



UOAA UPDATES are our way of communicating what is happening within UOAA to you, our members - and hopefully to your members too . We hope you are including some of the news in your newsletters or are discussing it at your local support group meetings. People continue to ask, "What is UOAA doing for me?" and this is our way of answering this time-old question

We continue to look forward to working with you and to being an active resource to ensure your success.

SEPTEMBER 28, 2009

□ NEW ORLEANS CONFERENCE PICTURES

Our Conference theme, "Let the Good Times Roll" is clearly evident in photos that were taken at this year's event in New Orleans. You can check them out by visiting UOAA.smugmug.com

In addition, one popular event of the Conference was the Fashion Show, coordinated by LeeAnn Barcus. For pictures of this "revealing" event visit **Hollister's C3Life website**, www.c3life.com and click on "What's New", UOAA Conference Fashion Show photos.

□ NEW PUBLIC SERVICE ANNOUNCEMENT

UOAA entered into a contract for the production of a 5-minute UOAA/ostomy public awareness tape that will appear on Public TV, National Medical Report as shown on cable, network TV and internationally as part of Voice of America.

This excellent project, coordinated by Kristin Knipp, can now be viewed on the UOAA website at: <http://www.uoaa.org> click on the sentence that says: "See the [New UOAA PSA](#)" and you will be taken to it.

□ COPYING ARTICLES FROM THE PHOENIX

The Editor of **The Phoenix** magazine has asked me to remind you that articles that appear in the magazine are copyrighted and, therefore, cannot be reprinted in your local newsletters without the written consent of the Editor. This policy exists because it is expensive to produce the magazine. The only articles that are allowed to be reprinted are those pertaining to Advocacy and the President's Message. ASG leaders are asked to encourage their support group's members to subscribe to **The Phoenix** since half of the subscription fees are used by UOAA to fund its activities.

□ UNITED WAY CAMPAIGNS

Remember UOAA in the United Way's Fall Workplace Giving Campaigns

If you, your friends or relatives participate in the United Way campaign within the next few weeks, UOAA can receive "designated" donations from your local campaign **if you write us in**.

Here is how to designate UOAA:

Please write in the 501 (c) (3) organization that you would like to receive your gift

Name: United Ostomy Associations of America

Fed Tax ID#: 134310726

Address: P.O. Box 66

City/State/Zip: Fairview, TN 37062

Phone: 800-826-0826

Contact: Joan McGorry

□ SPAMMING

Recently many of our ASG contacts have received an e-mail in which the writer talks of her son, who has an ileostomy, and then proceeds to describe a product she is manufacturing, and directs you to a website where it can be purchased. She obtained your e-mail address from the "ASG Contact" list that appears on our website, but failed to ask UOAA for permission to do so. There is a statement at the beginning of the webpage that states that the unauthorized harvesting of contact addresses is contrary to UOAA policy and violates the laws associated with spamming. This woman has been contacted and told to stop these marketing activities. We know that some groups did not object to this commercial message, but many do.

□ COMING SOON!

Within the next week or so you will be receiving two (2) copies of UOAA's premier "**Living with an Ostomy**" DVD. This DVD, excellent for showing to prospective and new patients, clearly depicts the positive quality of life attainable after ostomy surgery.

□ TAX CREDIT FOR “CLUNKERS”

Do you have an unwanted car, motorcycle, truck or boat?? ... Then donate to UOAA through DonateForCharity, Inc.



You, your family and friends can now donate a vehicle to DonateForCharity and UOAA will receive a percentage of the funds. To learn about the program visit www.donateforcharity.com

To get the required forms call 1-866-392-4483 or go to:

<http://donateforcharity.com/jumpform.html?ID=United+Ostomy+Associations+of+America>

Once you receive the forms, provide the necessary information, sign them and mail them back to DonateForCharity. You will be notified when the vehicle will be picked up and asked to leave your keys in the vehicle on that day. Donations are accepted from any location in the U.S.

- An Ina Brudnick Award (given in memory of the pioneering stoma care nurse), a \$1,000 scholarship, given to a young adult who has an ostomy, Crohn's Disease or ulcerative colitis to assist in their plans to pursue a higher education;
- And, a Comeback Kids Award that recognizes a young person who is living an active, productive life while managing an ostomy or other bowel or bladder disorder.

If there is someone in your support group that has an inspiring story that merits national attention, please do not hesitate to talk with this person and start the nomination ball rolling. For more detailed information about the Great Comebacks Program, visit: www.greatcomebacks.com

□ BATHROOM ACCESS OR “ALLY’S LAWS”

We need your help!

If you have the December 2007 issue of *The Phoenix* magazine, you already know about Ally Bain and her campaign to open up restrooms across the country to people with IBD or an ostomy. And if not, please read it at: <http://www.phoenixuoaa.org/december2007.html>

As of 2009, Ally's Law has been passed in nine states and its passage is pending in at least 10 others.

It has been passed in: **Illinois** (2005); **Minnesota, Texas** (2007); **Kentucky, Tennessee, Colorado, Ohio, Michigan** (2008); and in **Washington, Oregon** (2009)

The states where the legislation is pending and the state representatives/state senators who have introduced the bill:

Delaware - HB3, HR18; Senator Bebout
Indiana - SB191; Senator Deig
Wyoming -SB73; Representative Booth
Massachusetts - HB2121, SB1315; Representative Kafka, Senator Morrissey
New Jersey -SB823; Senator Ciesla
New York - AB10058, SB6669; Representative Paulin, Senator Padavan
Pennsylvania - HB1955, SB829, SR310, HB2085; Representative Grucela, Senator Greenleaf, Representative Evans
Rhode Island - HB7126; Representative Fellela
South Carolina - HB4406; Representative Huggins
Wisconsin - AB859; Representative Van Roy

□



As one of the sponsors of **The Great Comebacks Program**, UOAA applauds the 2009 Regional Award recipients whose names will be listed in my October UPDATE. It is not too soon to start thinking about those persons who can be nominated for 2010 Awards. Awards will be made to people in four geographic Regions of the US (East, Central, South and West).

In each of these regions the following Awards will be presented:

- A Great Comeback Award to the most deserving person who shares their story that will provide hope and encouragement to others with similar medical conditions;

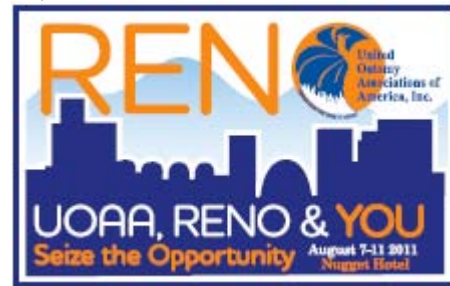
If this legislation is pending in your state, first make sure it includes a reference to ostomy and then **please write a letter or call your respective state senator and/or state representative and express the importance of the bill being passed into law.** Add as much of your personal experience as you feel comfortable doing -- maybe you have been denied access or have had to make some mad dashes because of a full pouch.

If there is no legislation pending in your state, please do what you can to get it introduced. The simple bill text as it was introduced in the Pennsylvania legislature can be seen at <http://tinyurl.com/mpalb6> .

One voice can really make a difference! We can create a culture of empowerment through a grass-roots effort.

We certainly appreciate Ally for all her inspiring work, as well as the updated information we obtained from the FaceBook group "Get Ally's Law Passed". If you are on Facebook you might want to join it at <http://tinyurl.com/klg4ld>

□ “UOAA, RENO AND YOU”



Monday, August 8 through Thursday August 11 are the dates for our next national gathering at the Nugget Hotel in exciting Reno, Nevada. The room rate will be **\$ 79.00 + tax**. Start thinking now about joining us for this stellar event. Be part of the 800+ attendees we anticipate!!!

□ DECADES OF EFFORT TO BEAT COLON CANCER

Colorectal cancer is the second leading cause of cancer deaths among men and women aged 50 and older in the United States. Screening has been found to be effective to detect cancers at a much earlier and more treatable stage. The campaign to make colon cancer screening available to the broadest range of Americans has taken a significant step forward, with the announcement by the Centers for Disease Control and Prevention that they have awarded \$22 million for colorectal cancer screening programs in 26 states and Native American tribal groups. The funding supports colorectal cancer screening for low-income, under- and uninsured men and women aged 50–64 years. Persons older than that are covered by Medicare. You can see more detailed information at <http://www.cdc.gov/cancer/crcccp/> .

UOAA, through its participation in the Digestive Disease National Coalition (DDNC) and the National Colon Cancer Roundtable (NCCRT), has been helping to work toward this goal for decades, beginning with the DDNC's lobbying for coverage of CRC screening by Medicare. It took 10 years of lobbying Congress to get that coverage, which went into effect in 1998.

Medicare coverage has resulted in decreasing incidence of full-blown colon and rectal cancer among the Medicare-age population - but sadly there are many other groups that are not covered. See the recent report from the American Cancer Society at this link:



The GYGIG Rides are held each year to raise funds for organizations, like UOAA that promote awareness about IBD and the ostomy surgery that these diseases often necessitate. Over the last three years UOAA has received funds totaling over \$ 150,000.

In the last 2009 Ride, that will leave from Libertyville, Illinois on October 2nd and circle through 210 miles of scenic farmlands in northern Illinois and southern Wisconsin, UOAA will be represented by: riders Dave Uri, Charlie Grotevant and Charlie's wife Joyce who will be part of the Crew Team.

To make a donation supporting their participation visit the GYGIG website www.IBDride.org You need to know that **Dave Uri's rider number is MW-19, Charlie's is MW-17 and Joyce's is MW-C11.**

http://www.nccrt.org/News/NewsDetail.aspx?article_id=1040 . And even among those covered by Medicare, some are still reluctant to have the screening, or have other barriers to getting it done.

We hope that your members whose lives have been touched by colon cancer are taking an active role in educating their close relatives, since many such cancers have a hereditary component, the extent of which we do not yet fully understand. To continue research into discovering things like that, as well as better tests and treatments, or funds for something like the CDC program announced here, we collaborate with the DDNC each spring at their Public Policy Forum. We get to talk with Congress-people and their staff about the need to continue to take action against colon cancer, whether it is passing legislation to require that insurance plans cover those aged 50-64 (still not accomplished), or funding for research, or similar programs.

UOAA also, as an organization, collaborates with other groups to raise the awareness of CRC screening: the Colon Cancer Alliance, the Colon Club, the Colon Cancer Coalition (C3) and so on.

This is a very long range goal with small successes - and occasionally big ones such as this. Please be aware that is it something we are always thinking about and working on, on behalf of UOAA, our members and their relatives. And please help us whenever you can to spread the word that with early screening, **colo-rectal cancer** is "**Preventable, Treatable, and Beatable**".

□ **PEORIA AREA ASG and CENTRAL ILLINOIS WOCN JOINT SPONSORED NURSING EDUCATION SEMINAR**

On **Tuesday, October 13th**, 2009 an "Ostomy 104: Managing those Ostomy Nightmares" seminar will be sponsored by UOAA's Peoria Ostomy Support Group and the WOC Nurses from Central Illinois. It will be held at the Proctor Hospital in Peoria. The fee is \$ 10. For which attendees will receive 2 CEUs.

Nu-Hope's Mickey Galindo, CWOCN, will be the featured speaker.

The target audience is RNs, LPNs, PCTs and Nursing Assistants who work in acute care, long term care, or homecare.

Contact Steve Vandevender for additional information at Steven.Vandevender@kci1.com

□ **NATIONAL FAMILY CAREGIVERS ASSOCIATION SURVEY**

Please pass this letter on to your members.

Dear Family Caregiver:

National Family Caregivers Association is partnering with Care.com, and [Care.com](http://www.care.com) needs your help!

We're asking you to take a few minutes to provide input into the **State of Care Index**—a survey that gauges the challenges families face when trying to find quality child care and special needs care.

We plan to use the survey results to help President Obama's White House Task Force on Working Families reach its goals of improving caregiving and work-life balance for families across the country.

You can join us to help improve care! By taking this anonymous survey, you'll provide invaluable feedback that can help shape the future of child and special needs care in America. Please either click on the link below, or copy and paste it into your web browser.

<http://resp.survey01.net/servlet/survey?surveyId=MTM4ODcS1&spEmailID=%Email%&spMetroAreaID=%MetroArea%&spSeekerSubscriptionPlanFee=%SeekerSubscriptionPlanFee%&spMemberId=%MemberId%&spType=%Type%>

Thank you in advance for your time and input on this important initiative.

The National Family Caregivers Association and The [Care.com](http://www.care.com) Team

PLEASE FORWARD THIS E-LETTER ALONG TO YOUR FAMILIES AND FRIENDS and ENCOURAGE ALL THE FAMILY CAREGIVERS YOU KNOW TO JOIN THE NFCA COMMUNITY OF CAREGIVERS. THERE IS NO COST! Just click here: <http://www.thefamilycaregiver.org/>

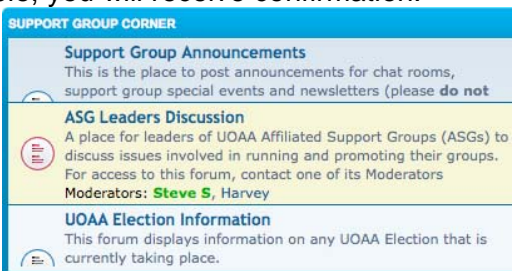
□ NEW TOOL FOR ASGs – A WEBSITE DISCUSSION FORUM SOLELY FOR ASG LEADERS

We have set up a discussion forum within the UOAA Discussion Board especially for leaders of our affiliated support group, so that you can talk about issues that pertain to managing your group. Suggest ideas for programs, share tips for making meetings more attractive, get some feedback about why things don't seem to be going so well, or simply vent ... all with people who are doing the same jobs in nearly 300 other groups across the country.

ASG leaders will become part of a special "users group" who can start a topic thread, add posts to on-going discussions and read what others have to say. There can be more than one ASG leader per group in the user-group, so we hope you will encourage both present and likely future leaders to join as well.

It's a 2-step process, and you can take **Step #1** step right now. Anyone wishing to participate needs to register as a user of the UOAA Discussion Board. Go to <http://www.uoaa.org/forum/ucp.php?mode=register>, read and accept the terms, and complete requested information on the next page (including two tests that we use to discourage spammers and automated 'bot' registrations). You will receive verification of your registration within a few hours (up to 24 in a busy period).

Once registered, log-in at <http://www.uoaa.org/forum/index.php> and look for a heading like the graphic at the top right that says SUPPORT GROUP CORNER. You will be able to see the ASG Leader Forum and read entries, but in order to post your own comments there you must take **Step # 2** to become part of the ASG Users group. Click on one of the Moderator names and send a Private Message or e-mail asking to be added. Once determined eligible, you will receive confirmation.



It might seem like a lot, but you do this just once to become part of the user-group - after that it's a

matter of logging on just as you would to any site you visit regularly. We hope you WILL visit regularly and make this a valuable resource for yourself and others to share thoughts about keeping our affiliated support groups vital and effective.

□ UOAA PATIENT RESOURCE MANUALS

Do you include UOAA's Patient Resource Manuals in your ASGs Visiting Program ... for visitors to give to new ostomy patients, or to be included in your Visitor Information Packets? To get a **FREE** supply of each of the four manuals (Colostomy, Ileostomy, Urostomy and Continent Diversion), call Joan at 800-826-0826.

□ IN CONCLUSION

Last week (September 20–26) the Clean Hands Coalition celebrated International Clean Hands Week and we want to share their message: **Hand washing is the single most important act you can do to prevent getting sick and making others sick.** Hand washing is important for food safety, infection and disease prevention, and personal health. Wash your hands before you eat and after you use the bathroom; before, during and after preparing food; after handling animals or animal waste; after playing sports; after changing diapers; and anytime your hands are dirty. Use soap and water, scrub, rinse for 20 seconds and dry.



With all of the "H1N1" warnings that we are hearing about from the national media ... that the "Flu Season" is here ... I urge you all to take every precaution and especially to get a flu-shot. I can tell you from firsthand experience that the dehydration that is often associated with the flu viruses can be quite severe and can even be life threatening. The old saying really applies ... an ounce of prevention is worth a pound of cure.

Do take care and stay well,

Ken Aukett