



UOASL 2017 MEETING SCHEDULE

www.uoaastl.org

July 10 St. Luke's – Ostomy Kits
and who & When to Tell

- August 7 St. Luke's – Coping with Change
- September 11 St. Luke's – Summer wrap-up. **Dinner provided**
Breakout Groups
- October 2 Christian Hospital – What's New? Coloplast
- November 6 St. Luke's – Leonard Naeger Lectureship-
Drugs and Your Ostomy
- December 4 Annual Banquet (**Starts at 6:30PM**)

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

Publication Deadline May 25, 2017

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.**

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.



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United Ostomy
Associations
of America, Inc.

LIVE AND LEARN Summer 2017

President's Message

To All Members and Friends of UOASL,

We had a great turnout at St. Anthony's this past week. Our topic was troubleshooting with humor and nurses, Carol DeBoard and Alalia Kraft did a great job reminding us that if you can laugh about it you can live with it. Just a month before that I saw many more of you at the Product Fair. Congratulations to our raffle winners, Bill Ward, Bill Kriete, and Carol DeBoard! We also had flowers donated by Medical West that went to Sallie Parker and Jeanette Huffman. The 50/50 winner was Gavin Schlarman, one of our Youth Rally attendees. We also learned how gratitude can make things manageable from our speaker, Larry Hagner of the Good Dad Project.

I am busy right now getting ready for our upcoming Youth Rally in San Diego. It is more than a month away but will be here before we know it. Several counselors from the area will be joining me as well as four campers. They are all returning campers. I am thrilled that they got so much out of it that they can't wait to return, but I know there are so many more out there who would benefit from attending! Please don't feel shy about sharing the word about Rally.

As Sheila and I were sorting through the many pages worth of great articles we wanted to include, we found that a number of them had been used in the past few years. I encourage you to go to the website www.uoaastl.org and look at the archived newsletters when you get a chance. Many things have not changed over the years despite all the technological advances. And what better way to learn more than to attend the conference in Irvine, CA, August 22-26. To find out more visit www.ostomy.org. Susan and her crew have been working to put together a wonderful program of education and fun.

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

Mary Beth Akers, President, UOA St. Louis

UOAA Advocates for You on Capitol Hill

by Jeanine Gleba, UOAA Advocacy Manager

As a member organization of the Digestive Diseases National Coalition (DDNC) UOAA attended their Public Policy Forum held on March 5-6th. On Monday, President Susan Burns and I rallied together with medical professionals, patients, representatives from a variety of organizations such as the American Liver Foundation, and Crohn's & Colitis Foundation. Ostomy patient advocates Robert Collins of Washington, and Lynn Wolfson of Florida also spread awareness on Capitol Hill during this critical time in America's healthcare reform. Our voices were heard on issues such as: Ensuring continued research funding to the National Institutes of Health (NIH). Garnering congressional support of the Removing Barriers to Colorectal Cancer Screening Act, which eliminates cost-sharing for Medicare beneficiaries if a polyp is found and removed during a screening colonoscopy. Preserving the basic patient protections from the Affordable Care Act, including minimizing patient out-of-pocket costs.

When it comes to healthcare, we stressed, "There is no red disease. There is no blue disease."

Not surprisingly the two greatest lessons learned were:

1. Staffers are very interested in hearing from the constituents in their District. I was on a team with NJ and Ohio residents and we visited those respective legislative offices. They listened to each of us, but there was definitely more of a connection between constituent and staffer.

2. Regardless of the state, all staffers paid particular attention to the patients sharing their story, and asked the most questions towards these individuals. Legislators need to and want to hear from you! Have you considered meeting your legislator to share your ostomy story and how healthcare reform will affect you? Visit our Action Center to look up your legislator contact information. Then call to request a meeting the next time your Representative or Senator is back home.

An interesting side note from my experience on the Hill was that in 70% of the legislative offices I visited, the staffer did not know what an ostomy was. So these visits are also the perfect opportunity to raise awareness and educate more people. Visits on the Hill are always very inspiring and empowering. At the end of the day as I boarded my train home I left with a feeling of optimism that both sides of the aisle were supportive of preserving the basic patient protections from the Affordable Care Act, including ensuring no discrimination for those with pre-existing conditions such as persons living with an ostomy or continent diversion.

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.

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.

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ODOR MANAGEMENT

Greater Cincinnati Ostomy Association

Isn't it interesting that people with normal intact bowel tracts and urinary systems manage odor problems in an acceptable manner in our society? But when disease or trauma strike, and the person is the owner of an ostomy, the one big concern is the fear of offending society with an odor. Basically, and simply, an ostomy is a man-made exit site that changes the point of exit from the bottom of our body to the front. Our eyes and nose are obviously on the front of our body, which leads us to be more aware of our changed body image and our odor-producing products. You've heard the statement "You've come a long way, baby." Yes, ostomy management has come a long way considering that as little as ten years ago we had very few 100 percent odor-free pouches. When ostomy surgery was first developed, ostomates wore anything to collect out-put. Presently, almost all ostomy supplies available to us today are made of odor-barrier materials. Therefore, if an ostomate does have a fecal or urinary odor about them, some detective work should be done: Check out the application of the pouch to the body, is it leaking? Check out the closure of the pouch—is it closed properly so that no fecal matter is oozing out after the closure is applied? Do not put holes in the pouch as gas will seep out continuously. A urostomate should rinse or wipe off the spout of the pouch with a bathroom tissue after emptying. Those few drops left in the spout after closing the pouch can cause a urine odor under clothing. It's interesting to note that most urostomy pouches on the market are odor-proof, but the connector tubing and bedside and leg bags are not. You must dispose of and replace these products when they take on odors, or else your entire living quarters will smell. Emptying an ostomy pouch is comparable to a person with an intact bowel or urinary tract having a bowel movement or emptying their bladder. How does the non-ostomate handle the odor produced by this normal function of their body? Room deodorizing sprays are popular; a quick flush of the toilet when defecation occurs, and striking a match or opening a window are some acceptable methods that have been used for odor management since the invention of indoor plumbing. Why then are we ostomates so "up-tight" about the odor produced when our pouches are emptied? This complaint has encouraged ostomy supply manufacturers to create products to meet this need of "odor control." The trouble is, the ostomy deodorants do not work for everyone and they are expensive. Can we then consider ourselves "as normal as blueberry pie" so far as waste odors are concerned? Just remember, there is not a man or woman on this earth whose wastes do not smell. If someone tells you their waste products are odorless, then a nose overhaul is in order.

Impact of Abdominal Changes

By Arthur Clarke, CWOCN Via Middle Georgia The Rumble

Only a finite amount of bowel eligible for use in the creation of a stoma. When you had your ostomy surgery, the surgeon was allowed—according to your personal physiology—only so much moveable bowel in the construction of a quality ostomy stoma. Once that piece of bowel was pulled through your abdominal wall, it was stitched to the inside of the abdominal wall and onto the outside of the skin. The length originally chosen by the surgeon will remain constant throughout the patient's life. Therefore, if the wall of the abdomen thickens: i.e., fat accumulates on the abdominal wall due to bowel segment used in the creation of the stoma will not change to accommodate the patient's increased girth. This being the case, one might expect the stoma to appear to be receding, since it and the peristomal skin cannot expand with the thickening abdominal wall all around it. This is in fact what happens. This condition is further exacerbated when the patient moves from a standing to a sitting position. This change in position causes the abdominal wall to move forward and down. However, the fixed dimension of the stoma bowel segment prevents the peristomal skin from shifting as much as the rest of the abdominal wall. The result is formation of a skinwell around the stoma, especially when changing from one physical position to another. The welling effect and excessive stress on the peristomal skin will most assuredly result in difficulty developing and maintaining the integrity of the skin barrier's seal. Ultimately, this results in untimely and frequent leakage challenges. There are two main approaches to resolve this issue. The ideal approach is for the patient to make a conscientious effort to maintain a constant and healthy weight, thereby returning the abdomen to the shape and wall thickness present at the time of the surgery. This approach would require regular exercising to firm up one's body as well as maintaining the correct weight for one's physical attributes. If one is unsuccessful with this approach, an option in pouching management is to switch from one's current pouching system to a convex pouching system. Many have found that a skin barrier with a convex surface—this has the effect of pushing the skin down and popping the stoma out—works much better than the highly flexible flat skin barriers. If you find yourself in a position where abdominal changes affect the integrity of your pouching system, there are positive solutions available. Should you experience any difficulty making the switch to a convex pouching system, enlist the aid of your local ostomy nurse. Convex pouching systems are being used successfully by people with ostomies with flat or retracted stomas, and they have been for a sufficiently long time to prove their worth

What Are the Withdrawal Symptoms of Decreasing the Use of the Steroid Prednisone?

UOAA UPDATE 5/17

Prednisone is a synthetic hormone. It belongs to a class of drugs called corticosteroids. Prednisone reduces inflammation but also decreases your body's ability to fight infections. It's used to treat many conditions, such as severe allergies, asthma, lupus and arthritis. When you take prednisone, your adrenal glands stop making cortisone like hormones (glucocorticoids). After you stop taking steroids, your adrenal glands need time to resume this function. The amount of time your adrenal glands need to fully recover depends on how long you took steroids and how much you took. Your doctor typically reduces your dosage of steroids gradually over several weeks or months. One potential consequence of steroid withdrawal is a flare-up of the problem you were treating with the steroids. For example, people with rheumatoid arthritis may have a recurrence of joint pain after they stop taking steroids. By slowly reducing the dose of prednisone, any worsening of the disease will be mild. Also, your doctor can adjust the rate of dose reduction. If the dose is reduced too fast, you may have fatigue, body aches, lightheadedness and difficulty recovering from minor illnesses. The greatest risks to your health during steroid withdrawal is the inability of your adrenal glands to respond to acute physical stress, such as serious injury, surgery or general anesthesia. Normally in these situations, your adrenal glands release large amounts of cortisol to help your body cope with the acute stress. If the adrenal glands are impaired, the lack of needed extra cortisol can cause shock and even death. For this reason, be sure to tell medical personnel if you currently take or have taken within the last year, prednisone or cortisol-like steroids.

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/UOAAInc)

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

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

One Handed Pouch Management

Compliments of Thom R. Nichols, Hollister, Inc.

Via UOA of Chicago, "The New Outlook" and Greater Seattle (WA) "The Ostomist" Jan/Feb. 2014

In regard to the unusual question that was asked this week about opening and closing a pouch with one hand, many of you had a very similar response: switch to a one-piece pouch. The reasons given were varied and somewhat divided between what would work better, a one-piece closed pouch or a one-piece drainable pouch. Those in favor of a drainable pouch generally state that using the Velcro roll up closure, such as Hollister's Lock n Roll or similar products from other manufacturers, would be better than the clip closure because they are easier to manipulate with limited dexterity and do not require pinching the clip to lock in place. As a personal note, when these products were first introduced, most manufacturers did consider the fact that many of their customers may have limited dexterity and they designed their products accordingly. The down side is that cleaning a pouch with one hand can be difficult. Many of the responses were similar to those following: "I have a pouching system with an integrated enclosure and I just tried opening and closing it with one hand and could actually do it. Cleaning the inside spout however, would be challenging." Those that favored closed pouches state that draining a pouch would not be necessary. "I had hand surgery to release trigger thumb and at another time carpal tunnel surgery. I used the closed-end pouches during that time to eliminate the need to drain my pouches. I practiced replacing my skin barrier and then snapping the pouch onto the floating flange using only one hand. I did it." However, some of you state that a two-piece closed pouch would work best because the barrier would not have to be changed as often. "I currently have a cast on my right hand/wrist following surgery. I am able to change my pouch. I do need the assistance of someone (in my case my wife) with replacing the skin barrier, which I do weekly." "I have been put in the position of being able to use only one hand. I use a two-piece pouching system. I switched from drainable pouches to closed-end pouches, which were easy to replace with one hand." "I have many problems with my hands. I have had seven hand surgeries. I use a two-piece." Many that have gone

through this state the need for practice before the surgery if you know this is going to happen. Buy the different types of products recommended and practice to see what works for you. One of you suggested the Bottom Buddy accessory (had to look that one up). It is sold on Amazon.com. and then there was this, which may take some of the fear away: “I work for a group of orthopedic surgeons and two of them perform shoulder replacement surgery. In fact, my brother-in-law has had both of his shoulders replaced by the doctor’s I work for. He was not immobile for weeks or months. In fact, they had him moving his shoulder right from the start. I do think such a person will be able to use his arm. It may be very painful the first couple of weeks, but I know he should be able to move his arm especially from the elbow down. Tell him not to fear. He will not be totally immobile. His surgeon will want to begin motion of the joint very early on to prevent stiffness. Thank you to all that wrote in to share your experience or voice your concern. Even if I did not have room in this missive to quote you directly, I hope I have summarized your voice appropriately. While this may be an unusual problem, it appears it is not all that uncommon. Life happens.

“I’M ALIVE . . . YOU’RE ALIVE - WE BOTH HAVE OSTOMIES ”

Via Springfield,MO, Central Indiana
and The Ostomy Rumble from Middle Georgia

They did not perform this surgery on us just for fun. They did not call it elective surgery. They hustled us off to the operating room to save our lives. They told our husbands, wives and other loved ones that it was necessary or we would die . . . maybe not today, but sometime very soon, too soon. So now, we have an ileostomy, a colostomy, an ileal conduit—or maybe two of these—and we are alive. We are alive because of this surgery and we can accept this or reject it. We can live a secret, sheltered life. We can be embarrassed and not talk about our affliction . . . or we can say “thank you for another chance to live this life in a helpful, hopeful way”. We can tell people that an ostomy is not the end of a normal life. Sometimes they may have a loved one who must face this surgery. We can hope that because we were normal, happy, well-adjusted and alive, and told someone about our ostomy, his/her loved one would fare better, perhaps as well as we did. Try it. Would it not make you feel good to think someone could benefit from your experience?

Pain You Should Never Ignore

by Dr. Mallika Marshal

Thanks to UOAA Articles to Share, Winter 2017

Pain is your body’s way of telling you something is wrong, and failure to address it could lead to serious problems. Chest/Shoulder Pain — It could mean that you’re having heart problems. Sometimes it’s a pain in the chest, sometimes in the left arm, shoulder, neck, or jaw. However, many people who’ve had heart problems say it’s not really a pain, but a pressure or discomfort. Now there are other things that can cause pain in the chest such as acid reflux, inflammation of the chest wall muscles, or inflammation of the lining of the lungs. But the thing we really worry about and want to rule out is a heart attack. So, if you develop these symptoms, especially if you have risk factors for heart disease or are over 40, you need to contact your doctor right away or call 911. Pain in the Mid-Back — If you experience pain in your back or between your shoulder blades, it’s most likely caused by arthritis. But pain in this area, especially if it’s severe or sudden can indicate an aortic dissection in which blood actually gets trapped in a tear of the main artery in the body, the aorta. This can be life-threatening. It more commonly occurs in people with high blood pressure or people with a history of heart disease, so if you’re concerned, call your doctor right away. Abdominal Pain — We all get the occasional bad stomach ache, but what we are talking about here is sharp pain that hurts so much that it takes your breath away. This kind of pain could signal appendicitis or a ruptured appendix that needs to be treated right away. Severe abdominal pain could also signal problems with your gallbladder, pancreas, or even an ulcer. Calf Pain — Whenever we hear someone complain of calf pain, we worry about a blood clot or deep venous thrombosis in the leg. These clots affect about 2 million Americans every year and can be life-threatening...if the clot breaks off and travels to the lungs. People most at risk are those with cancer, pregnant women, people who have had recent leg surgery, bed-ridden patients, and people who have been on long plane flights. So if you have pain in your calf, especially if there’s redness and swelling and no recent injury or muscle strain, you need to call your doctor right away. Feet or Leg Pain — Burning in the feet or legs could be a sign that you have peripheral neuropathy or nerve damage. One of the most common causes is diabetes which we all know is a very serious condition. And the sad fact about diabetes is that many people who have it don’t even know they do. So, a burning sensation in the feet could be the first indication. Other causes of nerve damage could be injury, inflammatory conditions such as Lupus, or vitamin deficiencies. So talk to your doctor.

STOMA FACTS

by Diana Kasner, RN, MS, ET; via UOAA UPDATE,

What is involved in “inspecting” a stoma? At each pouch change, check your stoma for color, shape and function. Watch for problems such as swelling, retraction, stenosis and prolapse. Urostomates should be on the lookout for crystal formation of alkaline encrustation (gritty white deposits coating the stoma). Any stoma complications should be reported to your MD or Ostomy Nurse. **Why does a stoma sometimes bleed?** Some bleeding may occur with rubbing of the stoma because the mucous membrane out of which the stoma is formed is highly vascular. This bleeding should stop quickly. Prolonged bleeding, an increased amount of bleeding or very easy bleeding may be indicative of another problem and should be reported to your MD. Wow! I didn't know that! **Can a stoma get cut?** Cuts or lacerations of the stoma can occur and some can be quite serious. Since a stoma has no pain nerves and, therefore, no feeling, it can be cut without causing any pain. Causes of stomal laceration include shifting of the faceplate or skin barrier, too small an opening (of the pouch), incorrect pouch application, etc. Your MD or Ostomy Nurse should be consulted for diagnosis and treatment in any case of stomal laceration. **How should a stoma be protected?** Stomas are fairly hardy, but some common sense rules apply. Stomas should be protected from direct physical blows, from too tight clothing and from rigid objects (e.g., belt buckles). This is not to say that these activities should be avoided. For example, ostomates engaged in contact sports can protect their stomas by wearing an additional binder for support.

UROSTOMY CARE Via Ostomy Rumble Mid Georgia

The urinary ostomy requires three kinds of preventive attention: care of the stoma; care of the skin around it; and care of the kidneys. Your routine care of kidney function includes: 1. Drinking at the very least – one quart of liquids daily. 2. Having your urine tested every six months. 3. Having an x-ray taken (IVP-intravenous pyelogram) of the kidneys once every two years. And observations: a) stoma for changes in size; b) check skin for signs of irritation, and c) kidneys – check the nature of urine (if dark - drink more liquids; unpleasant odor may be sign of infection – check it out with physician).

PROBLEMS THAT CAN HAPPEN WITH A STOMA

From The Ostomy Rumble, Middle Georgia

Most stoma problems happen during the first year after surgery.

Stoma retraction: Retraction happens when the height of the stoma goes down to the skin level or below the skin level. Retraction may happen soon after surgery because the colon does not become active soon enough. Retraction may also happen because of weight gain. The pouching system must be changed to match the change in stoma shape. **Peristomal hernia:** Peristomal hernias occur when part of the bowel (colon) bulges into the area around the stoma. Hernias are most obvious during times when there is pressure on the abdomen. For example, the hernia may be more obvious when sitting, coughing, or straining. Hernias may make it difficult to create a proper pouch seal or to irrigate. The hernia may be managed with a hernia belt. Changes may also need to be made to the pouching system to create a proper seal. Surgery may also be done in some people. **Prolapse:** A prolapse means the bowel becomes longer and protrudes out of the stoma and above the abdomen surface. The stomal prolapse may be caused by increased abdominal pressure. Surgery may be done to fix the prolapse in some people. **Stenosis:** A stenosis is a narrowing or tightening of the stoma at or below the skin level. The stenosis may be mild or severe. A mild stenosis can cause noise as stool and gas is passed. Severe stenosis can cause obstruction (blockage) of stool. If the stenosis is mild, a nurse may enlarge it by stretching it with his finger. If the stenosis is severe, surgery is usually needed.

ANTACID USERS BEWARE Via Ostomy Rumble Mid Georgia

Almost everyone has indigestion and heartburn occasionally, and it is probably alright to take an antacid pill now and then; but many health authorities warn that taking antacids regularly for more than two weeks may not be wise, especially for ostomates. Here's why: Magnesium hydroxide may cause diarrhea and reduced absorption of vitamins and minerals. Aluminum hydroxide may cause constipation, reduced phosphate levels leading to fatigue, poor appetite and bone loss. Calcium carbonate may cause acid rebound where, when the antacid wears off, stomach acid suddenly shoots up. It may also cause constipation, a potential disturbance in the body's calcium and phosphate levels called milk-alkali syndrome, which in turn may lead to nausea, headache, weakness and kidney problems. All antacids may reduce absorption of certain medications such as iron, digitalis and tetracycline. Many antacids contain lots of salt, which can elevate blood pressure.

Baby Boomers with Ostomies Via Ostomy Rumble Middle Georgia

As the millions of baby boomers in the United States age, there are a greater number of illnesses just waiting for them. Years of fast food and stress make a breeding ground for intestinal problems. When they can no longer deny that their fast-paced lifestyle, poor eating habits and lack of exercise have caught up to them, they seek medical help. When medical tests confirm intestinal problems that require surgery, their whole world seems to explode around them. Their doctor has just told his/her patient that he/she needs an ostomy. If the patient is fortunate enough to have a doctor who is aware of the local ostomy support group, he/she will advise the patient to visit them. In addition, the doctor will ask the WOC nurse managing the pre-surgery examination to make an appointment to see the patient. Experience has shown us that it is only when a person with an ostomy talks to another person with an ostomy that the problems that initially seemed insurmountable are gradually chipped away. This is what the UOAA and the local ostomy support groups embrace as their primary mission—people with ostomies helping other people with ostomies. We want everyone to know that one of the best places to find this type of information and assistance is with your local ostomy support group. Bring someone with an ostomy to a meeting.

Medicare and Ostomy Supplies Excerpts from Medicare.gov

Medicare covers ostomy supplies for those who have a colostomy, ileostomy, or urinary ostomy. Medicare covers the amount of supplies the doctor says you need based on your condition. An order (prescription) must be on file with the supplier. It must be signed and dated by the treating doctor. Make sure your supplier is enrolled in Medicare and has a Medicare supplier number. Suppliers have to meet strict standards to qualify for a Medicare supplier number. Medicare won't pay your claim if your supplier doesn't have a number, even if your supplier is a large chain or department store that sells more than just durable medical equipment. You pay 20% of Medicare-approved amounts. If a supplier doesn't accept assignment, there is no limit to what you can be charged. You also may have to pay the entire bill (your share and Medicare's share) at the time you get your supplies. Ask if the supplier is a participating supplier in the Medicare program before you get your supplies. If the supplier is a participating supplier, they must accept assignment. If the supplier isn't enrolled in Medicare, Medicare won't pay your claim. You must pay an annual deductible for Part B services and supplies before Medicare begins to pay its share. For more information call Medicare at 1-800-633-4227.

SUMMER HINTS...

GET BACK INTO THE SWIM OF THINGS!

Edited by B. Brewer, UOAA Update

For extra security during swimming and water sports, use water-proof tape around the barrier. This is called picture framing. Select a bathing suit made of textured or dark-colored materials that will better hide the outlines of the pouch. Some women prefer bathing suits with skirts and some men prefer boxer-style trunks, but snug-fitting suits can be worn. A light-weight 2-way stretch garment can be worn under a swim suit for extra support and flatness. And gentlemen, a pair of jockey shorts should do the same for you. Take precautions against sunburn. Besides being bad for your skin, a very bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes. Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, check with your doctor and/or to secure a prescription for anti-monilia powder. This may require an office visit for a consultation and visual examination. If plastic against your skin is uncomfortable or causes a heat rash, you should purchase your pouches with a mesh covering or consider using a pouch cover. Be careful diving, especially if you are a man, wearing boxer trunks. The shear forces encountered when you enter the water could, very easily, dislodge your faceplate and pouch.

Inner Peace

via February 2011 UOAA Update in LnL 6/11

If you can start the day without caffeine,
If you can always be cheerful, ignoring aches and pains,
If you can resist complaining and boring people with your troubles,
If you can eat the same food every day and be grateful for it,
If you can understand when your loved ones are too busy to give you any time,
If you can take criticism and blame without resentment,
If you can conquer tension without medical help,
If you can relax without liquor,
If you can sleep without the aid of drugs,

Then You Are Probably The Family Dog! Be Kind to Yourself!

Here and Now

by Patricia Johnson, Secretary, Ostomy Association of Greater Chicago; via Greater Chicago (IL) The New Outlook

At the March ostomy meeting [Chicago group], Steve from ConvaTec was the guest speaker. While he was talking about their new products and ease of use for new ostomates, I suddenly had a flashback to my first week home alone with my ostomy. I was so unsure of myself that to remember everything to do when changing the appliance, I wrote out all the steps and then read them as I went along. I laid out everything I needed even counting out the sheets of paper towel. Invariably I would still forget something and when finished there would be something left over and I would wonder, “where does that go?!” I would be so nervous my hands would shake. On one occasion, I couldn’t figure out why the wafer wasn’t sticking to my body. We made the long trip to the University of Chicago to see the WOCN. She looked at the wafer, and the backing over the adhesive was still in place. I had forgotten to pull it off. Over time I developed a routine for changing the appliance. I am much more comfortable with the whole procedure and it doesn’t take as long as it first did. (However, I do not think I will ever be able to do it in 10 minutes.) And there are still times when I forget something either because I am in a hurry or thinking about something else. When I do I am calmer and look at whatever is left over and decide if it will be a problem or not. Once in a great while, I have to start over. But those times are rarer. So, if you are new to this, I assure you it gets easier. And if you are an old hand at this you can look back and smile at some of your experiences adjusting to this new way of life with an ostomy. Maybe you have even achieved the 10-minute change. **Life is good.**

!! Bathing!!

You may shower with or without the pouching system. Water won’t hurt your stoma. Avoid using bath oils and soaps because they may interfere with the wafer sticking to your skin. When showering with your pouch, try turning your back to the water flow.

Ostomy Supply Manufacturers & Distributors

(Extracted in part from the United Ostomy Associations of America, Inc. (UOAA) website) Via UOA of NY

Suppliers

Finding the right type of ostomy supplies is an essential element for living well with an ostomy. After surgery we leave the hospital wearing a particular brand of ostomy equipment. Many people stay with their initial brand and live happily. However, there is more than one manufacturer of ostomy supplies, as well as more than one way to purchase them. Your WOC (ET) nurse is a good source of information for new products and for supplier recommendations. Your choice of both product type and place of purchase is limited only by your personal requirements, and in some cases, by your type of medical insurance. Medicare and many HMOs will impose certain restrictions on the purchase of ostomy supplies. If you are on Medicare, an important consideration in choosing a supplier is whether they accept Medicare assignment. Always check with your insurance carrier to determine the details of your insurance.

Selection Considerations, Problems, and Customized Options

Here are some tips to remember when choosing your type of ostomy supplies:

- Always consult with your ostomy nurse first for information and recommendations for your particular situation.
- Remember that every person is different and you need to find what works best for you.
- You should feel free to experiment with different manufacturers of the same product or different types of products. Call the manufacturer's toll free 800 number and request product samples, or ask your supplier for a sample.
- Check with your supplier for suggestions for new products. Ask if they have an ostomy nurse or other knowledgeable staff available to answer questions.

How to Handle Problems

Problems with your pouching systems generally split into two categories:

Problem: Defective product - e.g., pinholes or tears in pouch material, broken tail clips, damaged flanges/wafers.

Solution: Contact either the manufacturer or the place of purchase. Request either a refund and/or a replacement product. Write down the lot numbers from the box and return it for new products.

Problem: Product Incompatibility - e.g., an allergy to the tape or materials in the wafer or pouch, leakage due to the wafer not sticking or developing after weight change, etc.

Solution: Contact your ostomy nurse for trouble-shooting the exact cause, and for finding a better system.

If you find you've recently purchased a large amount of a particular product that is no longer appropriate for you, contact the place of purchase for their policies on exchanges or credit. They often will also suggest alternative products to try on a no obligation basis.

Custom-Fitted Pouching Systems

It is sometimes necessary for individuals to have ostomy products (usually the wafer) custom-fitted for their particular situation. Ask your ostomy nurse for recommendations.

Makers of Ostomy Pouching Systems

Listed below are manufacturers of ostomy pouching systems — i.e., pouches, wafers, etc. Most will send free samples if requested. Many also have an ostomy nurse on staff. For additional manufacturers, check with your ostomy nurse.

Aren't you amazed by all the choices out there?

Ave Cranston
RI 02910
800-545-4254
Full product line, including customized appliances.

Blanchard Ostomy Products
1510 Raymond Ave.
Glendale, CA 91201
818-242-6789
Karaya wafers, pouches, etc. for ileostomy, urostomy.

B. Braun Medical
824 Twelfth Avenue
Bethlehem, PA 18018-3524
800-227-2862
Two-piece products with Flexima 3S coupling system.

Coloplast Corp.
1601 West River Road
Minneapolis, MN 55411
800-533-0464
Full product line: SenSura, Assura, ColoKids, and full line of accessories.

ConvaTec
211 American Ave
Greensboro, NC 27409
800-422-8811
Full product line, Sur-Fit Natura, Active Life, Moldable Technology.

Cymed Ostomy Co.
1440C Fourth Street
Berkeley, CA 94710
800-582-0707
Full product line including the MicroSkin Ostomy Pouching System.

Hollister Incorporated
2000 Hollister Drive
Libertyville, IL 60048-3746
888-740-8999
Full product line: New Image, Premier, Adapt, Pouchkins.

Marlen Manufacturing & Development Co.
5150 Richmond Road
Bedford, OH 44146-1331
216-292-7060
Full product line: Ultra Duet, Ultra, Skin Shield.

Nu-Hope Laboratories, Inc.
P.O. Box 331150
Pacoima, CA 91333-1150
800-899-5017
Full line of pouches, Hernia belts, Non-adhesive systems.

Ostomy SuperSan
3551 Q St, Suite #103
Bakersfield, CA 93301
888-888-3095
A new company making ostomy pouching systems.

Perfect Choice Medical Technologies
2955 Pineda Plaza Way, Suite 209
Melbourne, FL 32940
800-665-3412
Pouches, deodorant, barrier rings & strips.

The Perma-Type Company
83 Northwest Drive
Plainville, CT 06062
860-747-9999 in CT; 800-243-4234 in other states
Reusable appliances for ileostomy, colostomy, urostomy.

Schena Ostomy Technologies, Inc.
2313 Harrier Run
Naples, FL 34105
239-263-9957
EZ-Clean™ Ostomy Pouching System.

Securi-T USA
12501 71st Court
Largo, FL 33773-3254
877-726-4400
Lower cost "Equivalent" products.

Torbot Group, Inc.
1367 Elmwood Ave.
Cranston RI 02910
800-545-4254
Full product line, including customized appliances.

**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



AMERICAN CANCER SOCIETY
4207 Lindell Blvd.
St. Louis, MO 63108
1-800-ACS-2345 www.cancer.org

Membership Benefits:

Education **Mutual Support from Fellow Ostomates**
Visitation Program **Conferences Country-Wide**
Product Information **Local Meetings and Programs**
Ostomy Guide Books and Informative Literature
“Live and Learn” Our Own Publication

CHAPTER MEMBERSHIP APPLICATION FORM

NAME: _____

SPOUSE'S NAME: _____

ADDRESS: _____

CITY: _____

STATE: _____ **ZIP CODE:** _____ - _____

PHONE: HOME: (____) _____ **OFFICE** (____) _____

OCCUPATION _____

E-MAIL _____

YEAR OF SURGERY: _____ **DATE OF BIRTH:** ____/____/____

Please check all applicable information

Type of ostomy: Colostomy Ileostomy Urostomy
 Continent Ileo Continent Uros
 Other (Specify): _____

Meetings: Send meeting notices Don't send meeting notices

Help: Would like to help on Phone Committee

Other Activities _____

Assistance Request *Complimentary Membership*

Medical Profession Doctor RN,WOCN Other _____

UOASL Chapter Membership Dues: (Effective Jul 2006)

\$12.00 annual

Make check payable to U.O.A.S.L.

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 115 Pine Street
 Old Monroe, MO 63369
 Phone: 636-661-5607

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