominal contours or modify the abdominal surface to create a flat pouching surface, such as filling in creases with paste, rings, or strips just where you need it.
- If you have folds/creases make sure you are using a flexible appliance, such as one that can be folded in half.
- If you have a flat stoma, use a convex appliance. If your stoma prolapses, it can sometimes be reduced by a cold compress.
- Convatec makes a good adhesive releaser spray.
- Any new products can be patch tested for sensitivity by putting it on your back for 2 days.
- If you get a wound under your appliance, extra protein in your diet is helpful.
- Fungal infections can get itchy and will have small satellite lesions.

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 314/725-1888.

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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

ONE-PIECE vs TWO-PIECE POUCHING SYSTEMS: WHICH IS BETTER?

Ostomy Association of NY: UOAA Update December 2014

This is usually a matter of personal preference, and other issues that might affect the decision, such as arthritis, fine motor coordination issues, etc. Two-piece pouching systems are easier to center around the stoma (although some one-piece pouches now have “windows” to make inspection of the stoma and centering easier). In addition, two-piece systems allow one to change the type of pouch used (e.g., size, or open or closed) without removing the skin barrier. The snap on variety also allows one to change the angle of the pouch. However, this type of two-piece system tends to have a higher profile.

UROSTOMY REVIEW

Via GAOA Newsletter: UOAA Update March 2015

Diet: There are no eating restrictions as a result of Urostomy surgery. (If the kidneys have been severely impaired, your physician will monitor your protein and salt intake, but the functions of your kidneys are not affected by the surgery.)

The urinary tract and digestive tract are separate. A few foods and certain medications may cause urine odor or a change in urine color (such as asparagus, fish and certain spices). Drink plenty of liquids each day following the health care team's recommendations.

Mucus: You normally have some mucus shreds in your urine. If the amount increases, if the urine changes color and has a strong odor, it may signal that you have a urinary tract infection. Be sure to drink six to eight glasses of liquid a day, unless your physician instructs you otherwise. Drinking fluids helps to decrease the amount of mucus in your urine.

Acidic Urine: Drink cranberry juice in place of orange juice or other citrus juices which tend to make the urine more alkaline. Take vitamin C daily (if approved by your physician). Keeping your urine acidic may help to: (1) prevent urinary tract infections, (2) prevent damage to your skin, and (3) decrease odor. Check the pH of your urine about twice a week to be sure the urine is acidic, with a pH of less than 6.0. Most fruits and vegetables actually give an alkalized ash and tend to alkalize the urine. Meats and cereals will usually produce an acidic ash. Unless otherwise indicated, the urine should be maintained in an acid state.

Fluid & Infection Management: People with urinary diversions no longer have a storage area, a bladder, for urine. Urine should flow from the stoma as fast as the kidneys can make it. If your urinary stoma has no drainage after even 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.

Infections in Urostomies

Via The Pouch

Germs are all over the world, but when they are in the urinary tract, either in the conduit, the urethras or the kidneys, they're in an abnormal location and that is what causes an infection.

What causes infection? Most of the reasons are unexplainable. Why do some people get more colds than others? Infections can be caused by an obstruction, kidney stones, tumors, cysts or scar tissue. Almost synonymous with obstructions is infection and then, too, often comes stone formation.

You can't get rid of the infection. It's kind of a cycle that goes around and around. Infection can be caused by urine being forced back to the kidneys through the conduit. This could be done by falling asleep with the pouch full or urine and accidentally rolling over on the pouch, 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.

In general, to prevent and treat infections, you need a good flow of urine much like a stream. That not only dilutes the bacteria of germs in the urine, but also helps wash them out. Consumption of two and one-half quarts of liquids daily is required for the average adult.

SOME ABCs OF UROSTOMY CARE

Philadelphia Newsletter: UOAA Update May 2015

Adherence: Urinary appliances adhere well with cement Stomahesive® and Colly-Seel™. The urinary stoma drains continuously. The urine may be mildly irritating to the skin and may be odorous.

Bleeding: Often blood is noted in the appliance and its origin isn't immediately clear. One source may be irritation of the stoma by uric acid crystals. These can be formed in the appliance or on the skin around the stoma if the faceplate is too large. This may be indicated by small white spots on the stoma upon removal of the appliance. The crystals have an abrasive effect on the stoma. The crystals may be

(Continued)

readily dissolved and the bleeding relieved by bathing the stoma and the surrounding area with a half-strength vinegar solution. Do this three or four times a day while the appliance is being worn.

Changing Appliances: Usually the best time to change a urinary appliance is in the morning before drinking anything.

Closed Bottom: Only drainable pouches should be used on urinary stomas. Closed bottom pouches should never be used.

Face Plate: A convex face plate may be extremely useful with the flush urinary stoma.

Fluid Intake: Two to three quarts of fluid daily provide adequate "traffic" through the urinary system to prevent an increase in bacterial growth. (This can occur in a slow moving system.) Increased bacterial growth may lead to urinary tract infection.

Leaking: Urinary pouches that are allowed to get too full will tend to leak. Connecting the pouch to the leg bag will be helpful if you're unable to empty often enough. Attach the strap of the leg bag loosely to allow good blood circulation.

Night Drainage: Bedside drainage bag or bottle, probably similar to the type you used in the hospital, may be used for children and adults. This is how you can avoid getting up during the night to empty the pouch. The average urinary pouch won't hold the amount of urine that may be excreted during the night.

Odor: Drinking cranberry juice is helpful in deodorizing urine.

Plugging: You should NEVER use anything to plug your stoma while cleaning, changing or emptying your bag. This could cause problems with your stoma.

Showers: You may shower with your skin barrier on and removing the pouch or you may take a shower with the entire appliance off. It is found that if you chose to leave your skin barrier on, using Pink Tape (available through your supplier) around the edges helps prevent water from seeping in and compromising the seal. This also allows you to keep the skin barrier on longer causing less stress and irritation to your skin. This applies to colostomates and ileostomates as well.

TEMPORARY OSTOMIES

by Nancy Brede, RNET, edited by B. Brewer, UOAA UPDATE and The Ostomy Rumble from Middle Georgia

Temporary ostomies are surgically created with the intent of reconnecting in the future. The anatomy of the gastrointestinal system or urinary system is left intact.

Permanent ostomies are created with the intent that the ostomy surgery will not be reversed and usually the anatomy in the gastrointestinal or urinary system has been removed. Permanent ostomy surgery is usually performed when disease or injury prevents maintaining the anatomical structures needed for reversal.

A large number of temporary ostomies involving the colon are done on an emergency basis. The colon becomes obstructed or blocked, and stool cannot pass through. Because of the emergency nature of the surgery, the bowel cannot be cleaned and prepped ahead of time. Reversals, or reanastomosis (hooking the normal anatomy back up), then can be done later, when infection is not as likely and proper healing can take place.

The most common situations and diseases requiring a temporary ostomy are: Cancer of the colon with obstruction (or other abdominal cancer affecting the colon).

Hirschsprung's Disease, a disorder/malfunction in infants that prevents passage of stool. Due to lack of nerve cells in certain areas of the large intestine, stool is not moved through, and an ostomy is necessary.

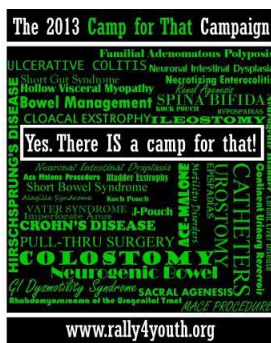
Diverticulitis, small out-pouchings in the wall of the intestine, called Diverticula, becomes infected. The Diverticula may rupture or cause obstruction.

Inflammatory Bowel Disease or Crohn's Disease may necessitate a temporary ostomy to allow the diseased bowel to heal.

Persons with temporary ostomies face many of the same problems permanent ostomates may have. It's just as important for them to have support, reassurance, and teaching as it is for persons with permanent ostomies. They must learn proper skin care, stoma care, and pouching techniques. Often, stomas are not ideally situated on the abdomen, because of the urgency of the surgery. Thus, pouching and skin care can pose difficult problems. Following temporary surgery, measures need to be taken to improve the patient's health. He or she must be in the best condition physically to undergo the major surgery for reconnection. There is also a time for the patient to deal psychologically with past surgery, upcoming surgery, and possibly a newly diagnosed disease. It may be a difficult time with all the changes and new challenges. Often, there are many fears and unanswered questions. Other people with ostomies and WOC Nurses (ostomy nurses) may provide reassurance and the answers to many questions.

YOUTH RALLY

This year will be in Boulder, Colorado. Next year will be in Seattle. Start sharing the word now with youth 11-17. **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 marybethakers@excite.com for more info or log on to www.rally4youth.org



THE UNCONTROLLED COLOSTOMY

Montreal, Canada & Ostonoma News, CA: UOAA Update March 2015

Some people in the medical and nursing professions are under the impression that people who have colostomies have very little difficulty in managing them, in comparison to people with ileostomies or ileal conduit. Very often a patient is told that in time, he can learn to train the bowel to evacuate once every 24 to 48 hours. This, they are told, can be achieved by either irrigation of the colon or by diet, and then all that is required is a dressing over the colostomy or a piece of colostomy equipment if more protection is desired.

While the above situation is true in a large number of cases, there are those who find it an impossibility to regulate the bowel no matter what method they try. These people often become discouraged, especially after hearing other colostomates report how well they manage with a minimum amount of care, with no problems at all.

Usually the person who had an irritable colon prior to surgery will experience problems post-op. Irrigations are recommended in these cases, to help regulate the colon. Persons in this category should consider being measured for a good appliance, one that will keep them clean, dry and odor free. This is a possible solution to this particular problem at the present time.

Note: There are some cases where a large amount of the colon and or ileum (small bowel) has been removed. In that case, a colostomy can act more like an ileostomy, therefore CANNOT be controlled. Best to check it out with your doctor.

CARING FOR YOUR OSTOMY

By Pat Murphy, RN, CETN, Middle GA, Ostomy Rumble
UOAA Update May 2015

Here are some simple pointers for ostomy care. They may not be new, but sometimes it is good to be reminded of them. Good ostomy care habits can catch and nip problems in the bud-the rosebud that is.

Inspect your stoma and skin each time you change your skin barrier. Your stoma should be bright red, smooth and shiny. Inspect the lower edge especially well. Use a mirror if necessary. Look for any signs of irritation or bleeding. These signs may mean your skin barrier is rubbing there.

Your skin should not be pink, purple or gray, even right next to the stoma. You may, however, notice some pink skin under pressure points when you first remove the skin barrier from your body. This is the same as when you take off your watch or a pair of stockings and is normal.

Inspect your skin in a sitting position to see if creases or low areas form around the stoma. This will tell you where to take special steps to even out the area when you put on your skin barrier. Stretching the skin to make it smooth may be all you need to do, or you may need a dab of ostomy paste to help seal the area.

Remember: a new stoma can change size for up to a year. Re-measure your stoma every time you change the skin barrier for the first six months after surgery and every month thereafter. Always re-measure if you are having a leak. Measure the stoma at the base from side to side and from top to bottom.

Many stomas are oval. If you are cutting a skin barrier of a one-piece pouching system, no skin should show when it is in place. However, making sure the skin barrier doesn't touch the stoma unless it is an extended-wear skin barrier manufactured to be able to touch the stoma (these skin barriers are designed to "turtleneck" where they touch the stoma). Since it can be tricky to cut the opening to the correct shape without leaving gaps around the stoma, manufacturers have developed skin barrier seals and ostomy paste that can be used to fill the gaps.

If your stoma is not perfectly round, do not trace and cut a round circle. Instead, make the skin barrier fit exactly. Your ostomy nurse can show you how. It should just miss the stoma, sealing down on the skin right next to it. Your skin barrier should not go over any red, wet mucosal tissue, the kind that forms the stoma. If you wear a pouch with a Karaya ring on it, the ring should gently touch the stoma all around.

On the Short Side

By Kathy Ward, administrative assistant of the United Ostomy Association of America from the UOAA Update, November 2014

We get a lot of questions here at our national office. I thought I would address some of them from time to time in a short article. So whenever you see On the Short Side, you know it's from our home office.

1. My wafer and barrier ring won't stay on. What can I do?

I recently found out by accident that the amount of softener in your water can make a difference in the effectiveness of your barrier ring seal. This is because the softener in the water is not being rinsed off. The softener solution remains on the skin, compromising the seal. The dispenser was broken on our water softener, and the result was that we were getting an abundance of softener in our water. After it was fixed, I found that my wafer and barrier ring stayed on my body much longer. It used to get compromised by the second day. So if you can't determine any other reason, check how much water softener is being dispensed daily.

2. My stoma emits so much liquid, I can't keep it dry enough to put a new barrier ring and wafer on. What can I do?

Try eating bananas or apples. They will help to absorb the liquids. There's a Diet and Nutrition Guide on our website* that has other suggestions as well. If you get late-night hunger pangs, try not eating your snack too late, especially if you intend to put on a new ostomy wafer the next morning. On those days, try to avoid all after-dinner snacking.

3. For those of you who are short-waisted, try placing your pouch diagonally on your body. This gives your pouch more room to expand. If you find it's still too long, bags with a Velcro® seal can be folded-up once or twice at the end to give you more comfort.

* Go to ostomy.org and click "Ostomy Information" "Diet & Nutrition" "Diet & Nutrition Guide" In English (or en Espanol)

Flanges, Faceplates, Barriers, Wafers? What's the Difference?

There is no difference! They're all just different names for the same thing, the part of the system that sticks to your skin.

Thanks to Winnipeg Ostomy Assoc, Inside/Out

HELPFUL HINTS

UOAA Update January 2015

from AICM- Montreal Nov/Dec 2014 Newsletter

Posture Matters: When you return from the hospital, you will be feeling sore and uncomfortable. You may be anxious about the front of your body getting bumped, or self-conscious about the stoma which can lead to a habit of hunching over to "guard" that area. Try to focus on keeping your head up and your back straight.

Walking Works: Don't lie or sit about all day. Walking helps restore lost muscle tone, gets your circulation going and just generally perks you up. Get up and walk several times a day.

Stomahesive Paste: If your stomahesive paste becomes hard and will not push through the end of the tube, heat a glass of water filled half way in the microwave for 45 seconds. Remove, and place the tube cap down in the water. Let stand for a few minutes and dry. You should now be able to push the paste out easily.

Vitamins: Vitamins should be taken on a full stomach. Otherwise, they irritate the lining of the stomach and produce the sensation of feeling hungry.

Diuretics: Try strong-brewed tea before the purchase of a "diuretic". Hot tea twice a day will wake up your sluggish kidneys.

Juice vs. Gatorade: Tomato juice provides as much sodium and 5 times more potassium and is a low cost alternative to Gatorade. Orange juice is another alternative providing the same amount of sodium and 15 times the amount of potassium to Gatorade.

For Colostomies: If you use just a pad instead of an appliance, use a little K-Y Jelly over the stoma to keep things soft and lubricated. If you irrigate, allowing too much water to enter the stoma too quickly may cause a sudden evacuation of waste, leaving much of the feces still in the colon, along with most of the water. Periodic evacuation may follow. This is not diarrhea, but is simply a delayed emptying of the colon.

For Ileostomies: Usually ileostomates experience hunger more often than other people. When this happens, they should drink fruit juice or water, eat soda crackers, followed by a meal as soon as possible. If you do need to eat a snack at bedtime or during the day in order to ward off nausea, try to cut down on calories somewhere else in the daytime or you will gain weight. Never skip meals in order to lose weight. An ileostomy keeps working whether the ostomate has eaten or not.

Sorbitol: the Hidden Laxative

By Lisa Robinson, Pharm. D. From the ostomy newsletter of Saint Paul and the UOAA Update

Diet, exercise and adequate vitamin and mineral supplementation are essential for an ostomate's healthy immune system. Excessive and/or chronic diarrhea increases the speed at which food goes through the digestive tract, which leaves less time and surface area for nutrient absorption. In an ostomate, this may be apparent by the speed at which the ostomy bag fills. Medication therapy in an ostomate is individualized, and an oral liquid is generally preferred to tablets or capsules. Many oral solution and suspension formulations contain a sweetening agent called sorbitol.

Sorbitol is a poorly absorbed polyalcohol sugar that is also used therapeutically as a laxative. Therapeutic laxative dosing of sorbitol for an adult is 20 to 50 grams per day. As little as 10 grams of sorbitol has been shown to cause cramps and diarrhea. Sorbitol is classified as an inert ingredient, therefore, manufacturers don't routinely list the amount of sorbitol. The laxative effects are cumulative based on the total daily dose.

Patients receiving multiple drugs containing sorbitol are more likely to experience adverse reactions. Take a look at the bottles of your liquid medication and see if it lists sorbitol under inactive ingredients. If it's a prescription, call your pharmacy and ask them to tell you who the manufacturer is and if sorbitol is listed as an ingredient. If you're taking several sorbitol-containing medications on a daily basis, you may want to call the manufacturers and find out how much sorbitol they contain.

Examples of commonly used oral liquid medications that may contain large amounts of sorbitol include: acetaminophen aluminum hydroxide calcium carbonate calcium glubionate cimetidine dexamethasone docusate sodium digoxin diphenhydramine ferrous sulfate furosemide ibuprofen lithium metoclopramide propranolol theophylline.

Relay for Life 2015

Relay for Life of Lincoln County, MO
Friday August 7, 2015 6:00 PM – 2:00 AM
Troy, MO – Contact Brenda Schulte
636.661.5607 aschulte@centurytel.net



KEEPING WEIGHT DOWN

(Saskatoon Ostomy Assoc. Bulletin - Nov.2014, via Evansville Indiana Ostomy Chapter, via Winnipeg OA "Inside/Out" Feb. 2015.)

Keeping weight down is especially important for ostomates. Even a few extra pounds can affect the fit of our appliance and cause the stoma to recess. For new ostomates, extra weight may put pressure on healing tissues. Here are a few ways to drop or maintain weight.

- Eat your biggest meal at noon and then have a very light dinner by 6 pm.
- Eat an apple, or two bread slices, or other fiber-type food 20-30 minutes before dinner. It will help curb your appetite at the table. These foods, combined with a glass of water, will expand in your stomach and reduce your capacity to eat.
- Chew well and eat slowly. It takes up to 20 minutes for the brain to receive the messages of fullness from the stomach.
- Don't eat after 6 pm. Resist snacking late at night, and your body will reward you with more restful sleep and lots more energy in the morning. Food eaten in late hours will generally go directly into fat production because the body's energy needs are low at night.
- Remember that vegetables are considered free of calories when not covered with dip, butter, or other extras – so you can have these healthier foods without guilt.
- Finally, instead of plunking down in front of the TV until bedtime, how about a relaxing evening stroll? You'll sleep better and feel better in the morning.

Gas and Bloating

Via The Pouch of the Ostomy Support Group of Northern Virginia
Eat peppermint to reduce gas and bloating. Instead of clearing the room next time you're feeling gassy, try sucking on a peppermint.

In one Italian study, 75 percent of people with irritable bowel syndrome saw a major reduction in symptoms, including bloating and flatulence, after taking peppermint oil capsules for four weeks. The researchers aren't exactly sure why, but in another study in the journal PAIN, researchers from the University of Adelaide found that peppermint soothes inflammation and pain in the gastrointestinal tract.

CDC Changes Anti-Smoking Ads after Complaints from Ostomates

Via Ostomy Outlook, North Central Oklahoma

In late March 2015, the US Centers for Disease Control and Prevention (CDC) began running a new series of anti-smoking ads, some featuring smokers who developed colorectal cancer that required a temporary ostomy. While the goal of stopping smoking is laudable, many ostomates were offended by the ads which, unfortunately, tended to reinforce popular misconceptions and stigmas regarding ostomy surgery.

If you'd like to watch these ads, you can view some at:

Julia's Ad: <https://www.youtube.com/watch?v=TuRRbub-FJ4>

Julia and Mark's Ad:

<https://www.youtube.com/watch?v=V4VQlzi5iCs>

and you can watch a longer version of Julia's story (edited by the CDC to remove the most offensive parts) at:

<https://www.youtube.com/watch?v=Wc6RVIC0BQQ>

As an early response to these ads, Robert Rund of Asheville, NC posted an online petition to remove them. As of this writing, the petition has collected over 10,500 signatures and is still running. You can view this petition (and sign it if you wish) at:

<https://www.change.org/p/centers-for-disease-control-and-prevention-remove-tobacco-colon-cancer-advertisement>

On April 11, 2015, UOAA posted a statement on its website, emphasizing the dangerous nature of the CDC ads due to their reinforcement of society's negative image of ostomies. See UOAA's web page at: [www.ostomy.org/Statement on CDC antismoking colostomy ads.html](http://www.ostomy.org/Statement_on_CDC_antismoking_colostomy_ads.html) which includes more links documenting the ongoing events in this story. Also see UOAA's Facebook page at:

<https://www.facebook.com/UOAAinc>

Among major additional events:

On April 13th, UOAA, jointly with the Crohn's & Colitis Foundation of America (CCFA) and the Youth Rally, sent a formal letter to the CDC (Read it on UOAA's website).

On April 17th, The Washington Post published an article about the CDC ads and UOAA's attempts to get them removed.

On April 21st, UOAA officials had a very productive phone call with senior representatives of the CDC.

Also on April 21st, The Washington Post published a follow-up article explaining that the CDC had modified the online versions of some of the ads. For example, in the long version of Julia's story, they removed the part where Julia said that, for the year while she had her ostomy, she hardly ever left home for fear it would leak and smell.

The CDC has admitted they made a mistake by failing to reach out to UOAA and other ostomates while they were developing these ads. And they've added links to UOAA on the CDC web page at: www.cdc.gov/tobacco/campaign/tips/diseases/cancer.html

In another interesting way, this incident highlights general ignorance about ostomies. Julia said in her ad that she had a "colostomy." But her temporary ostomy was almost certainly an ileostomy — probably a "loop" ileostomy. Most Americans, including many healthcare workers, use the name "colostomy" for all fecal ostomies (including ileostomies). And the CDC was apparently no better informed on this matter than the general public when they prepared these ads.

Why I Go To the Support Group Meeting

Anonymous via Insights of Southern New Jersey

I've had my colostomy for a long time now and I don't think much about it anymore. But I come to the meetings because I like to learn about all the latest news about ostomy products.

I still remember what it was like at the first meeting I attended. I was pretty nervous but I soon realized the people would talk about anything I was brave enough to ask about. Before I went I felt like I was the only one in the world who had this and I was real embarrassed. I learned I don't have to be embarrassed, and I'm not the only one by a long shot. I keep coming so I can let the new ostomy folks know that they'll soon feel normal again.

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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NEWSLETTER ARE NOT NECESSARILY ENDORSED BY
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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



AMERICAN CANCER SOCIETY
4207 Lindell Blvd.
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NAME: _____
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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
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 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.
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949 Chestnut Oak Drive
St. Charles, MO 63303



Local website is www.uoaastl.org

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“If you want to lift yourself up,  
lift up someone else.”

Booker T. Washington

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LIVE AND LEARN – Summer 2015

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