UOASL 2006 MEETING SCHEDULE

Feb. 6 St. Luke's 7:00PM - Institute of Health Education Rm.4&5 - Sharing

March 6 St. Luke's 2:00PM - Institute of Health Education, Rm. 4&5

April 3 St. Luke's 7:00PM - Institute of Health Education, Rm. 4&5 - Dr. Todd Arends – Laproscopic Surgeries

May 1* **St. John's 7:00PM - VonGontard Conference Center Product Fair** - Guest Speaker – Peggy Nelson

June 5 St. Anthony's 7:00PM Hyland Education & Training Building in the Great Room.

July 10* St. Luke's 2:00PM - Institute of Health Education, Rm. 4&5 - Stump the Ostomy Nurse

Aug. 7 St. Luke's 7:00PM - Institute of Health Education, Rm. 4&5 - Dr. Ron Gould, Topic TBA

Sept. 11* St. Luke's 2:00PM - Institute of Health Education, Rm. 4&5

Oct. 2 Christian Hospital NE 7:00PM - Dietrick Building

Nov. 6 St. Luke's 2:00PM - Institute of Health Education, Rm. 4&5 HOLIDAY FOODS – What to eat or not to eat

December 4 St. Luke's **6:30PM** - To be announced

HOLIDAY MEETING

For more information call: Bill Lawson, 636-256-7703 or Betsy Naeger, 314-725-1888

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Any articles welcome for consideration:
personal experiences, health, obituaries, find a pen pal, etc.

Publication Deadline: February 25, 2006

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

United Ostomy Association, Inc.
REBORN FROM THE ASHES OF DISEASE

marybethakers@excite.com

LIVE AND LEARN

Fall 2005

President's Message

Hello Members and Friends of UOA - St. Louis,

Happy New Year and I hope you had a wonderful holiday season. Our next meeting is February 6th at 7 PM at St.Luke's. The time and place of our 2006 meetings are listed in this edition.

Kate Lobstein has given our chapter a web site and it is great. Check it out at www.lobstein.org/uoa. We thank her for her hard work, and allowing members and future members to see what is happening in our local chapter as well as the upcoming national events.

United Ostomy Association is no longer, but we now have the United Ostomy Association of America. It replaces the old national organization, with new people and board of directors. They will be publishing an ostomy magazine called "The Phoenix" and the same editor of the OQ is continuing to publish our new magazine. It will be a great source of information and inspiration. I will continue to update you on the new UOAA. There will be a Youth Rally and a Regional Conference in April on the East Coast.

Please let us know if you have ideas for speakers or topics that you would like discussed at meetings. We want to make the meetings meaningful.

Upcoming events will be the May Product Fair, and a UOA-St. Louis bar-b-que this spring or summer.

See you soon,

Susan Burns
President of UOASL

WOCN AWARD of the YEAR

This year the award was presented to Colleen Cole of St. Luke's Hospital fame. The Board presents the award based on nominations by WOCN peers. It was presented at the WOCN Holiday Party by President and Vice President, Susan and Mary Beth. Two of our Board members were present as they are also WOCNs, Betsy Naeger and Linda Guerrin.

From the left: Mary Beth, Linda, Colleen, Susan, Betsy

RELAY FOR LIFE - ACS

The UOASL chapter will once again be putting together a team headed by Bill Lawson and Bob and Ginny Mattingly. The tentative time and place are August at St. Louis Community College at Meramec. Stay tuned for more details in the next issue.

Relay for Life represents our hope
that those lost to cancer will not be forgotten,
that those who are battling cancer will be supported,
and that cancer will one day be eliminated.

If you would like to join us or sponsor us in the upcoming year, contact Bill Lawson at 636-256-7703.

For meeting dates, times, and place, contact:
Retta Sutterfield RN CNS CWOCN
Phelps County Regional Medical Center
Rolla, MO 65401
retta@fidnet.com 573-458-7688

The Annual Youth Rally will continue!

Rally 2006 will be held July 8-12th at San Diego State University. If you know of any youth ages 11-17 who would benefit, call for more info. Mary Beth Akers, UOASL, Youth Rally Chair 636-916-3201. The rally's new website it www.rally4youth.org Make sure to check out Trey's article about this year's rally.

Local UOASL members at the holiday party.

YOUNG ADULT GROUP

A new group is forming in our local chapter. We have had a young adult group in the past and have interested members in getting it started again. Our definition of Young Adult is 21-40ish. The plan is to make social outings in addition to the monthly meetings. The first gathering will be on January 27th. We will start with dinner at Applebee's on Clayton Road followed by bowling nearby. If you would like to join us, please call LeeAnn at 636-240-3551 by January 20th so we can make reservations.

2005 At Ostomy Camp

By: Treyvionne D. Norman

My Trip to Six Flags

This year at UOA camp we went to Six Flags. The first ride I got on was the roller coasters. Next I went with Zack, one of my counselors to the arcade and played some of the games. I left Zack to go rock climbing and made it to the top more than once. I then found Jessica and Alana. We went on water rides until it began to get dark. Since I was alone I hung out with those two for the rest of the night. Jessica and Alana paid for the cork game I played for them. I won stuffed animals for them and their mom. Next I played a shooting game and I shot all the balls off the wall with the gun so they let me choose a stuffed animal. When we went back to the camp grounds to leave Six Flags at night I gave away all the stuffed animals that I won in every game I played that day. After that night I learned that giving to your friend is a great feeling.

Casino Night

On casino night I went to the check-in area and the game I played the most was black jack. I won most of the hands that I played in black

jack, but I lost money on the roulette table. I know that you're not always going to win. Others lost money gambling just like I did. I started with $500 and left with about $634 after we were finished. That left me with fewer prizes to choose from. I have learned the most important thing in this world about gambling. When you gamble you can lose a lot of money and just because you spend more it doesn't increase your chances of winning. Losing money can make you go crazy every time that you lose. Some people become homeless because they lose so much money.

Dance Night

Hours before the dance, I went to YMCA with Bret and some other friends. We went rock climbing there and swimming. Bret helped me get started on learning how to swim. Then after that I went back to the rock climbing site and Bret video taped me climbing up the hardest wall at the YMCA. Then I went back to camp with Bret and all the campers ate lunch and got ready for the dance. It was the last day at camp and everyone was excited. I wore my black suit. It was fun hanging out with people like me, not being judged but just being and having fun while doing it. I'm glad the UOA exists for kids like me. I look forward to next year's adventure!

What I Learned

I learned this year that everyone deserves to be loved and not be judged. I learned it's important to be responsible and a man/woman of your word. I also learned it's important to take care of family and friends.

Reflection

As was announced in the last issue, Lisa Caraffa passed away recently. We have lost many remarkable members at UOA--St. Louis. Pennye Pollard comes to mind. I think some of us knew Lisa better than others, as Lisa's involvement in UOA was not always consistent due to her busy life. I wanted all members to know how lucky we were to have her as a part of UOA--St. Louis. She was a caring person and never refused to assist others or encourage them during desperate times. Personally, Lisa was responsible for my interest and ultimate career path in Social Work. In addition, she talked to me many a time.... you know, those times when you get discouraged and don't always see your ostomy as a strength. I will miss Lisa. We hadn't talked in years, but it was comforting to me just know she was there, helping others. I hope my thoughts help you understand what type of person Lisa was. Thanks.

Paul J. Schoenig

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.

For a visitor or info on being trained, call Betsy Naeger, 314-725-1888.

UOAA Info

*Due to the closing of the United Ostomy Association, a new organization was founded with the name United Ostomy Associations of America.

*The new website is operating but under construction at www.uoaa.org and the telephone number is still the same. 1-800-826-0826.

*The previous website is being left in operation for a year. All national publications can be downloaded and printed from the site – www.uoa.org

*The new advocacy hotline is advocacy@uoaa.org

HOLIDAY PARTY RECAP

Thanks to all who were able to join us for the Holiday Party. It is always a pleasure to see faces we haven't seen in years. We know that some members no longer come to the meetings because of time issues or your needs have been met, but it sure is nice to renew friendships at the holiday time of year. Consider joining us for the BarBQ we will be planning.

We had the added gift of hearing from a past Great Comebacks Winner, Charlie Grotevant. He and his wife were in town for a Farm Bureau convention and came to join us. He gave a great presentation. We also heard from LeeAnn Barcus about the Annual conference and Trey Norman about the Annual Youth Rally.

Hank Thill played the piano for us again and we enjoyed a delicious meal with wonderful desserts after the presentations. Everyone went home with a door prize and party favor. We also had representatives from Hollister and Convatec set up tables with info. Santa Claus stopped by to give candy to all.

The Overactive Ileostomy

From So. NV Town Karaya; via Stillwater-Ponca City (OK) Ostomy Outlook September 2001., via Inside Out On-line Sep/Oct 2002.

An overactive ileostomy can result from a variety of problems. If the small bowel is inflamed due to Crohn's disease, radiation injury, or bacterial/viral enteritis, the output will be profuse. If there is narrowing of the small bowel close to the stoma, where the ileostomy goes through the abdominal wall, a pressure backup can lead to explosive high output. Any food that has a laxative effect should be eliminated or, at best, kept to a minimum. People with lactose intolerance will have high output if they use any kind of milk product, including powdered milk, which is found in many prepared foods. Excessive drinking of fluids will also increase the ileostomy output. An ostomate who has had a gall bladder removed may have increased output. Medicines to counteract bile salts can be used if the problem is related to gall bladder removal. Many prescriptions and OTC drugs list diarrhea as a side effect. The ostomate should work with his physician to evaluate the problem. Once disease can be ruled out, therapeutic emphasis can be placed on diet, utilizing foods that decrease output. Bulk laxatives can be used with each meal to absorb and solidify some of the liquid output.

About Colostomies

from Philadelphia (PA) Journal via Oklahoma City (OK) Ostomy News
From Stillwater-Ponca City (OK) Ostomy Outlook May 2002

There are several types of colostomies. The word "colostomy" means to create a new opening in the colon for stool to pass through. A stoma is the opening on the abdominal wall for the colostomy.

The location of the stoma defines what type of colostomy a person has. An Ascending Colostomy is on the right side of the abdomen and is made from the upward (ascending) portion of the colon. The stool is usually semi-soft to liquid.

Bowel movements usually occur shortly after a meal. The pouch should fit well around the stoma without any skin showing. Stool will irritate any skin that is exposed. If skin shows between the stoma and pouch opening, a pouch with a smaller stomal opening is needed or the skin should be protected with paste.

A Transverse Colostomy is on the upper part of the abdomen and can be located anywhere along the horizontal (transverse) portion of the colon. The stool is usually soft to slightly formed. Usually a bowel movement will occur a few hours after a meal. Again, the pouch must fit well to prevent skin from being irritated by stool.

A Sigmoid Colostomy is on the lower left side of the abdomen and is made from the downward (descending) portion of the colon. The stool is usually soft to firm.

After a period of time a person's bowel movements may occur at about the same time of day as they did before surgery. People with sigmoid colostomies usually have a choice of whether or not to irrigate. An irrigation is an enema given through the stoma to help the colon have a bowel movement at a certain time of day.

Whether or not a person irrigates is that person's choice, depending on how regular bowel movements were before surgery. Irrigation is not painful but needs to be done on a regular schedule to train the bowel with a new habit.

Regardless of what type of colostomy a person has, once strength is regained, they may return to a normal day's activities. Having a colostomy will not handicap anyone in any way as long as they manage the colostomy instead of letting it manage them.

Vitamin B-12?

Via: Ileo Info Bulletin, Montreal, QC; Oshawa, ON;
Metro Halifax News, September 2005, via Inside Out On-line Nov/Dec 2005

If a large section of the small intestine has been removed many ileostomates will require Vitamin B-12. Your body can store B-12 for about three years so this vitamin deficiency may not show up for several years.

Ileostomates should test periodically with their physician. Symptoms may come very slowly. They include anemia and neurological symptoms, i.e., numbness in the feet and difficulty walking, sore tongue, muscle spasms, appetite loss, weight loss and forgetfulness. Your vitamin B-12 is check through a simple blood test. It can become part of your annual check-up.

If the deficiency continues too long, some the symptoms cannot be reversed, leaving the patient severely impaired. The treatment consists of B-12 injections. Since the section of the bowel which absorbs B-12 is no longer available, taking Vitamin B-12 tablets will not work. A new product, NASCOBAL, delivers B-12 by nose instead of by needle. After the blood level has been stabilized by injection therapy, many people can maintain the proper level of B-12 with this intranasal product. The odourless, flavourless gel comes in a nasal squeeze bottle. This convenient inject-free method delivers a precise 55 mg. once weekly. Only available by prescription.

B-12 blood levels and peripheral blood counts must be monitored initially at one month after the start of treatment and then at intervals of 3-6 months. People sensitive to cobalt or having Leber's disease will suffer swift optic atrophy.

Memorial

Carolyn Doyle died October 16th after a long battle with pulmonary disease.
Please let us know if you hear of the death of a chapter member we don't include.

Medications and the Ostomate

Via: The Mailbag, Jacksonville FL. April 2004,& Inside Out On-line Sep/Oct 2004

Dry (sigmoid) colostomates have fewer problems absorbing medication. The ileostomate and wet (transverse) colostomate may not absorb some formulations as well. Therefore, they may not get the full benefits from the medication.

Liquid medications are more easily absorbed. Chewable tablets are also in this category, be sure to chew thoroughly for best absorption.

Uncoated tablets begin to dissolve in the stomach but the time it takes to completely dissolve varies with different products. Gelative tablets are less effective than liquids but are still effective. These may be ineffective for the ostomate with short bowel syndrome.

Generic coated tablets delay dissolving of the medication. Because of the rapid transit time of ileostomates and those with short bowel syndrome, these types of meds are not recommended.

Sustained release medication takes 8 to 12 hours for absorption. Ileostomates and those with short bowel syndrome should avoid this medicine. **Pain medication** may cause constipation. Diuretics that deplete potassium should not be used by the ileostomate. Antibiotics may cause diarhhea and may not be well absorbed by these same people.

Vitamins, other than B12, in tablet, chewable and liquid varieties and be used. Vitamin B12 is only effective if given by injection.

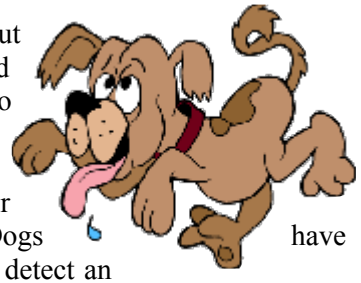
Antacids that contain calcium should be avoided by urostomates. This can increase the possibility of stone formation. Oral contraceptives should not be used by ileostomates since they may not be completely absorbed.

Sulpha may lead to crystal formation in urostomates. Drink at least 10 to 12 cups of fluid a day, and, if using ascorbic acid, discontinue it while taking sulpha.

" Here's something new:
large type alphabet soup for senior citizens."

Pets & Ostomies – Your Ostomy - Not Theirs!!

Via: Vancouver Ostomy HighLife, VIA The Ditty Bag, Chilliwack, B.C. Nov/Dec 2004, via Inside Out On-line Jan/Feb 2005



It may seem like an unusual concern, but enough pre-op patients have expressed worry over how their animals are going to react to their ostomy to warrant addressing the question. Will a new ostomate's pet(s) behave inappropriately or shun someone wearing an appliance? Dogs have an acute sense of smell and yes, they can detect an ostomy appliance. They may check it out as something new but after that it is business as usual for a dog. They really don't care. Same for a cat. Animals don't categorize scent the way we do - what we think is objectionable is natural to a dog or cat (or a horse, or a rabbit, or any other member of the animal kingdom). If pets could speak, they'd probably tell us to lay off the perfume and soap! As far as a pet seeing their owner wearing an appliance, it's just another article of clothing as far as the animal is concerned. Have you ever worn a new hat, or an unusual belt, carried a new item of sporting equipment? Did you pet get upset or even notice? They really don't care.

Pets jumping on you or in your lap is another matter but not really a big issue. You'll have to "guard" the stoma area to keep an enthusiastic Rover or Fluffy from landing directly on the stoma but aside from that they can't hurt you. If you have a cat that like to do that 'kneading' thing with its claws you will have to move it to the other side.

A recent poll on this question on an internet ostomy forum regarding this question received 31 replies from all kinds of pet owners. Owners of big dogs, small dogs, cats galore and none of them reported negative or unwanted reactions from their owners. Many owners reported their animals could sense if they were upset, or sad or ill and would become more attentive during those times.

The Aging Ileoanal Pouch: What Happens When The Pouch Gets Older

Via: Metro Halifax News: The Bulletin, Ostomy Toronto, via Inside Out On-line Jan/Feb 2004.

It has been 20 years since the Ileoanal Pouch was first introduced as a treatment for ulcerative colitis and familial polyposis. Thousands of patients all over the world have had pouch surgery. What will happen as the pouch gets older?

The small intestine and the large are very different, both in structure and in function. The small intestine absorbs small nutrient molecules from the liquid stool, whereas the large absorbs water and stores the stool until evacuated. The small is long and narrow, the large is short and wide. Stool passes quickly through the small - 6 meters in 2 to 3 hours. Stool passes slowly through the large, taking about 26 hours for 2 meters. These differences in structure and function are reflected in the incidence of cancer in the small and large intestine. Small bowel cancer is very rare as the carcinogens in the stool don't have the opportunity to cause any changes in the cells lining the bowel. In the colon and the rectum, however, stool sits there and carcinogens have plenty of time to live and have effect. Colon and rectal cancer is the most common cancer in the United States.

When we make a pouch, we are changing the structure and function of the small intestine to make it work like a colon. It now stores stool and absorbs water. It comes as no surprise, therefore, to learn that as an Ileoanal pouch gets older, it starts to look like a colon.

Under the microscope, the lining of the colon is flat. The small intestine normally has finger-like projections called villi, that help with nutrient absorption. There are no villi in the colon. As the pouch gets older, researchers have found that they tend to lose their villi. The colon has a lot of mucous producing cells (goblet cells), much more than the small bowel. Older pouches have increasing numbers of goblet cells. Older pouches also lose the look of the small bowel and start to look like rectums. These changes usually take several years to start becoming apparent. What does this mean for the patient's state of health?

Our concern as physicians who care for patients with pouches is whether this tendency of the small bowel will mean there is a risk of cancer or colitis developing in the pouch. Polyposis patients are certainly prone to getting polyps in their pouches, but nobody has reported a cancer yet. As far as colitis is concerned, we already know about the syndrome of pouchitis which mimics colitis and can occur very early after pouch

Continued on page 6

construction. This is different from a true return of colitis in older pouches.

Because of the theoretical risk of colon cancer developing in the Ileoanal pouch, we recommend that pouch patients come in for yearly pouch checks. At this time, biopsies will be taken to look for dysplasia, an appearance of the cells lining the pouch that suggests that cancer may possibly develop. As time goes by and the number of patients with maturing pouches increases, the natural history of the elderly pouch will become more obvious. Stay tuned for more information.

Urology Concerns

Via: The Rosebud, & G.B News Review; S. Brevard, FL; Evansville, IN; Metro Halifax News, June 2004, via Inside Out On-line Sep/Oct 2004.

Germs are all over the world, but when they are in the urinary tract, either in the conduit, the ureters, or the kidneys, they are in an abnormal location, and that is what causes an infection. What causes infection? Mostly, the reasons are unexplainable.

Why do some people get more colds than others? Infections can be caused by obstructions, kidney stones, tumors, cysts, or scar tissues. Almost synonymous with obstruction is infection, and then too often comes stone formation. Once you have stone formation, it's hard to get rid of the infection. It's a 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 happen if you fall asleep with the appliance full of urine and accidentally roll over on the pouch, causing urine to be forced back through the stoma and the urinary tract with tremendous pressure. Invariably, the urine in the appliance is contaminated. In general, to prevent and treat the infection, you need a good flow of urine, much like a stream. That not only dilutes the bacteria or germs in the urine but also helps wash them out. Two and one-half quarts of liquids daily are required for the average adult.

Night drainage is a MUST. Otherwise, you run the risk of urine backing up into the kidneys which can cause irritation or infection. This is especially important for urostomates with only one kidney. It's important to be aware of the symptoms of a kidney infection: elevated temperature, chills, low back pain, cloudy urine, or decreased urine output. People with ileal conduits normally produce mucus threads in their urine which give a cloudy appearance, but bloody urine is a danger

sign. You must see your doctor if any of these symptoms occur.