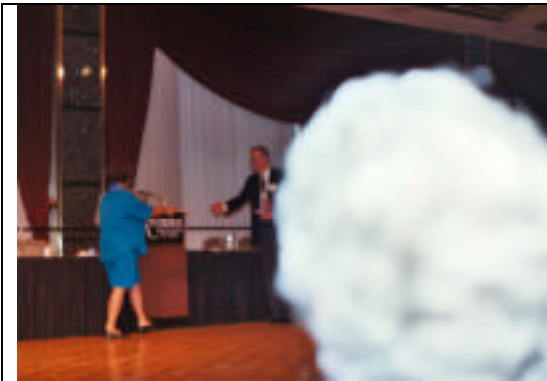




Opening Ceremony motivational speaker has fun.

Thank you for sending me to gather information at the UOA conference. It was very informative and I'll try to share some of what Doug and I learned with you. We went to separate sessions at times, in order to bring back more information. It was my pleasure to represent the BOA in accepting the Thank You Award from the UOA for the BOAs contribution. The Awards program has doubled in contributions this year and produced \$6,000 for the UOA. It was also nice that BOA had several of our own members in attendance and we were able to enjoy one another's company and get to know each other a little better. World Ostomy Day is in 2005. The following is information from the different sessions Doug and I attended. As always, remember to check with your doctor before you try anything new.



Accepting the Award for BOA



### **UOA GENERAL MEETING**

A few of the brand new and exciting features UOA have provided for us are: a new web page, new networks with the opportunity to have their own web page section, message board, chat room and electronic newsletter. A Parent Network, Teen Network which established Teen Mentoring, Young Adult Network, and Continent Diversion Network (separated into two groups, bowel diversions and continent urostomies). There is a wealth of information on the UOA's Web site. A new membership program has been developed, Multiple membership. It involves growth of UOAs networks and association memberships and finally moving these members to local chapters. A person can join into

either a chapter or a network and then they are offered free membership into any other entity in the organization. The best way to do this is electronically. It is supposed to increase membership at the national and local levels.

Several issues were brought up in the general meeting. The BIG issue of this year's conference was the concern that we need to have the younger ostomates more involved. The focus was on having them attend and be part of meetings at local chapters and at the national level. Once they attend chapter meetings, sub-groups can be formed. It is up to the chapters to ask for their input and see what items of interest we can share with them. A large part of what the younger ostomates are doing is going on-line and networking. Many of you remember that's what helped keep Katie going while she was in the hospital all those months. It was stated that 'if you don't do things differently you won't be in business in ten years.' We also have to pay attention to why we lose our lapsed members. On another note a good point was brought up by the president, "Always find your replacement," he said. You may move or have to relinquish your duties as an officer suddenly. Keeping others involved will make an easier transition for the club to continue. Also a little bookkeeping note is that you have to be sure you are in compliance with the IRS by filing a timely tax report even if you don't have to pay taxes. The message boards on the UOA Web site are highly used. You can order publications, make donations, etc. There are Spanish translations. A new visitors training video has been produced and two help guides. One copy has been sent to each chapter with a participants book. More may be ordered.



Katie at the Closing Ceremony

Organization information: **GLO** - The UOA Web site will be sectioned into zones for the USA. Inquiries will come into the web then be directed to GLO. The members thanked UOA for all their support and encouragement. **Continent Diversion** -Web site is linked through the UOA. They are trying to increase their membership. **2006 UOA Conference** -a vote was passed to have the 2006 conference held in Toronto, Canada. It will be a joint venture with the US and Canada. **Field Service** - the UOA has a group that will communicate with local chapters. If needed/asked they will come and visit. This new service is for a variety of reasons, including providing resources, low attendance, chapter development, chapter advocates, fund raising, attracting younger ostomates and much more.



Main Street Las Vegas



## MEDICARE

The advocacy group has increased reimbursement from Medicare, helped change California's outlook on optional services paid by Medicaid so supplies are still covered and their major win was to have United Health Care Ins. put **a)** a special rider to the employer for coverage of supplies, we don't know what the cost will be to the insured; **b)** employees for companies that don't choose to take the rider will be able to have a 30-40% discount on products. Hollister, Byram and Edgepark have signed on for the discount.

Ostomy supplies are considered Durable Medical Equipment and fall under the Durable Medical Equipment Regional Center (DMERC) of Medicare. Florida is Region C, it goes by where you reside for 6 months of the year. UOA advocates have fought for 70 different codes for supplies. You can get 20 pouches or 60 closed pouches per month, 4 irrigation sleeves and I forgot the number of extended wear pouches. Some of the twenty new codes are for larger size skin barriers w/ flange, waterproof tape, absorbent & high output pouches, different types of pastes and one-piece systems, skin barrier and flange and there are increased fees for new technology on items. On April of 2003 the fee schedule was changed. Payment of three-out-of-four items were increased 25-75%. Pectin based pastes went up 70%.

An interesting point was covered. Home care companies must supply the ostomy supplies even if they are coming to treat you for non-ostomy problems such as a broken leg. This is covered under the bundle payment. "**Perspective Payment System**" and UOA is fighting this. We may know if they won sometime soon. The reason this is not a good option is because the Home Health Agency does not have to supply you with the ostomy supplies you are currently using. This may cause discomfort, less wear time, leakage and other complications. The next item that is being addressed for us is **Competitive Bidding**, which may be in place by 2006. The different companies bid to cover Medicare products and one company wins the bid. All beneficiaries of Medicare would have to go to that vendor. This is not cost effective and may put the small vendors out-of business. It would not save Medicare much because of the lower numbers of ostomates. There would be no choice or competition of pricing. A letter has been prepared by the UOA to go to the Conference Committee to help change their minds to

vote against this. This letter may be found on the UOA Web site. The Advocacy web sticker on the Web site gives updates on Medicare.



A young ostomate becomes a ballerina.

### **ASK THE DOCTOR**

Information we learned: Obstructive benign prostate disease. A scope can be used to check the prostate. After the procedure you should be better in 4-6 months. An alpha-blocker medication may be used to improve the flow.

An A-tonic Bladder is a bladder without tone. Medications that make the bladder squeeze or an implant to stimulate the bladder to contract can be used. It's still best to catheterize the bladder.

Some Cancer detection tests are: for colorectal get a CEA blood test, for prostate a PSA blood test. Do a CT Scan first then a PET Scan to look for smaller pieces of cancer. Follow-up with a colonoscopy one year after surgery..

It's hard to differentiate between Crohns disease and Ulcerated Colitis. There is a blood test that may help. Cleveland Clinic is doing a study on this.

Bladder cancer is mainly thought to be environmental not hereditary.

If you have a wound that won't heal after anal surgery you may need a muscle graft in conjunction with plastic surgery. You may need medication if it is due to Crohns. A new procedure to heal wounds is called a Vacuum Assisted Closure (VAC). This is presently used to close large leg and vascular ulcers. A foam sponge is inserted into the wound, a membrane dressing is put on, tubing is inserted through this then the machine (VAC) is turned on and suction begins to take fluid out of the wound so it will heal. There has been much success.

For adhesion sufferers there is a new product called Seprofilm. (I'm not sure of the spelling) It is a film that they wrap the intestines in and adhesions disappear in about 5 days.

Bizmet (peptobismal) for pouch odor - there is no health risk in taking it since they have taken aspirin out of it. Ask your doctor about other medications, Fossamax or Tums.

**DEHYDRATION** - *The Winter 2003 OQ carried a story on this subject.*

Symptoms of dehydration are increased heart rate and blood pressure, muscle cramps, irritability, sleepiness, dry/parched, nausea/vomiting, tissue change and finally comatose. The N&V are due to low fluid in the intestines, the tissue change shows by pinching your skin up and it goes back slowly, and dry/parched is due to dry mucous membranes. Your input and output should equal one another so the body can compensate by moving fluid in/out of cells. Vitamin K (Potassium) is what the inside of your cells consist of. You loose fluid by breathing, through skin, urine and stool. You loose .3 liters from the Ileum, .5 liters from the colon and 1 liter from urine. Caffeine and certain medications and diseases may change your output. A 150-160 lb. person should have 2 liters of fluid every day. Children need more fluid. Guidelines - drink fluid high in electrolytes and water. Bananas have 1 mg. Potassium per inch, tomato juice 100 mg potassium and sodium.

To prevent dehydration stay indoors if it is too hot, know what fluids you are taking in, watch what your output is and remember if you are on diuretics or have diarrhea your output will be greater. You can make your own electrolyte drink with orange juice, salt, and sodium bicarb. The higher your potassium level the more sodium comes out of the cells and the fluid goes with it.

The best treatment to avoid dehydration is to increase fluids with water and PowerAde's. The PowerAde's replenish your electrolytes. Use Imodium for loose output and don't eat a heavy meal if you are overheated. If you are too bad, go to the hospital and they will start IV fluids.



Opening Ceremony – Elvis and Dancers. These ladies are in the 70s and 80s!

**URINARY INFECTIONS**

Never take a urinary specimen from your pouch. It is contaminated. The doctor's office has to catheterize you through your ostomy. Surgilube should be used to lubricate the catheter instead of Vaseline. Bacteria grow in an alkaline environment and this atmosphere helps promote it. Only drink orange juice and grapefruit juice in small quantities because they are alkaline. Drink cranberry juice or lemonade. These are acidic which helps kill bad bacteria. Blueberries and vitamin C help keep bacteria away. There is a powdered vitamin C called Emergen-C that absorbs into your bloodstream faster.

Two types of internal urinary pouches are the Indian Pouch also called the Continent Diversion Pouch and the Neo Bladder which is a new bladder formed from a piece of the intestines and placed in the area your bladder came out of.

## **MEDICAL SELF CARE**

This is an approach used to assist you in making an informed decision. In today's world you or a loved one have to be your own advocate. Have your doctors' telephone number(s) with you at all times. This would include family, gastrointestinal, urology doctors as well as your surgeon. Also, your surgery information. Teach someone how to change your appliance. Keep a list of supplies and where you purchase them from, and when you last had the flu/pneumonia vaccine. In case of an emergency all your information is at hand for the new healthcare specialist to be able to help you more efficiently. Review your insurance policy to see if you can go for a second opinion.

In order to have better partnering with your doctor write your doctor a letter of what you want to discuss and what other doctors have said. Keep a copy for your records so you have a follow-up and can ask questions.

Good books to read are "*Self Care Advisor*" it explains symptoms and "*Well Informed*" by Work Care Group this discusses signs & symptoms and what you are at risk for. Also the American Cancer Society has books you may read. Another book is the *Rights Of A Cancer Patient* the UOA and American Cancer Society have these to distribute.

*TIP:* If you are in the hospital have your doctor put your appliance changes in your care plan. This allows the nurse to change the appliance more frequently. A fever melts down your flange.

If you have cramps, no output or liquid output you may have an obstruction. If you do have an intestinal obstruction you will first have a more fluid output to try to move the obstruction then you get less fluid. Ways to help move a minor obstruction are to first try and relax. If that doesn't work you can also try one or several of the following: drink white grape juice with one tablespoon of mineral oil in it, massage the area, get on your hands & knees and rock, try a warm bath, drink more fluids, walk for a little while then lie down and roll from side-to-side, bring your knees to your chest several times. If you can't get relief go to your doctor or the hospital.

There were two articles, part 1 and 2 about peri-stomal skin in the Spring/Summer 2003 OQ. Basically it said to resize yourself periodically. If you have a yeast infection it will be itchy with or without red pimples. Use an anti-fungal powder.

## **AGING**

A few tips are: Avocado are good for your heart and salmon is good for your prostate and heart. Drink 5-6 glasses of water a day. Smart water has no carbonation. Watch your salt intake as it retains water. There is an article on Power Foods in the Sept/Oct 2003 AARP.

If you are a vet you may be able to get free supplies.



BOA members at the Convatec Party

### **THINGS THAT GO BUMP IN THE GUT**

This sessions information was regarding problems with ostomies. Infections, allergic reactions, stoma ulceration's, skin breakdown, leakage causes itching, burning, pain, and/or discomfort. Pouching difficulties, *Candida* (yeast infection) prevention- keep your skin clean dry, use statin powder or kenologg powder, it appears as a bumpy, reddish rash with white on top. *Pressure necrosis* (death of tissue) is caused by the belt or pouch being too tight or the convexity too deep. *Obstruction*-lack of output, cramps, abdominal distention, nausea & vomiting, abdominal pain. *Food blockage*-high fiber foods get blocked behind the stoma (raw fruits and vegetables). Remember to chew, chew, chew. There is a new laporoscopic surgery technique. It lowers the rate of post surgery blockages and there are new medications for pain instead of narcotics to jump start the intestines. *Stoma stenosis* is caused by poor blood flow to the stoma area. *Peri-Stomal Hernia*- if it isn't causing a problem then do nothing. If you have pouching problems or pain you should consult your doctor about getting it fixed. After surgery you are at an increased risk of the hernia coming back. To help with a hernia, use belts to reduce the outside pressure.

### **VITAMINS**

We can't process foods without special substances. Vitamins are a huge family that work together. Our food group should include protein, fats, carbohydrates, vitamins, minerals, and water. The RDA suggests a dose on the vitamin bottles but the therapeutic dose we need to take may be higher than the RDA requires. Fat soluble means that it is stored in fat, these are vitamins A, D, E, and K and they are stored in your body. Be careful because they may become toxic in larger doses. Water soluble means it lives with water and the excess is excreted. These are vitamins B and C. Increased vitamin E can cause impaired vitamin K (potassium) and blood clotting. Vitamin B12 also called the vitality vitamin increases your energy. Symptoms of a vitamin B12 deficiency are fatigue, shortness of breath, pallor, rapid heart rate, loss of appetite, diarrhea, tingling and numbness of the fingers, sore mouth/tongue, unsteady gate, personality changes and bleeding gums.



Fred Moore

### **FRIENDS OF OSTOMATES WORLDWIDE (FOW)**

Our very own Fred Moore is president of this organization which supplies ostomy supplies to third world countries. These people are in great need of supplies. FOW is an all-volunteer organization. The UOA Chicago North Suburban Chapter has supplied most of the volunteers that work in the warehouse since it has moved into the Chicago area. They gather the donated supplies and get them ready for shipment. Shipments went to Zambia, Uzbekistan, Latvia and Jamaica. The next shipments will be going to St. Lucia, Russia and Bolivia. FOW rely on grants and donations to exist. You can become a member of FOW for \$45 per individual or \$60 for a family. If you have supplies or would like to make a donation please contact Fred Moore at 954-484-0794.

Doug and I also went to see the vendors and I am happy to say that our chapter is quite up-to-date. Bev brings in speakers that keep us well informed. The new supplies shown at the show we had already heard about at BOA. We did learn a few new things. Cook and VPI are merging in November 2003 and will have an ET on staff. CyMed has products that use MicroSkin. It is a fiber not an adhesive but sticks until you pull it at an angle. It was impressive. Well, thanks again and I hope you enjoyed these sessions as much as we did.

Respectfully Submitted By