

UOASL 2007 MEETING SCHEDULE

- June 22 *Relay for Life St. Louis Comm. College - Meramec*
July 5-12 *Youth Rally in Boulder, Colorado*
July 9 St. Luke's **2:00 PM** – Inst of Health Ed. Auditorium
Sharing “Summertime Blues”
Aug 6 St. Luke's **7:00PM** - Inst of Health Ed, Rm. 4&5
Aug 16-18 UOAA Conference in Chicago, Illinois
Sept 10 St. Luke's **2:00 PM** – Inst of Health Ed. Auditorium
“Stump the Ostomy Nurse”
Oct 1 **Christian Hospital NE 7:00PM** – Dietrick Building
Nov 5 St. Luke's **2:00 PM** – Inst of Health Ed. Auditorium
Dec 13 St. Luke's **6:30PM** Inst of Health, Atrium
Holiday Dinner and Meeting

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

Publication Deadline: August 25, 2007

Send articles to: Mary Beth Akers
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St. Charles, MO 63303
636/916-3201
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Rolla Satellite News

For meeting dates, times, and place, contact:
Retta Sutterfield RN CNS CWOCN
Phelps County Regional Medical Center
Rolla, MO 65401



LIVE AND LEARN

Summer 2007

President's Message

Hello St. Louis UOAA Chapter members and friends,

We had another great product fair held at St. John's Medical Center in May hosted by Sheila Kramer, RN, WOCN. I would like to thank the board of directors and all the volunteers that helped make our night a great success. Thank you to our exhibitors: Hollister, Convatec, Coloplast, Salk, Medical West Medical Supply, St. Louis Medical Supply, Nu Hope Ostomy Supply, OstoFresh, WOC Nurse Association, Crohn's and Colitis Foundation of America, and The American Cancer Society. Convatec sponsored the refreshments for the evening. This was a good opportunity to talk with industry representatives and wound ostomy continence nurses.

We have the upcoming National conference in Chicago area in August, check out the **The Phoenix** magazine, the national publication, for details. Let's get as many St. Louis members to attend this exciting & educational conference. LeeAnn Barcus, a national director, attended the Board of Directors meeting recently and she tells us that this will be an inspiring and fulfilled conference.

We are always looking for great articles for our Live and Learn, so if you have an experience that you would like to share, write it down and let Mary Beth or Bill get it published in our newsletter.

The American Cancer Society Relay for Life for our chapter is June 22, a Friday, so please support our "Gutsy Folks" Team with your contribution and or your participation. The ACS is our partner, and we are so fortunate that they send out our reminder post cards for our meetings as well as print and mail this newsletter.

We are also asking you for your opinions for speaker or programs that you would like to see at our monthly meetings, please share your thoughts with us.

I hope that you all have a fun, safe and healthy summer.

Susan Burns, President of UOAASL

UOAA UPDATE IN BRIEF

Fall 2007 Election

In the election we will have later this year, there are three candidates for Director who are vying for two seats on the Management Board of Directors. The candidates elected will serve for a two-year term commencing January 1, 2008 and expiring December 31, 2009. There are four Directors on the UOAA MBoD, each serving a two-year term. Their terms are staggered so we will be electing two Directors every year. Directors can be re-elected once. This year's candidates are LeeAnn Barcus, Michael Guss and Steve Strizic. Both LeeAnn and Steve are presently on the MBoD and are seeking re-election. Ginnie Kasten will continue to Chair the Nominations and Elections Committee.

GYGIG: "Get Your Guts in Gear" is a 3 day bike ride that benefits individuals with IBD. The UOAA is a beneficiary of these rides and in 2006 we received a check for \$47,000. Each rider has to come up with \$1900. In June the UOAA is being represented by 5 ostomates and their family members at the NY ride. In August there will be another ride in the Pacific Northwest and if you'd like to sponsor those riders you can go to www.ibdride.org and click on donate. To find out who, log onto www.uoaa.org.

Distribution of UOA Assets

As part of UOA's "Going Out Of Business" process the Superior Court of New York (the State in which UOA is incorporated) and the IRS required UOA to distribute its remaining financial assets to not-for-profit organizations that have 501(c)(3) Charity Status. The UOA Board of Directors determined that the following

organizations would participate in this asset distribution: The Youth Rally Committee, Inc; The Pull-Thru Network, FOW-USA, Get Your Guts In Gear, Inc., and Goldie's Fund, in addition to UOAA.

UOAA's portion amounted to a check for \$ 130,000, and a note for a building formerly owned by UOA at 2001 W. Beverly Boulevard, Los Angeles valued at \$ 306,000. I am pleased to advise that this note was paid off and a check received in the full amount during the 3rd week in April. As a result of this action by UOA, UOAA is in a solid financial position.

Affiliated Support Groups –The number of support groups that have affiliated with UOAA now totals 239. To see a complete list go to <http://www.uoaa.org/supportgroups.shtml>

IN CONCLUSION ... What a wonderful time of the year Spring is ... when I started writing this UPDATE the flowering bulbs were in bloom ... then it snowed and almost froze them ... high winds tried to knock them over and a Nor'easter nearly drowned them ... yet today when I looked in the garden there was a sea of purple violets! My back yard is like our life experiences ... things are good for a while, then old Mr. Fate tosses a few curve balls in our direction ... but we hang in there and sure enough, our world gets its act together and all is right again! See you in August!!

With warmest wishes,

Ken Aukett, President, UOAA

For more information about any of these topics you can call the UOAA office at 800.826.0826.

Inaugural UOAA National Conference – Thursday, August 16th through Saturday, August 18th, 2007

**Lincolnshire, Illinois!! More info at uoaa.org
(Lincolnshire is a northern suburb of Chicago.)**

Thank You, Volunteers

UOAA UPDATE 4/07

Take this quiz:

1. Name the 5 wealthiest people in the world.
2. Name the last 5 Heisman trophy (that's for football) winners.
3. Name the last 5 winners of the Miss America contest.
4. Name the last 5 Academy Award winners for best actor and best actress.
5. Name the last 5 World Series and Super Bowl winners.
6. Name the last 5 Nobel Prize winners.

How did you do?

The point is that none of us remember the headliners of yesterday!

The above are certainly no second-rate achievers.

They have been the best in their fields. But the applause dies.

Awards tarnish. Achievements are forgotten.

Accolades and certificates are buried with their owners.

Here is another quiz. See how you do on this one:

1. Name the person who was your ostomy visitor before and/or after your surgery.
2. Name the person who helped you through a difficult adjustment period following your surgery.
3. Name the person that encouraged you to attend your first ostomy meeting.
4. Name the ostomy speaker that seemed to have a message "just for you."
5. Name the person that gave you some helpful ostomy hints.
6. Name the person that smiled at you and said, "See you at the next ostomy meeting!"

Easier?

The point of all this: The people who really make a difference in your life aren't the ones with the most money, prestige, or fame.

They are the ones who have shown that they care!

SWIMMING WITH AN OSTOMY

Via: Chicago North Suburban Chapter and Re-Route

Ostomates swim. We put together a few little items we have gathered to help make you feel more secure. First, allow some time after changing a barrier before swimming so that the seal is secure. Overnight is best, but even taking that extra minute to let the barrier seal should be fine. The newer barriers actually melt to obtain adherence. You have to make sure this chemical action has taken place. To be extra secure, it may be best to picture frame the barrier with a waterproof tape. There is a "pink tape" available through most suppliers that works well to assure the appliance stays on your body. Hollister's new skin like tapes as well as other similar types may be made more waterproof by covering them with a skin prep after they are in place. Cloth belts stretch in water. If you wear a belt, it may be preferred to substitute a rubber one while you are swimming. Swimsuits, with busy patterns camouflage the appliance better than solid colored suits. Skirts, bows, sashes, ties, drapes on a swimsuit may also help camouflage the appliance. Boxer-style trunks work well for men. A tight garment under your swimsuit can help hold the appliance in place. Depending on how active you are and the level of comfort you desire some of the following are good suggestions: A lightweight two-way stretch panty girdle; the top part of old panty hose; biking shorts; or sewing a pocket in the lining of your swimsuit to support the pouch. These are unisex ideas. Men can also try a pair of jockey shorts for similar support. Mini, non-drainable pouches are an alternative to people who use two-piece systems. They may be more comfortable and have a lower profile under swimsuits than your usual pouch. Avoid pouches with built-in filters for swimming. Water can get in and make a real mess. Try and plan ahead for swimming. Even non-ostomates should wait two hours after eating before going swimming. Try to roughly calculate your transit time, how long it takes food to get from mouth to pouch, and eat your meals at a time that will allow you to have the least amount of output when you plan to swim. For most people, the first few hours after getting up in the morning will be the time of least output.

The conclusion to all of this, the main reason for writing this article, is so that you go swimming. An ostomy does not stop you, or even slow you down from swimming and enjoying all the different type of water activities like hot tubs, beaches, pools, scuba diving, snorkeling, diving, swimming, etc. Enjoy it...you have been given a new life.

ILEOSTOMY RETRACTION

by Gail Wilhite, RN, ET, from Metro Maryland,

Via: Ocala FL & S. Brevard FL Ostomy Newsletter and Re-Route

An ileostomy stoma should be at least 3/4" in length and some surgeons advocate a longer length of 1" to 1 1/2 ". A spout-like stoma is necessary to deposit the effluent into the bag preventing pooling of contents at the base of the stoma. Conversely, a stoma that is too long is subject to external trauma and injury. Weighing the consequences, it is preferred to have a stoma somewhat too long than one too short. There is a difference between the creation of colostomy and ileostomy stomas. Frequently, when fashioning a left-sided colostomy, the surgeon will create a flush stoma. The contents of the left colon are relatively inert and usually regulated with irrigation, therefore, little or no functional problems occur with a flush colostomy stoma. An ileostomy stoma is never constructed as a flush stoma; nevertheless, sometimes the stoma may retract for various reasons. The common cause of stomal retraction is post-op weight gain. Prior to their operations, most ileostomates have lost considerable weight. Following surgery, weight gain can be rapid, and, many times, excessive. What once was an adequate stoma, now retreats within the expanding environment! Another cause of retraction may be inadequate fixation of the opposing serosal layers following eversion. If these layers fail to adhere, healing and subsequent scarring may tend to draw the stoma into the abdomen. Problems resulting from retraction are decreasing adherence of the appliance and skin breakdown. The pooling of the excoriating intestinal contents cause the loosening of the adherent bond resulting in leakage of ileal effluent on the skin. This skin –effluent contact naturally produces breakdown. The combination of irritated, weeping peristomal skin and continual pooling leads to an unbearable situation, which must be remedied. The treatment for a slightly retracted stoma is the use of a convex faceplate. The convexity applies pressure on the skin surrounding the stoma, thus pushing the stoma up. When using a convex faceplate, it is important not to lose the convexity by applying thick washers or foam pads, etc. The skin and faceplate should suffice to maintain the advantages of both convexity and skin protection. If the use of a convex faceplate proves unsuccessful or if the retraction is severe, then surgery is advised to create a new, longer stoma.

THOUGHTS ON ODOR MANAGEMENT

by Rosemary Van Ingen, ET, Via: Northern Virginia, *The Pouch*

Isn't it interesting that people with normal intact bowel tracts and urinary systems manage odor problems in an acceptable manner in our society, but when disease or trauma strikes, and the person is the owner of an ostomy, the one big concern is the fear of offending society with an odor.

What's an ostomy? Basically an ostomy is a man-made exit site that changes the point of exit from the bottom or back of our body to the front. Our eyes and noses are obviously on the front of our body, which leads us to be more aware of our changed body image and our odor-producing products. I'm sure you've heard the statement, "You've come a long way, baby." Yes, ostomy management has come a long way—considering that as little as ten years ago, we had very few 100% odor-free pouching systems.

Ostomy Collecting Receptacles When ostomy surgery was first developed, ostomates wore anything to collect output. Tin cans, rubber gloves, cups of all shapes and sizes, bread wrappers, and plastic margarine cups just to mention a few, were standard equipment for the ostomate. Not only the feasibility, but the odor problems this type of equipment produced, was enough to give ostomy surgery and people who had ostomies a very deplorable place in our society. Presently, almost all the ostomy pouching systems available to us today are made of odor-barrier materials.

Odor Detective Work Therefore, if an ostomate does have a fecal or urinary odor about them, some detective work should be done: Check out the application of the pouching system to the body. Is it leaking? Check out the closure of the pouching system—is it closed properly so that no fecal matter is oozing out after the closure? Do not put holes in the pouch as gas will seep out continuously.

Urostomy Odor Cautions The urostomate should rinse or wipe off the spout of the pouching system with a bathroom tissue after emptying. Those few drops left in the spout after closing the pouching system can cause a urine odor under clothing. It is interesting to note that most urostomy pouching systems on the market are odor-proof, but the connecting tubing and bedside and leg bag are not. You must dispose of and replace these products when they take on urinary odors, or else your entire living quarters will smell.

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Elimination in Ostomates vs Non-Ostomates Emptying an ostomy pouching system is comparable to a person with an intact bowel or urinary tract having a bowel movement or emptying their bladder. How does the non-ostomate handle the odor produced by the normal function of their body? Room deodorizing sprays are popular; a quick flush of the toilet when defecation occurs, and opening a window are some acceptable methods that have been used for odor management.

Why are Ostomates so uptight about elimination odors when our pouching systems are emptied? This constant complaint has encouraged ostomy supply manufacturers to create products to meet the need for odor control. Just remember, there is not a man or woman on this earth whose wastes do not smell. If someone tells you that their waste products are odorless, then a nose overhaul is in order for them!

HOT OR COLD COMFORT

Via: Southern Maryland Counties Chapter, Clinton, MD and Re-Route

It's all in knowing which one you need. A hot water bottle is the purpose of life, a physical therapist says, unless you need an ice treatment instead. In general, active people find more relief with ice and less active people find more relief with heat. Always put a cloth between your skin and water bottle or ice pack.

USE HOT FOR: tense, tired shoulders; back of the neck during a headache; chronic low back pain; kink in the neck; joints stiff in the morning with osteoarthritis, to improve circulation.

USE COLD FOR: inflammation indicated by warmth, swelling, pain and/or redness; injury to joint or muscle, especially during the first three days of recovery; forehead during a headache; joints swollen with osteoarthritis. For an ordinary headache, use either hot or cold wherever it helps.

RELAY FOR LIFE UPDATE

This year's relay will be held June 22nd at St. Louis Community College – Meramec. It goes from 7 pm to 7 am on the 23rd. If you would like to join our team of "Gutsy Folks" give Bill Lawson a call at 636-256-7703 or email bill-jaci@sbcglobal.net

UROSTOMATES & FLUIDS

By: Juliana Eldridge, RNET Via: The Green Bay Ostomy News Review

People with urinary diversions no longer have a storage area, a bladder, for urine. Therefore urine should flow from the stoma as fast as the kidneys can make it. In fact, if your urinary stoma has no drainage for even an hour, it is time for serious concern. The distance from the stoma to the kidney is markedly reduced after urinary diversion surgery. Any external bacteria have a short route to the kidneys. Since kidney infection can occur rapidly and be devastating, prevention is essential. Wearing clean appliances and frequent emptying are vital. Equally important is adequate fluid intake, particularly fluids which acidify the urine and decrease problems of odor. In warm weather, with increased activity, or with a fever, fluids should be increased to make up for body losses due to perspiration and increased metabolism. It is important that you be aware of the symptoms of a kidney infection:

- * Elevated temperature
- * Chills
- * Low back pain
- * Cloudy, bloody urine
- * Decreased urine output

All ileal conduits normally produce mucus threads in the urine which give it a cloudy appearance. Bloody urine is a danger signal. Thirst is a great index of fluid needs. If you are thirsty, drink up. Also develop the habit of sampling every time you pass a drinking fountain. Important...if urine is collected for urinalysis, called C&S, sterile specimen, checking urine for infection; etc., be sure your doctor and nurse know a sterile specimen must be taken directly from your stoma and not from the pouch. Bacteria builds up in the pouch immediately. It will give false test results. If they are not sure how to do this, do the following:

- * Remove your pouch
- * Clean the stoma
- * Bend over
- * Catch the urine in a sterile cup

If there is a slow flow of urine being expelled, drink a glass or two of water...the kidneys will work. Urostomates who do not use a night drain are running a big risk of puddling and the backing up of urine into the conduit up to the kidneys. This may cause not only irritation but serious infection.

FOR COLOSTOMATES

Via: Rose City Ostomy News and Re-Route

- ❖ If you use a Stomahesive wafer and cut your own center hole, save the leftover pieces and use them to fill any skin indentions around the stoma underneath the wafer. Apply the pouch standing, lying or sitting down, but do not allow abdominal wrinkling or this will break the seal when you straighten out.
- ❖ Colostomy diet is fairly normal. You will discover which foods may not agree with you by trying everything, a little at a time, wait a few weeks and try it again. If it doesn't work then, leave it alone for a few months, or forever if necessary.
- ❖ If you have difficulty with constipation, glasses of apple juice every morning and the night before irrigation may prove helpful. If you prefer, you might try taking your apple juice heated (add a little cinnamon.)
- ❖ Colostomates who take antihistamines during the sneezing season may find that certain drugs have a tendency to slow down intestinal action and the irrigation process becomes slower. Some report relief from the drug reaction by increasing the fluid intake the day they irrigate, or eating laxative foods (in moderation.)
- ❖ If you are irrigating and having problems with leakage between irrigations, try using less water. Too much water contributes to leakage.
- ❖ If you are a colostomate who uses a convex insert in your faceplate, and the insert becomes gunky or sticky, try good old Uni-solve to remove the gunk. It really works great!!!
- ❖ Especially in hot weather, wear protection between the pouch and your skin to prevent rash from perspiration. You can make a pouch cover with an old handkerchief, a baby's bib, etc. Pouch covers can be purchased also.
- ❖ If you are taking a bismuth preparation, try to stop taking it for one day before having an intestinal x-ray or tell the doctor, because it sometimes shows up opaque on an x-ray.

Thank You So Much!

A big word of **THANKS** goes to Hollister for sponsoring the printing of our updated Youth Rally Brochure. Thanks also to Convatec for sponsoring the refreshments at the Product Fair. Thanks for all you do for our chapter!!

Thanks to Dr. Angela Grupas, our motivational speaker,
and all who attended.

Unanswered Questions

Via UOAA Update

1. Ever wonder about those people who spend \$2.00 apiece on these little bottles of Evian water? Try spelling Evian backwards: NAÏVE
2. If 4 out of every 5 people suffer from diarrhea...does that mean that one enjoys it?
3. If people from Poland are called Poles, then why aren't people from Holland called Holes?
4. Do infants enjoy infancy as much as adults enjoy adultery?
5. If a pig loses its voice, is it disgruntled?
6. If Fed Ex and UPS were to merge would they call it Fed UP?
7. With income tax time so fresh in our memories, did you ever notice: When you put the two words "The" and "IRS" together, it spells "**THEIRS**".

Product Fair Recap

Congratulations to the winners of the Okawville Mineral Springs B&B package. The Grand Prize winner was R. Schumann.

Because last year's winner was unable to use it, they donated it back to be awarded to a second winner, Arpad de Kallos. Also given away were a number of attendance prizes, several \$50 gift certificates as well as prizes donated by exhibitors.

YOUNG ADULTS

Looking for ostomates 21-40ish to get together and share fellowship. Please email LeeAnn Barcus and let her know if you have an idea for an outing or would like more information. leeann@uoaa.org

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.

Youth Rally! July 7 - 11, 2007 University of Boulder, Colorado

We will have four counselors and 2-3 campers representing our area. Help us find more campers for next year. Start now. Mary Beth Akers and friends can present info to any interested individuals or groups.

Please share this information about this unique opportunity with any youth who has had bowel or bladder surgery or who have a condition which could lead to an ostomy. St. Louis Chapter UOAA pays first year scholarships (Tuition and Air fare 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. They can also log on to www.rally4youth.org

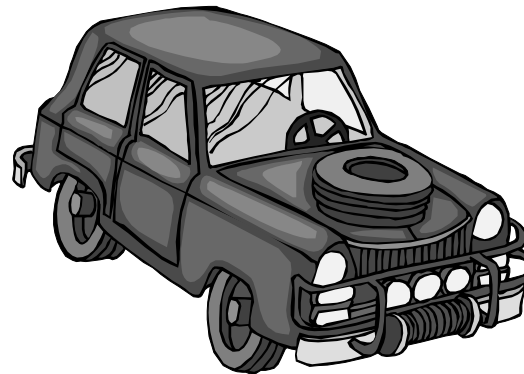
Charitable Search Engine

There is a new search engine that gives back to a charitable organization of your choice. If you use goodsearch as a search engine instead of google, a penny for each thing you search will go to the UOAA if you choose that as your organization. Please think about doing this, as it will and does add up. It is a way to donate free money to a great cause. I have been using it for a few days and it is as good as google. <http://www.goodsearch.com/> Thanks, LeeAnn

Phoenix Renewals - Don't forget to renew your subscription to *The Phoenix*. Remember that ½ of your subscription cost helps to fund the activities of the UOAA and it's tax deductible.

If My Body Were a Car

Via the Ostomy Outlook,
Oklahoma & The New
Outlook, Chicago



If my body were a car, I would be thinking this time about trading it in for a newer model. I have bumps, dents and scratches in my finish and my paint job is getting dull, but that is

not the worst of it. My headlights are out of focus and it is especially hard to see things up close. My traction is not as graceful as it once was. I slip, slide, skid and bump into things even in the best of weather. My whitewalls are stained with varicose veins. It takes me hours to reach my maximum speed. My fuel rate burns inefficiently. But here is the worst; almost every time I sneeze, cough or sputter either my radiator leaks or my exhaust backfires.

ICE

UOAA UPDATE 4/07

Recently, the concept of **ICE** is catching on. It's a simple, important method of contact during emergency situations. Since cell phones are carried by most people, all you need to do is store the number of a contact person or the person that should be contacted during an emergency as "**ICE**" - meaning **In Case of Emergency**.

The idea was thought up by a paramedic who found that when they went to the scenes of accidents, there were always cell phones but the responders didn't know which number to call. He thought that it would be a good idea if there was a nationally recognized name for this purpose.

Following a disaster in London, the East Anglican Ambulance Service has launched a national **In Case of Emergency** campaign. In an emergency situation First Responders and hospital staff would then be able to quickly contact your next of kin by simply dialing the number stored as **ICE**. For more than one contact name simply enter **ICE I**, **ICE II**, etc. This is a great idea that will make a difference!

Let's spread the concept of **ICE** by storing an **ICE** number in our cell phones!

HILLBILLY MEDICAL TERMS

Benign: What you are after you be eight.

D&C: Where Washington is.

Enema: Not a friend.

G.I. Series: World Series of military baseball.

Pap Smear: A fatherhood test.

Urine: Opposite of mine.

Impotent: Distinguished, well known.

Labor Pain: Getting hurt at work.

DOCTORS DO THE PRESCRIBING, BUT IT'S UP TO YOU TO TAKE CHARGE

Via: Green Bay Area Ostomy Newsletter

Be curious – Know what your condition is and how the drug will help you.

Don't play doctor – Never tinker with the dosage on your own.

Share your life story – The doctor needs a complete picture of your health and habits.

Make friends with your pharmacist – You can never get too much information.

Plan a review session every 6 months – One in five Americans over 65 takes at least one inappropriate prescription drug.

One size doesn't fit all – The amount of medicine you may need may vary with age, weight, gender and ethnicity.

Send old drugs packing – Review your medicines at least once a year and get rid of oldies that are no longer goodies. (Don't flush them down the toilet as they get in the water supply.)

Timing is everything – Some side effects can be avoided by adjusting the timing – but ask your doctor before changing.

Request samples – Ask your doctor for free samples, particularly if you need only a one-time supply. Make sure that the doctor knows all the prescription and over-the-counter medication you are taking.

Be aware of interactions – Drug-Herb, Drug-Drug, Drug-Condition, or Drug-Food interactions are all potential problems.

UOAA Info

*The national website is www.uoaa.org
and the telephone number 1-800-826-0826.

*Our local website is www.uoaaastl.org

*The advocacy hotline is advocacy@uoaa.org