### **UOASL 2014 MEETING SCHEDULE**

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

See enclosed flyer

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

Publication Deadline February 25, 2014 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 <a href="mailto:marybethakers@excite.com">marybethakers@excite.com</a> 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 that, too.

### 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

Winter 2014

### **President's Message**

To All Members and Friends of UOASL,

I hope this newsletter finds you enjoying your holiday season or recovering from it as the case may be. I hope you are all blessed with a wonderful beginning to our new year, 2014.

It was wonderful to see so many of you at the Annual Banquet at Orlando Gardens a couple weeks ago. The accompanying music on the harmonica by Arpad DeKallos was wonderful addition to an evening of great food and even better fellowship. We had a couple new folks join us who expressed to me the wonder at being able to have an open conversation about issues involving their ostomy with people who really understood. That is why we all continue to do what we do!

The following week the WOCN of the year award was presented to Retta Sutterfield. See the pictures on the next page.

I want to thank those stepping off the board after serving us well. Thanks to Les Anderhub, Al Lincoln, and Marty Henricks. We welcome our new members Herschel Austin, Bill Kriete, and Shanan Rodgers. They will join us at our first Board Meeting in January.

One new development for the new year that we were not anticipating is losing our funding from the American Cancer Society. We have benefited from their generosity for quite a few years. They have been printing and mailing this newsletter as well as sending us postcard stamps to mail the monthly meeting notices. We received word that they had to make deep cuts. Therefore we will be paying for the printing and postage. That being said, we don't want anyone to have to read the newsletter on the computer if they are more comfortable reading a hard copy. If, however, you would like to receive the newsletter via email instead of the mail, just let us know.

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

Mary Beth Akers, President, UOA St. Louis

### The Flu and What to Do

UOAA Update 7/13

The flu brings with it headaches, upset stomach, diarrhea, muscle aches and pains!!!! The advice: plenty of fluids and rest in bed - this remains sound medical advice for your general attack of the virus. But if your case of the flu includes that "bug-a-boo" diarrhea, you may find the following hints helpful.

For those with a colostomy, it is usually wise not to irrigate during this time. Your intestine is really washing itself out. After diarrhea, you have a sluggish colon for a few days, so again, "leave it alone". Start irrigation again after a few days when your colon has had a chance to return to normal.

For the ileostomate, diarrhea is a greater hazard. Along with the excess water discharge, there is a loss of electrolytes and vitamins that are necessary in maintaining good health. This loss is usually referred to as a loss of fluid which, in turn, brings a state of dehydration. Therefore, you must restore electrolyte balance. First, eliminate all solid food. Second, obtain potassium safely and effectively from tea, bouillon, and ginger ale. Third, obtain sodium from saltine crackers or salted pretzels. Fourth, drink a lot of water. Cranberry juice and orange juice also contain potassium, while bouillon and tomato juice are good sources of sodium.

Vomiting also brings the threat of dehydration. If it is severe and continuing, your doctor should be notified or go to the ER. You should know also that diarrhea may be symptomatic of partial obstruction or an acute attack of gastroenteritis. Since the treatment of these two entities is entirely different, a proper diagnosis should be made as rapidly as possible if obstruction is suspected because of localized cramping. **Do not play games**. Remember - always call your physician unless you are 100% certain of what you are doing.

For urostomates - be sure to keep electrolytes in balance by following the general instructions for colostomies and ileostomies.

No ostomate should take medicine for pain or a laxative without the physician's order. Do not use antibiotics for colds or flu unless the doctor orders it.

In colostomy patients, drugs or certain foods can cause constipation. This can be prevented during a cold by drinking plenty of liquids. Increased water intake in the ileostomate results in increased urine output rather than increased water discharge through the appliance.

When returning to a normal diet, use fiber-free foods at first, then gradually increase to regular, normal diet.

### **OSTOMY RELATED WEBSITES**

Much information of interest to Ostomates can be found on the internet at various Ostomy Related Websites.

www.ostomy.org, www.ostomates.org, www.cancer.org, www.ostomy.evansville.net,

www.ostomyinternational.org,

www.hollister.com, www.convatec.com, www.ostomyok.org/oanco,

<u>www.greatcomebacks.com</u>, <u>www.vcn.bc.ca/ostomyvr</u>, <u>www.c3life.com</u>, <u>www.uoachicago.org</u>,

www.browardostomy.org

Check out the **Frequently Asked Questions (FAQ)** on the *United Ostomy Association of America* Website, http://www.ostomy.org/ostomy\_info/faq.shtml

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.





☐ One-year subscription \$29.95 ☐ Two-years for \$49.95 Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

To order go to www.ostomy.org and click on the link.

### 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.

### The Value of an Ostomy Visitor

Source: The Newsletter of the Winnipeg Ostomy Association via Green Bay

There are times when a certain person can make a difference that no one else can make . . . so it is with the ostomy visitor. You help someone at a time when they are vulnerable. They in turn might be the visitors of the future. Do you remember your ostomy visitor? Just when you thought you couldn't possibly deal with this operation...a friendly face at your hospital door (or home). This person assured you that he or she had once been the patient in the bed. They could also empathize with your aches and pains, depression and your fear for the future.

You can reflect back on your questions when you first had surgery. Am I still lovable? How will I ever wear clothes? Will there be an odor? Won't my pouch leak at an embarrassing moment? How well you remember these feelings. The visitor somehow made you feel loveable. The idea dawned that if he or she could make it, you would too. The possibility of participating in your own ostomy care didn't seem quite so overwhelming. Perhaps you could start learning...one small step at a time. You are living proof that life goes on. You are there doing the very thing that the new patient wonders about. You are indeed a symbol of hope in the midst of their pain, confusion and fear.

Making a visit may seem like a small thing to you. It is like lighting a candle in the midst of darkness. It is helping them to help themselves. Not everyone is blessed with an ostomy visitor so they struggle to find the answers. A visitor can make all the difference.

### **Annual Banquet**

We had a wonderful turnout for the banquet at Orlando Gardens in Webster Groves. Thanks to those who donated gifts for raffle: Jenny

Hoffman from Coloplast, Jackie Kreitz, Nora Henricks, Betsy Naeger and Brenda Schulte. Thanks to Betty and Marge for making our stocking favors. I'll be hanging mine on my tree. We were treated to some after dinner entertainment by Arpad DeKallos on the harmonica. The



food was delicious and the fellowship even better.

Look for information in upcoming newsletters on the location of the banquet next year.

### **WOCN** of the Year

On December 10<sup>th</sup> the award was presented at the WOCN Holiday Party. This was the 12<sup>th</sup> year we presented the award to an ostomy nurse nominated by her peers or a member of our chapter. Congratulations to this year's winner, Retta Sutterfield of Christian Hospital. She was indeed very surprised at the whole thing! She joins a great group of previous winners: Betsy Naeger, Lyn Kramer, Sheila

Kramer, Colleen Cole, April Kuhlman, Linda Guerin, Janet Knebel, Sharon Waldman, Zoe Shepard, Diana Occonomon and Roxie Lupien. Congratulations to all our winners and thank you to all the nurses who serve us so well!

We also thank the WOCN Network for the generous gift of \$1000 they gave to UOASL to keep doing what we do. *Li* 



Linda Guerin, Betsy Naeger, Mary Beth Akers, Retta Sutterfield, Hank Thill, and Susan Burns



The next UOAA National Conference will be held at the Hyatt Regency St. Louis at the Arch on September 1-6, 2015.

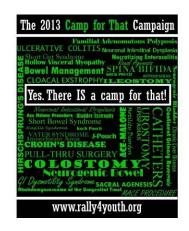
The theme is a "Gateway to a New Life."

Plan now to "Meet us in St. Louie!"

### **YOUTH RALLY 2014**

As you know, we are always looking for youths, 11-17, to send. This year will be in San Diego, California. We have several possible new campers but would love to send ten! Don't let them find out about it when they are past the age. Spread the word!

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

### MATCHING GIFT TO YOUTH RALLY

Thanks to those who have been able to take them up on this. Two of your current UOASL Members, Herb and Jim, have agreed to match the contributions received for the YOUTH RALLY from your DOCTORS (not from you personally) up to a total of \$300.00. This should be an incentive to every member to talk to your doctors about this very worthwhile cause. Their office is not Bashful about collecting theirs fees. This is also a great way to get the word out and find youth to send!

### **Urostomy Care**

UOAA Update 7/13

The urostomate should keep in mind that the stoma may shrink for several months following surgery. It is important that your appliance fits well so that the skin around the stoma does not become thick and white due to contact with urine. This crust may rub against the stoma, causing bleeding. To cleanse the pouch of crystals, soak it in a solution of 1 part vinegar to 2 parts water. Several glasses of cranberry juice each day will help restore the acid level in your body and there is less crystallization.

The urinary pouch should be emptied often. There is no odor when the pouch is kept clean. The portion of the intestine (the ileum) that is used to form the "conduit" is mucous forming, so it is not unusual or abnormal to see some mucous in the urine. Before attaching the night drain, leave sufficient urine in the pouch to fill the entire length of the tube. This eliminates air bubbles which prevent the flow through the tube and causes backup problems.

Please remember that for best results, you will want to change your appliance first thing in the morning before you eat or drink anything. This may give some breathing room for a few minutes (when your stoma will not be active) to get the skin dried off and the new appliance in place. If you bend over and try to be sure all stored liquid is forced out before you begin the change, it may also help give you a few minutes of inactivity to complete the change.

### From INTERESTING FACTS & HINTS ABOUT OSTOMIES

By Connie Kelly, RN, MS. CETN from It's in the Bag, St. Catharine's, Ontario, Canada Via Springfield, MO

### Review your pouch change technique

I would like to encourage you to look at how you change your pouch. After many years of living with an ostomy, people often keep adapting what they use and often find themselves using many products and taking hours to change their pouch instead of 15 to 20 minutes. Therefore I encourage you to look at each product you use and ask yourself: "Why do I use this?" and "What's the purpose of this step?" The procedure should be as uncomplicated as possible, and no one step should duplicate another.

### From United Ostomy Associations of America's Facebook Page

Disclaimer-This video uses questionable language and discusses adult topics. Viewer discretion advised.

Wonderful exposure for ostomates. Comedy Central did a segment on ostomies. If you are on Facebook, the easiest way to see it is to go to the link on Dec. 5<sup>th</sup> on their page. If not, you can search for it using keywords "Tosh Ostomy Video Interview."

### Don't Assume

by Lyn Rowell, Anne Arundel County (MD) Ostomy Association, Inc. via The Pouch, OSGNV and Insights of NJ

When you live with an ostomy, it is easy to forget that most people, including medical professionals, don't know much or anything about stomas. Even those who have heard of ostomies, assume they are all colostomies.

When a doctor ordered an abdominal scan I discovered that it involved drinking a lot of contrast fluid in a short period of time. I told them that everything I drank came out through my ostomy very quickly and I thought there might be a problem. I was assured there shouldn't be so I commenced drinking the contrast. Unfortunately, as I expected, it didn't take long for it to start coming into my pouch (it had a very obvious color). I went to the desk and told them that the contrast was already coming through into my pouch. The tech took me aside and after my explaining what was happening, he said, "can't you put a plug in it (meaning the ostomy) or something?" Now anyone who has been around ostomies knows that no, you can't "put a plug in it" (believe me there have been days when I wished I could) but the tech hadn't come across my situation before. We were able to complete the test only with less than optimal contrast, but it did show me that just because someone works in the medical field, I shouldn't assume they know about or understand ostomies.

Sometimes a medical professional treating you for something not stoma related may forget you have an ostomy and need to be reminded. Once during a physical a doctor told me that as part of the exam he would do a rectal—I had to remind him that it was physically impossible for him to do that since it had been removed and that area sewn up! So always inform and never assume.

### **Moderation**

By The Ostomy Rumble from Georgia via Newsleak

It is several months since you had your surgery, and you have adapted just fine to your new plumbing. You have a beautiful stoma. Changing your pouching system is almost a routine. Your skin has now adapted to the patch you apply, and you may wear your pouching system 3-4 days before changing it.

Boy, this is living again! No more pain! You can go out without worrying about bathroom locations and even your arthritis seems to bother you less (prednisone can do wonders). You accept an invitation to a party for the first time in 2 years and really rejoice in being out with your friends again.

You drink with freedom and down quite a few handfuls of peanuts. You wander to the table with raw vegetables and try them again and again joining in with your friends. The dinner is delicious—including the corn on the cob. This has been a truly great night—just like old times. It is 2 in the morning, and you have not slept a wink. There has been a persistent pain around your stoma that will not let you sleep. And now it is getting worse. You recall that you have not had much effluent in your pouch. What you do have is mostly water.

By 3, it is much worse and by 4 you are considering going to the emergency room. You remember reading about blockages and try to remember remedies that were mentioned. You drink some warm tea, pull your knees to your chest and rock back and forth.

You eat some crackers, drink some grape juice and knead the area around the stoma. You drink some more, have a little mineral oil, get in the shower and let warm water roll down your back to relax. About the time you decide to go to the hospital, you feel a little better. You notice that your pouch is no longer empty. When you empty your pouch, it is like pouring out a bag of peanuts in the toilet.

You have learned a great lesson. Sure, you can eat nuts, popcorn, raw vegetables or corn on the cob—but common sense will now tell you in the future not to eat huge quantities of them all at the same time. Eat them in moderation, drink and chew your food better. Let me repeat: Chew your food better. Eat in moderation. Drink plenty of fluids.

### **Loss of Sponsorship**

We have been incredibly fortunate for many years to have had the American Cancer Society of St. Louis sponsor this publication's printing and mailing as well as paying for the postage on our monthly meeting reminder postcards. We cannot forget how grateful we are for all they have done. Unfortunately, they have decided that they needed to make big cuts in outside expenditures. Our chapter has felt the blow. We will now be paying those costs out of our local UOASL's funds. We will not be raising dues just yet however. We want to give it a year. We have been having 500 copies printed and 200+ mailed out. The remainder of that 500 are handed out at pharmacies and hospitals, etc.

One way we are going to try to cut costs is to offer a digital copy emailed to those who are interested instead of getting a printed copy. We are also offering email meeting reminders in place of postcards.

If you are interested in receiving electronic newsletters and/or postcards, send an email to <u>marybethakers@excite.com</u> indicating that we stop mailing newsletters, postcards, or both.

Thank you for helping us get over this hurdle.

### Stoma Guards

Sent in by Sheila Reddick, UOASL member

Being a new ileostomy patient I have been worried about continuing to wear some of my favorite trousers because of possible pressure leaks. This summer after my surgery I bought a couple pair of pleated front trousers in a size larger than normal thus preventing pressure on my wafers and pouches. But as the weather turned cold I wanted to wear my favorite old comfy trousers. There were ads for stoma guards on line. The first ads that I found emphasized that they were for those who were involved in sports. Those 'permanent' stoma guards cost \$150.00, too much for an experiment. But then I spotted an advertisement in "Phoenix" magazine for lightweight plastic stoma guards that are sold bundled in packs of 5 for \$30.00. I bought and tried them, they don't come off without pulling off the whole appliance so I just wear them all the time even under pajamas. While they do bulge a bit they protect my appliance from getting squashed which could cause a 'back up' and a breach of the adhesives. So stoma guards are not just for young athletic types, they are for those of us who want to get more use out of the clothing that we had before our surgery.

### IT'S A MATTER OF SHARING

Via Ostomy News Review, Green Bay, WI, Ostomy Support Group of Middle Georgia, and Springfield, MO

I know a man, a colostomate, when asked why he didn't join the ostomy chapter said, "I've adjusted just fine. I don't need the group." His complacency set me back a bit. I thought it over.

So, maybe he doesn't need the chapter—whatever that means. But the group needs him and others like him—well-adjusted ostomates who walk around flat-tummied and non-odorous. Of course, I'm not talking about after-shave or perfume.

An ostomy chapter is not a "half-way house" sort of thing. We don't get together to feel sorry for ourselves, to talk exclusively about the "fun and games" of our various operations. We get together because we want to help each other or maybe to get some help with some little problem that's been bugging us. Something our doctors can't answer but another ostomate may. We want to prove to all those non-believers—oops, guess I'd better call them skeptics—and non-ostomates who may think an ostomy is the end of the world—well, it's not. In most cases, it's the beginning.

### **Happy Holidays to All!**

Copied from Insights of OASNJ

We are alive because we are ostomates. May you find Peace, Health, and Prosperity!



Happy Holidays dear Ostomates, We wish you good cheer,
May your health-cares lessen, In the coming New Year.
We carry extra baggage, But we do it with Grace,
Even embarrassing accidents, Won't make us lose face.
With the support of our friends, Whose similar problems we share,
We're there for each other, We know that you care.
Never give up! Keep a prayer in your heart,
We're tough – we're survivors! And the New Year's a fresh start!

### 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

### **SPONSOR**

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:	
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ADDRESS:	
CITY:	
STATE: ZIP (	CODE:
PHONE: HOME: (	) OFFICE ()
OCCUPATION	e-mail
YEAR OF SURGERY:	DATE OF BIRTH://
Type of ostomy:	Please check all applicable information () Colostomy () Ileostomy () Urostomy () Continent Ileo () Continent Uros () Other (Specify):
Help: () Would like t	ting notices () Don't send meeting notices o help on Phone Committee
Assistance () Request Complimentary Membership	
<b>Medical Profession ()</b>	Doctor () RN,WOCN () Other
UOASL Chapter Membership Dues: (Effective Jul 2006)	
	\$12.00 annual
Make check payable to	
SEND CHECK TO:	Hank Thill, Treasurer U.O.A.S.L.
	970 Imperial Point
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(ANY CONTRIBUTIONS OVER \$12.00 ARE TAX-DEDUCTIBLE AS WE ARE A NON-PROFIT ORGANIZATION)

# mind, just as well strengthens the strengthen the Difficulties as labor ----0000 body. 00000



Local website is www.uoaastl.org

# Officers and Board of Directors

**Vice President:** President: Mary Beth Akers 636-916-3201 Susan Burns 636-926-2737

Treasurer: Hank Thill 636-225-5099 Secretary:

Our current Board Members include Mary Beth Akers

Betsy Naeger, RN, CWOCN William Kriete **Shanan Rodgers** 

Linda Geurin, RN, CWOCN

Herschel Austin

Bill Ward

Marge Blomenkamp

Brenda Schulte

Betty Kaltenbach

Email version does not include back side of schedule page.

Meeting Schedule 2014 All meetings are at 7:00 PM

St. Luke's Hospital - Breakout Groups!

St. Luke's-Leonard Naeger Lectureship

Annual Banquet - TBA

See directions and website information for each hospital on the back of this page.

Mercy Hospital Product Fair

St. Anthony's Hospital

St. Luke's Hospital - TBA

Christian Hospital

\*\*denotes hospital other than St. Lukes' for meeting.

\*denotes second Monday due to Holiday

St. Luke's Hospital - Youth Rally Presentation - Mary Beth Akers

St. Luke's- Peristomal Skin Care: Troubleshooting and Treatment

St. Luke's Hospital - Summer Wrap-up: Dinner and Breakout Groups

St. Luke's - Peristomal Hernia Management - Sheila Kramer RN, WOCN March 18th Tuesday - Conf A (by the Cafeteria, main hospital. 1st floor) 6:30

No meeting

January:

February 3:

March 3:

April 7:

\*\*May 5:

\*\*June 2:

July 7:

August 4:

\*September 8:

\*\*October 6:

November 3:

December:

United Ostomy Association of Greater St. Louis

Jan 20th Monday - Conf room 6 (auditorium area) 6:30

June 23rd Monday - 3rd floor conf room (main hospital) 6:30

Oct 20th Monday - 3rd floor conf room (main hospital) 6:30

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