

LIVE AND LEARN

Winter 2005

President's Message

Hello members and friends,

This Live and Learn will be an informative issue. We will tell you about upcoming local events and new programs for the coming year. Make sure you check the dates of the meetings. Some had to be changed from the first Monday of the month due to conflicting events. Thanks to Betsy Naeger, program director, for all of her hard work.

We had another great holiday party this past December, and I hope that you and your families had a joyous holiday season. Thank you to all board of directors and members for their assistance with this special evening, and all the great donated prizes. Thank you Convatec, Coloplast, and Hollister Corp. again this year for your sponsorship of this event. Without these sponsors, we could not have such a wonderful holiday event. A big thank you goes out to Hank Thill, Treasurer, for his great piano playing. Thank you to Kate Lobstein and LeeAnn Barcus, from the Young Adult Network for their sincere contribution to the program, and to the Youth Rally camper, Trey, that gave us many reasons to continue to support this great program.

We are going to again this year sponsor campers for Youth Rally, have a product fair at St. John's in May with industry representatives attending, and a National Conference in Anaheim, CA.

The Live and Learn, edited by Mary Beth Akers and Bill Lawson, will give the details for these programs in the newsletter and reminders on your meeting notices that we send in the mail. If you have questions, please e-mail me at suerayjr@aol.com or call 636-926-2737.

I have been given a new opportunity from the national UOA. I have been asked to be the program chair for the 2005 conference. I will be responsible for obtaining speakers and working with the National Conference Co-chairs Linda and Ken Aukett. I am looking forward to this challenge and hope that many of you will come to California in August.

Since we don't meet in January, I am looking forward to our February 7th meeting, 7 PM at St. Luke's. **Susan Burns, President**

Direct Member Billing

The new Direct Member Billing method is now in effect. Chapter members whose membership expires February 28, 2005, will

receive an invoice from UOA in early January for \$17.50. Chapters will invoice for and collect the additional local dues.

I like what the Hartford Ostomy Association told its members:
“Direct Member Billing” Is:

- θ A new way of billing to allow UOA to manage the needs of over 400 chapters
- θ Two easy checks per year, one to UOA and one to the chapter
- θ Easily explained by chapter officers or UOA staff
- θ Going to make administration of local chapter dues and membership much easier

“Direct Member Billing” Is Not:

- θ Intended to cost you more money
- θ Meant to confuse you
- θ Nearly as confusing as Algebra
- θ Going to cause UOA or chapters to limit services provided --in fact services can be expanded since less time will be devoted to the old awkward administrative process

It should be noted that as a member of a local chapter you receive the benefit of the Chapter discount rate of \$17.50. If you are not a member at the local level, a national membership is \$25.00 for an Associate Membership.

The Board of Representatives of the St. Louis Chapter will be meeting January 17th, 6:30pm at St. Luke's Cafeteria Meeting Room to make final decisions on our local membership and dues process. All additional will be published in the next issue of the Live & Learn.

Yet Another Ostomate's Revelations

By Martha Weaver

Everyone who travels in foreign countries knows how being in strange situations and circumstances can throw some curves, and traveling in eastern Europe this October, I was caught completely off guard. Ten years ago we became well acquainted with the famous hole-in-the-ground toilets in Russia, but that was pre-ileostomy, and I was physically able to deal with them a little better.

This October, I was unaware we would encounter any bathrooms other than the ordinary, which sometimes were challenging enough! This particular day our tour group was traveling in Serbia by bus and stopped for a restroom break. As we were getting off the bus we were informed our accommodations would be the hole-in-the-floor variety.

As usual using the women's restrooms always involved standing in a long line. All the women started rolling their pants legs up which did help some, as it turned out. There were 5 stalls with doors, and all I had was a cone shaped paper container, which wasn't large enough. My pouch was very full, overflowed, and hit the hole and surrounding area with quite a splash. Needless to say, I needed a large plastic bag. I spent the next hour grumbling to myself and my husband, and wiping my shoes, ankles, and pants off with the few wet wipes I had. Thank heavens for them. I just spent the rest of the day hoping that I didn't have too strong an odor. So I now know to always include quart size zip lock plastic bags in my emergency supply kit.

As I was leaving and washing my hands, some of the ladies were complaining about the situation, and I couldn't resist! I said, "Try it with an ileostomy sometime," and walked out. I don't know whether they even knew what I was talking about, but I bet it made them curious.

My reason for having an ileostomy puts me in a class by myself. I was born with a hemangioma, or in laymen's terms, I had very enlarged veins in one leg, and they extended all the way up into the colon, which wasn't discovered until my first child was born during an emergency C-section. I've had at least 20+ surgeries starting at age 12, and they include stripping the veins, hemorrhoidectomies, partial and finally complete colon removal, temporary colostomies and ileostomies, radiation treatments, internal pouch for 3 years, and finally a permanent ileostomy, for which I am truly grateful.

I was buying the book "Yes, We Can" about traveling with an ostomy and the store clerk said she was probably going to have one of those someday as chronic Crohn's disease runs in her family. I told her an ileostomy is not something you set out to have but that there are much worse things!

(Article continues on this sheet....)

(Yet Another Ostomate's Revelations ...continued)

I've been

healthy, pain free, no more anemia, free to leave home anytime to travel

with my tolerant wonderful husband only because of my ileostomy! While it's inconvenient, unpleasant, and a nuisance at times, I was running out of options and I realize how fortunate I am.

United Ostomy Association's Annual Youth Rally University of Colorado in Boulder, Colorado. Saturday, July 9 through Wednesday, July 13, 2005.

For information, please call
Mary Beth Akers, UOASL, Youth Chair 314-522-8523.

UOASL MEETING SCHEDULE

SEE COMPLETE SCHEDULE ON SEPARATE SHEET

Rolla Satellite News

Several members will be attending the National Conference.

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

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

Publication Deadline: February 25, 2005

Send articles to: Mary Beth Akers
8 Harneywold, St. Louis, MO 63136
314/522-8523
marybethakers@excite.com

Visit the UOA Website: www.uoa.org

**For access to information on cancer 24 hours a day, call the
AMERICAN CANCER SOCIETY**

1-800-ACS-2345 or visit the web at www.cancer.org

Information from National's E-mail

(To receive their email, register online at uoa.org)

We're Goin' to Disneyland!

Plan your summer vacation around the **2005 UOA National Conference**

in Anaheim, CA, August 3–6. The special \$99 conference rate at the Marriott Hotel will be hard to beat in the Disneyland area, so pack up the kids and grandkids next summer to join “the conference with a sunny attitude.” Register online at: http://www.uoa.org/events_conference.htm.

Ride the Hudson River Valley in June

On June 10–12, join an impressive group of novice and dedicated cyclists to raise awareness and funds for the fight against IBD. **Get Your Guts in Gear—The Ride for Crohn’s & Colitis** is a 3-day, 210-mile cycling fund raiser that will again benefit UOA, the Crohn’s & Colitis Foundation of America and the IBD Quilt Project. We are looking for riders, volunteers, crew and donations. Nearly two dozen riders from 11 states—including Hawaii—have already registered. For more information and registration forms visit www.ibdride.org or call 646-536-7408.

Hank Thill tickling the ivories at the Holiday Party

Santa Claus spreading Christmas Joy and candy at the Holiday Party

**Sheila Kramer receiving her WOCN of the Year Award
from UOASL Board members**

Bill Lawson, Betsy Naeger, Susan Burns, Sheila Kramer, Linda Geurin,
Hank Thill, and Mary Beth Akers

Kate's Top 10 most memorable events of the Louisville conference

As shared at the Holiday Party by Kate Lobstein

On Friday night, the Young Adults ate at the Old Spaghetti Factory. I have never laughed so much in my entire life. The waiter spilled water on Mike and his food. Julielyn laughed so hard she choked on her fettuccini. Mike build a tower of empty spumoni dishes, and had to walk around with ice cream spots on his shirt after it fell on him. For some reason, I was crawling around under the table. I think they should change our UOA network name from the "Young Adults Network" to the "Overgrown Children Network".

While eating at a food court down the street, some random woman I'd never seen before came up to Derek and offered him a half-eaten plate of food, then offered her dessert to me. I refused... I thought she was some crazy homeless person. When she left, I turned to Derek and said "I can't believe you're actually going to eat that!" Turns out she was Derek's mom.

Since we were in the hometown of the Louisville Slugger, we decided to play some baseball. Unfortunately, all we had was a miniature souvenir Louisville Slugger and a foam baseball from Coloplast. This didn't work too well and the ball didn't get hit very much. We did, however, manage to accidentally hit a sleeping homeless man with a Frisbee. Oops.

We asked the hotel desk clerk where we could find a dance club that was for ages 18+ instead of 21+, so we could all get in. We walked (in my estimation) about 20 miles around Louisville in the dark, only to get to the address and find out that the club had closed six months before and was now a gay bar. Oh wait, that's still not funny.

The hotel's fire alarm went off and we all had to leave the hotel... Julielyn, Ami, Alan and I walked a few blocks from the hotel to go to Starbuck's. And got lost trying to go back.

Around 3 AM one night, I said I absolutely had to go to bed, I was so tired. Zack was sitting next to the door and he yelled, "No, not yet!" and to keep me from leaving, he grabbed my shirt.... and accidentally grabbed the top of my bag. I fell to the floor screaming, "I've been violated!"... and laughing hysterically. After that incident, we labeled Zack a serial bag grabber, made him join the national registry of bag grabbing offenders, and my bag filed a restraining order against him.

Some idiot (I think it was me) suggested going swimming. It was 72 degrees out and "swimming" lasted about 20 minutes before we all ran back to our rooms to take hot showers.

(Cont...)

(KATE'S TOP 10 continued)

Unfortunately for Derek, 20 minutes was more than enough time for him to jump in the pool with his cell phone in his pocket.

I performed ostomy surgery on a horse. That is, I stuck a bag on the side of the horse statue outside the hotel and we had our picture taken by it. Unfortunately, my mother was convinced we'd be arrested for vandalism and made me take it off. I can't wait till next year's conference... if we can find a statue of Mickey Mouse, he's definitely getting it.

During the above mentioned incident, a woman walked by with two small children. We were laughing and pointing to the ostomy bag on the horse, expecting her to laugh too. She looked at us angrily and yelled, "You shouldn't do that in front of the children!" It took us a few minutes to realize that she wasn't with the conference... I wonder what she thought... whatever it was, it wasn't good.

We went on a horse and carriage ride on Wednesday night. The horses had these large canvas bags attached between them and the carriage, underneath their tails. One of the Young Adults, Anson, said to the man getting out of the carriage, "I bet I could outrun your horse." The man replied, "Well maybe, but I bet he can poop more than you!" We all started laughing... Anson smiled and said, "You don't know who you're talking to." The man in the carriage replied, "No really, look at this, he's got a whole bag full of poop!" Anson yelled back, "So do we!"

I have never laughed so hard in my life. Too bad the other guy didn't get the joke =)