

UOASL 2013 MEETING SCHEDULE

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

October 5 – Ostomy Awareness Day

****October 7:** Christian NE –Lighten Your Load Through
Yoga with Leslie

November 4: St. Luke's- Dr. Leonard Naeger Lectureship

December 2: Annual Banquet – Orlando Gardens
8352 Watson Rd. <Naples Ballroom>

Any articles welcome for consideration:

personal experiences, health, obituaries, tested tips, etc.

Publication Deadline November 25, 2013

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? If you would like to try it, 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 that, too.

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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

Fall 2013

President's Message

To All Members and Friends of UOASL,

Are you feeling the summer heat yet? So that was the first line from the last issue. Strangely, I find it more appropriate as I write this message. I have just finished my second week with my students and had the hottest day of the year, I think! The weather was great in Seattle in July with no rain getting in our way of having a great time. Down in Jacksonville a few weeks ago was warm, but not this warm!

Susan Burns, Past President of UOASL, did a wonderful job on the conference planning committee in Jacksonville and our chapter had a great showing there. Look for more about the conference later in this newsletter. We expect you all to join us in two years when it is right here in St. Louis! It will be awesome to have our National UOAA President open the conference right here at home!!

The Youth Rally was amazing and powerful again this year with the memory of a wonderful woman spurring us on to make it both informational and great fun. More to follow on that as well!

Last issue, I put out a search for someone to help with the newsletter, and Sheila offered her help. A while back Jane was able to help but I can certainly relate to people getting overbooked! I also want to give a shout out to Paula who is helping with our website. There are many others who do great things. Take a chance to thank them at the next meeting.

It has been a very busy summer for me and I am looking forward to some great meetings leading us to our Annual Banquet in December. I am hoping you all decide to join us for that. We have decided not to put the RSVP form here in the newsletter and are mailing the notice to all members. We also decided not to increase the cost but will be covering the balance with chapter funds.

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

Mary Beth Akers, President, UOA St. Louis

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!

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.

A training session is in the works for the Fall. If you are interested in being trained as a visitor, call Betsy at 314-741-4544 and she will send you more information on the exact details of the training.

Recap of the September Dinner and Sharing Meeting

During the last 30 minutes of the September 9th meeting, our group broke up into smaller groups to share experiences and issues related to their particular type of ostomy as well as the caregivers who had their own group. Each group was led by a WOCN. Thanks to Sheila Kramer who led the ileostomates, Linda Geurin who led the colostomates, Eileen Fahy with the Urostomates, and Roxy Lupien who met with the caregivers with Betsy Naeger floating among them all. Here are some of the things shared.

Ileostomy Notes: (Thanks, Sheila) The range of time that our members have been living with ostomies ranged from a few weeks to 52 years,

Arpad de Kallos had his surgery in 1962. The issues that were discussed included getting comfortable with the appliances and finding products that are comfortable and feel secure. People shared experiences with paste vs. rings and products that reduced odor as well as products that control gas. An anti-flatulent, Simethicone 80 mg, can be found at The Medicine Shoppe Pharmacy (Order #220-4899) or WalMart. Because it is generic, it costs less than Gas-X and is as effective. We also discussed controlling odor. Na'Scent is a product which is squirted directly into the pouch to control odor while Devrom (1-800-453-8898) is a chewable tablet taken with meals to control odor.

“Coolostomy” notes: (Thanks, Courtney) Things discussed in this group included the new kit put out from the American College of Surgeons to educate pre-op patients. (The chapter will be getting one to have on hand to loan out.) Does it make a difference what brand you have for the closed end clip? What do you do about a hernia around the stoma? Are there any “no-nos” with foods? Who do you go to if you have a problem?

Urostomy notes: Unfortunately, these guys were too busy sharing to write anything down! ☺

Caregiver notes: (Thanks, Kim)

- *Eat 2 marshmallows before you change an ileostomy. It gives you time, you will not have a much output. It works for intimate times, too.
- *5Day pads – Use it to help stop leaks and antiperspirants.
- *Sure Seal – Use it around the flange to give it more stability. It helps in the heat.
- *JoAnn's – Sells a diaper change material. It comes on a bolt and is nice for travel. Put it on the mattress to protect from leaks.
- *Support belts – Many different kinds of bands: Ostomy Secrets; Stealth Belts (Stingray belt has a zipper on the bottom); NuHope; Tytek; StomaFix—all ideas the caregivers saw as beneficial for their loved one.
- *You can print out a travel card from UOAA.com to make traveling easier.

All in all, this session was found to be very helpful and most concluded that more group discussions would be welcome.

Talking Back to Your Doctor Works

UOAA UPDATE 7/13

Next time you visit your doctor, keep in mind one crucial if little-known rule: catch 23. The catch works this way: Doctors typically will listen to a patient's "opening statement" little more than 23 seconds before changing the subject or "redirecting" the talk.

That means you, the patient, must talk not only fast, but compellingly, even knowledgeably, to get his or her attention. That's important for your doctor to fully grasp what's bothering you. Too often doctors don't. In fact researchers increasingly are finding that one big reason treatments don't work—or aren't prescribed at all—is because of problems in the way doctors and patients communicate. Or, more precisely, fail to communicate. And when communication fails, the results can be disastrous.

Last year the National Academy of Sciences (NAS) reported that some 7,000 patients die every year because of medication errors. Even more alarming, the NAS found that medical errors in hospitals cause between 44,000 and 98,000 deaths every year. Some mistakes can be avoided, experts believe, if doctors and patients do a better job talking to each other. Medical authorities are coming to the view that patients themselves must be more assertive in the doctor-patient relationship.

Studies show that doctors remember best the cases of assertive patients. Medical outcomes are also likely to be better. "The pattern is very strong," says Johns Hopkins University behavioral scientist Debra Roter. "When you get patients to be more engaged in a visit, they do better in terms of satisfaction, understanding and recall of doctors' instructions." Moreover, she adds, "there's also a reduction in markers for diseases such as high blood pressure."

Patients can do some things on their own to improve communication. First, keep in mind that doctors are under growing pressure to see many patients and may not have time for idle chit-chat or even friendly conversation. In fact, your doctor may be in a greater hurry than you think. A 1999 report in the *Journal of the American Medical Association* found that doctors in one study "redirected the patient's opening statement after

a mean of 23.1 seconds." That means you must get to the point fast. Start before you get to the doctor's office. Think about how you're feeling, what is bothering you and what you want.

And when you go in, know what you're talking about. Do your homework to find out as much as you can about your health problem. Go to the library or make judicious use of the Internet to ferret out facts about the medical issues that concern you.

Then write your questions down and prioritize them. "Bringing in a list of questions is really essential," says Michele Greene, a researcher on doctor-patient communication at Brooklyn College in New York. "And then [don't] be afraid to ask those questions."

Make a list of all your medications. The physician may find two prescriptions for the same drug (one a generic and the other a brand name), outdated medicines or medicines that conflict with one another. Keep a notebook and, with your doctor's help, write down instructions, diagnoses, and descriptions of medicines, their purposes and side effects.

Make sure you grasp your condition and the risks and benefits of recommended treatments. In doing your research, experts advise, learn about alternative treatments. Watch for biases on the part of your doctor. An orthopedist, for example, may be more apt to propose surgery for a back or knee problem than, say, a rheumatologist. One patient who's glad she sought additional options is Washington writer and editor Elder Wellborn, who some years ago was diagnosed with early-stage breast cancer. She first visited a surgeon who described, among other treatments, surgery.

Then she and her husband visited several oncologists, all of whom proposed chemotherapy, although her disease had not spread to the lymph nodes. "We pushed them hard on what the gain would be," Wellborn says. "It turned out you'd slightly improve the odds [of remaining disease free], but you'd go through six to 12 months of miserable existence." Wellborn opted for radiation therapy.

Advice from a Physician About Safety Belts

by John. L. Rowbothan, MD via OSGNV The Pouch

Dear Ostomate: You mentioned criticism some people had about wearing safety belts in their autos. It is reported that safety belts are harmful to abdominal stomas. You have asked for my opinion; it is simple and straightforward.

I would rather treat an injured stoma in a live patient than look at a healthy stoma in a dead one. There is no question in my mind about the value of safety belts in autos. Anyone arguing that such a belt should not be worn is making an excuse, not giving a reason. Inevitably, the failure to wear a safety belt is sheer laziness and stupidity. Any further discussion of the matter is irrelevant.



Relay news from Herb Boerner

Howdy to all. Here are some preliminary totals from the 2013 Relay. Our current total is just under \$54,000, with 300 registered Participants and 20 teams. Our fundraising goal this year was \$66,000, so we're hoping that the money keeps coming in - **if everyone raises only \$42 more**, we'll more than meet our goal!

(Thanks, Herb, for going and representing UOASL as you do so well! mb)

The Ten Immutable Laws of Colostomy Maintenance

by John Lafferty, Hamilton (ON) Osto-Info; via Niagara (ON)
It's in the Bag; and North Central OK Ostomy Outlook

- Law 1 – Poop happens.
- Law 2 – Poop happens constantly.
- Law 3 – The probability of your colostomy going off during changing is directly proportional to the expense of the carpet or bedspread beneath you.
- Law 4 – Once on the carpet or bedspread it is impossible, no matter how solid it looks, to pick it up with your bare hands. Once on your hands Law 5 becomes self-evident.
- Law 5 – Poop is the stickiest substance known.
- Law 6 – The probability of getting toilet paper off the roll with one hand is inversely proportional to the amount of poop on the other hand.
- Law 7 – The probability of remembering to get toilet paper in advance of emptying your bag is inversely proportional to how far the toilet paper dispenser is located behind and below you.
- Law 8 – The probability of getting a useful piece of toilet paper off a large commercial roll is $p=0.0000001$.
- Law 9 – Poop exhibits unique gravitational forces that allow it to mysteriously attach to anything within a meter of the toilet. Anecdotal evidence suggests this is related to Law 5.
- Law 10 – No matter how much you chew, it is impossible to adequately masticate corn.

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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UOAA National Conference 2013 Jacksonville, Florida

I went to the UOAA National Conference in Jacksonville, FL and helped out at the registration table. I met people from all around the USA and several other countries and had a very interesting time talking to them. The new timers I talked to were very

happy they went to the conference because they met so many people that were in the same shape they are. They learned things they found helpful about how to handle their ostomies or diet or stomas, etc.

Some people who visited a stoma nurse were extremely happy to have had the chance to do so. They said the stoma nurse suggested different products they might try, or things to help with a skin problem, etc. For a lot of them it was the first time they had been to a stoma nurse.

All in all the majority of conference goers I talked to said it was well worth it. Hope to see you in St. Louis in 2015.

Brenda Schulte, UOASL MCCC chair and Board member



I really enjoyed my first conference. I'm so glad I made the trip. I went to the Stoma nurse who suggested that I cut my appliance a little bit different, so for it has worked better for me. I also worked in the store, where we sold shirts and Stoma pins, UOAA pins, and Bracelets. Working in the store provided me the opportunity to talk with other people about their experiences with managing daily life. You get a warm feeling knowing you are not alone with the things you face every day. There were a lot of nice people who shared information with me. I truly look forward to 2015. I hope others will experience it with us.

Marge Blomenkamp, UOASL Board member



Bill and Jackie Kriete, Mary Beth Akers, Marge and Dave Blomenkamp, Pat Ward, Brenda Schulte, Bill Ward and Susan Burns, future President of UOAA

More Conference reflections from our local members...

Pat and I were very impressed by the amount of information that was available at the convention. You had a choice of many talks that I wanted to hear. They all had good speakers. All of them had a Q & A time. All my Questions were answered. We have very good speakers at our meetings in St. Louis, but with so many people asking questions I heard many things I had not thought of. We met many people from all across the country, and all of them had ostomies of some kind. I think that if you have a chance to go to one of these you would be glad you did. In **2015** the conference will be in **St. Louis**, and you should make every effort to go. I could not believe how nice things worked out. You could tell that a lot of people put a lot of time and work into making this great, and they should be proud of it!



Bill Ward, UOASL Board member

As someone who has been to dozens of conferences, I spend my time there a bit differently than those who have never been or even those who have been a few times. This conference had me helping out at the Registration table, running errands for the Stoma Clinic, manning the Youth Rally booth in the Exhibit Hall and even making a presentation about the Youth Rally and Linda Aukett at the Opening Session. I continue to go, even when I know I will not be able to go to very many sessions, because I feel I am there for another reason. I am there to help people find answers to their many questions.

I was able to attend a session on a new product, so anyone who uses a two piece closed end ostomy pouch, make sure to ask me about it! It is life changing! I also was able to share the amazing news of Youth Rally to anyone who cared to stop and listen.

Overall, I consider it a very rewarding way to have spent my week after the 13 hour drive to get there!

Mary Beth Akers, UOASL President

UOAA Conference Reflections— “Bridge to Acceptance”

by Barbara and Bill Hawes via OSGNV The Pouch
(Thanks, Barbara, for putting together such a great overview of the conference! mb)

Visit <http://vimeo.com/72312463> to view a slide show of the Conference.

There was a great spirit of unity and camaraderie among the 450 or so attendees. The workshops were very good and included Be Your Own Advocate, Reimbursement and Insurance Issues, Basic Colostomy, Ileostomy, Urostomy and Continent Ostomies, Short Bowel Syndrome, Skin Issues, How Cancer Treatments Affect Your Ostomy and Gay and Lesbian Open Forum. They also had some unique topics included this year— Yoga and Meditation, Veterans Outreach Network, Anatomical Apron, Social Media, and Massage Therapy. Bill attended all of the ASG Leaders Workshops, Ask the Pharmacist—Drug Effects, Male Urinary and Prostate Issues and Massage Therapy. Many of the speakers gave us email addresses or websites where we can get copies of their presentations—one is even 70+ pages long!

I visited the free Stoma Clinic for a problem that I had and the volunteer WOCN’s working there had lots of support from the vendors with all kinds of supplies, etc. for the many who attended it.



complete with gals in poodle skirts and songs from that era. It brought back a lot of memories of dance steps that a lot of us learned in high school, etc. We played Ostomy Jeopardy prepared by **Edgepark** at the 50s-60s Beach Party on Friday night. Other major sponsors included

Hollister provided the food for the ice cream social and a 1950’s dance band,



Coloplast—First Timer’s Reception and keynote speaker Margaret Goldberg, Medical Chair; **NPS Pharmaceuticals** —Exhibit Hall Breakfast; **The Phoenix Magazine**—Appearance by Dr. David E. Beck; and **Nu-Hope Laboratories, Inc.**—Nu-Hope Fun Run/Walk on Friday morning. Our support group was one of the Hospitality Room Sponsors. (St. Louis sponsored the last day to welcome them to our city next conference!)

The exhibit hall was very good and it included many companies that manufacture ostomy accessory items.

Another featured event was the return of COCO the Colossal Colon. This exhibit, 40 feet in length that while crawling through it allows you to observe polyps, cancer of the rectum, diverticulitis, ulcerative colitis, Crohn’s Disease and hemorrhoids. COCO’s primary purpose is to promote colon cancer awareness. Along with COCO was the presence of “Captain Colon” whose celebrity identity will become known to all in a special national appearance in 4 to 5 months.

There were several meaningful tributes to Linda Aukett, who passed away in March, including dedication of the Conference in her memory. She and her husband Ken, were co-founders of the UOAA.

Another by Youth Rally Board Member, Jude Ebbinghaus, who made a quilt using some of the t-shirts that were designed each year for the Youth Rally along with t-shirts from other events and conferences Linda attended. Linda was a member of the Rally’s Executive Committee and a Rally counselor for 20 years.



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 2013

This year's Youth Rally was held in Seattle, Washington July 15-20th. See the full page with an overview. Here is what those who attended from St. Louis had to share.

I was a counselor again at Rally this year. It's always exciting to see the exciting faces of the campers every year, or see the shy campers become more confident at the end of the week. This year was Rally's first time going to Seattle, WA! Rally had a full week full of fun activities for the campers! As always day one is full of crazy, but fun. Campers coming in with smiling faces and even some shy. We visited the music museum, which was pretty awesome and interesting. Afterwards, rally gathered at a park and let the campers hang around and have fun. Our guest speaker this year was very interesting and inspirational. Get ready to sweat because it's fitness day! We teach the campers how important fitness is, especially with our bodies. Lights, camera, strut your stuff and action! The fashion show is always fun to see the awesome outfits of the campers and it's also the day of the talent show. Free time, dance and graduation is on the last day of camp which is always exciting but sad because we all know rally is coming to an end. All the girls and boys could get beautified in the beauty room. I always like seeing everyone dressed up and looking gorgeous. The seventh day was the saddest day because rally is over and I have to say goodbye to amazing people. Youth Rally is the best camp for kids with bowel or bladder issues. They get to experience things they might never do before or wanted to but didn't think they could. If you know anyone with a bowel or bladder issue, please send them to Rally, it'll be a life changing experience.

Thank you! -Courtney Mangin

Youth Rally is amazing!!! This was my fifth year at Rally, and it's my favorite week of the year. I love getting to see all the friends I've made in previous years, and getting to make new friends that I never would've met otherwise. Youth Rally is my favorite place because when you're at Rally, there are no secrets; you get to just be yourself, and it's the best feeling in the world!!!

I can't wait to go next year!!! ~Mikayla Hoffmann, 5th year camper
And more on the Youth Rally from a new counselor from St. Louis.....



My name is Chris Parsons and for 6 years I suffered from a very severe case of Crohn's Disease. I was diagnosed at age 14 and had no clue what it was. I accepted it and moved on and said "whatever." Over the next six years I went in and out of the hospital, usually a week at a time, connected to IV's and monitors. I started getting the feeling that "I was alone" and "no one understands." Felt like I could not talk to anyone about my problems because they just did not understand at all. April 20th 2012 I ended up in the hospital in severe pain and weighed 110 pounds. I was so sick I thought I wasn't going to make it through the night. Two days later on April 22nd I had emergency surgery and had my colon completely removed. The moment I woke from the surgery was the start of a new battle. I felt so different from anyone else than any other point in my lifetime.

I heard about this camp called the Youth Rally shortly I got out of the hospital through the local UOA Saint Louis Chapter. I spent my first summer after my surgery recovering and getting my weight back (now weigh 165 pounds). While at college my mom was calling me saying, "Honey, you should really attend this camp!" I agreed to go and had no clue what to expect.

As my parents are dropping me off at the airport I said to myself, "Gosh... I'm going to poop camp!" As I got on the plane I met someone who was also going to the Rally and realized how "simple" I was and how "complicated" she was. I thought I was complicated for 6 years! As I arrived at the Rally I started getting a good education of what other things people had, most of them being things I had never heard before including bladder exstrophy, cloacal exstrophy, spina bifida, etc. More importantly I realized just how much I have needed a camp like Rally. I think I needed the camp more than it needed it me. I had people to talk to and they understood every bit of it. They understood the pain, tears, needles, and hospital visits. I finally had the feeling of "I'm not alone." I had a new family that have been through things just like me.

I love helping kids with issues like mine and steering them in the right directions on how to cope with certain things. I hope no child ever has to grow up feeling that they are alone. Youth Rally was the opportunity of a lifetime for me. Now that I have gone and experienced the Youth Rally, I will be attending that camp until the day I die.

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
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PLEASE CONSULT YOUR DOCTOR OR WOCN (ET) FOR
THE ADVICE THAT IS BEST FOR YOU.**



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“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.

SEND CHECK TO: Hank Thill, Treasurer U.O.A.S.L.
 970 Imperial Point
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Local website is [www.uoaa-stl.org](http://www.uoaa-stl.org)  
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A truly happy person is one who
can enjoy the scenery on a detour.
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LIVE AND LEARN – Fall 2013



Officers and Board of Directors

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