



These UOAA UPDATES are our way of communicating what is happening to you, our members. It is our hope that this information is being passed on to your members, either by including some of the news in your newsletters or by 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.

AUGUST 22, 2009

□ NEWS FROM NEW ORLEANS

When we started planning UOAA's 2nd National Conference two years ago we selected "Let the Good Times Roll" as the conference theme ... and let me tell you, for the **655*** attendees it was indeed ***Laissez Les Bon Temps Roulez!*** The weather cooperated, the Sheraton Hotel facilities were great and the spirit of the attendees resembled that of a family reunion.

The proceedings were enhanced by our key corporate sponsors: Coloplast (1st Timers Reception), ConvaTec (Gala Social Evening), Edgepark (appearance of CoCo, the Colossal Colon), Hollister (A Sweet Taste of New Orleans) and Nu-Hope (Fun-Run).

Key events included a sold out Exhibition Hall and premiers of two UOAA-produced DVDs, a public relations feature "***Living with an Ostomy***" produced by Bob Baker and a "***Visitor Training***" DVD produced by Dave Rudzin, plus a showing of the new Public TV/Cable UOAA documentary tape (see article at right). Everyone enjoyed the fashion show with the women in the first row nearest to the runway showing their enthusiastic approval of the young muscular man who flexed for them wearing nothing but his ostomy appliance and a "Speedo". Tim Mitchell's Opening Night Ceremonies presentation, Abby Ryan's Luncheon motivational story of her engagements with Crohn's Disease; and, Rob Hill's "6 up and one to go" story of his mountain climbs with only Mt. Everest left in his "No Guts, Know Glory" quest to climb the highest mountain on each of the earth's continents, were all greeted with standing ovations.

There will be picture review of all of the events and the attendees who brought them to life in the Winter Issue of ***The Phoenix*** magazine. We will have photos on a publicly viewable website soon. And you can see our photographer Nick Duncan's ***montage of the conference, set to music, right now, right here:*** <http://vimeo.com/6224545> .

*Of these 655 attendees 10 were recipients of UOAA's **C**onference **A**ttendee **R**eimbursement of **E**xpense**S** or CARES Program. Applications will again be solicited for the 2011 Conference, in the Spring of 2011.

□ PUBLIC TV/CABLE DOCUMENTARY TAPE

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 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/uoaa_psa.shtml ; or on the UOAA Blog at: <http://uoaa.wordpress.com/> ; and, if you are a member of Facebook, on the UOAA Cause at:

<http://apps.facebook.com/causes/261710/6284310?m=611088da>

We encourage you to send one of these links to any of your ASG members, local medical professionals, or to family and non-UOAA friends who might want to have a better understanding about the organization to which you donate some of your time and energy.

□ AWARDS AND RECOGNITION

At the Recognition Luncheon, awards were presented to:

ASG Leadership Awardees

- Robert Cohen - Venice Florida Ostomy Support Group
- Stanley Cooper, Philadelphia Ostomy Association
- Bill Johnson - Chattanooga Ostomy Association
- George Salamy - Morris County New Jersey Ostomy Association
- Steve Vandevender - Peoria IL Area Ostomy Support Group

WOCNurse of the Year Award

- Sonya Perry, BSN, CWOCN, Charleston Area Medical Center, Charleston, West Virginia

FOW–US Person of the Year Award

- Janice C. Colwell, RN,MS,CWOCN,FAAN

ACKNOWLEDGEMENT of UOAA CO-FOUNDERS

- Linda and Ken Aukett (see attached press release)

FOUNDERS' AWARD (by Linda and Ken Aukett)

- To Charlie Grotevant for his outstanding assistance in establishing the UOAA organization and his dedicated service to all ostomates as a *UOAA Ambassador Extraordinaire*

KEN AUKETT OUTSTANDING ACHIEVEMENT AWARD

- I was completely surprised and quite humbled when I was presented an award adopted by the Management Board of Directors in my name. This award will be presented at future times when an individual is deemed to be deserving.

□ MAKE PRESS RELEASES WORK FOR YOU

One of the easiest and most effective ways to spread word in your community about your support group, its activities, programs and accomplishments is through the use of “press releases”. As an example I have attached a press release that was written about the honor that Linda and I received at the New Orleans Conference when we were acknowledged as Co-Founders of UOAA.

Reading this release you will note that there is a statement about the specific “thing” being called to the public’s attention. This is followed by background information about the organization, its mission and then detailed information about, in this case, the award recipients.

Excellent opportunities to issue a press release would be if your support group presents an annual award to someone special in your group, either a volunteer, a member of your medical community, or a corporate backer. You can tell about the election of new officers, about special events that will be happening (such as World Ostomy Day on October 17th), about special programs or speakers that will be at your monthly

meetings, or you may want to use a visitor training program as an opportunity to tell your community about your ostomy patient visiting program. Use any newsworthy happening to get your group’s presence out into the media, either print or electronic. If we are going to be successful in removing the stigmas that surround fecal and urinary stomas then we have to seize the opportunity to spread the word about ourselves, and the positive quality of life that ostomates can enjoy.

We even have a simple tool you can use to send press releases to new outlets in your community, whether print, radio or TV. Just go here: <http://capwiz.com/uoaadbq/media/> ; add your zip code or pick your state from the map and the resulting state list; insert your details; and click it on its way.

□ UOAA, RENO AND YOU



Above is the logo for our 2011 Conference that will be held at the Nugget Hotel in Reno on August 7th to the 11th. This Conference will have the opening ceremonies on Monday night and continue through Thursday. The room rate will be \$ 79.00 + tax. Plan now to join the fun in Reno as they observe their “Hot August Nights” festivities.

□ THE HEALTH INSURANCE DEBATE

In case you have been in Outer Mongolia for the past several months, there is a major debate going on in the United States about health care insurance. I have **attached** a special newsletter from our patient advocate Jennifer Jaff Esq., Executive Director of Advocacy for Patients with Chronic Illness, Inc. that addresses this subject and sheds some light on the myths that are being circulated.

If you wish to comment about Jennifer’s findings she may be reached at her home office in Farmington, Connecticut by phone at (860) 674-1370, by fax at (860) 674-1378, by e-mail patient_advocate@sbcglobal.net or at her website www.advocacyforpatients.org .



The four Regional Great Comeback Awards for 2009 will be presented in conjunction with WOCN Regional Conferences as follows:

The South Region GCB Award ceremony will be at the Hyatt Regency Hotel in Jacksonville, Florida on September 10th; the Central Region GCB Award ceremony will be at the Crowne Plaza Hotel in Dayton, Ohio on October 1st; the East Region GCB Award ceremony will be at the Crowne Plaza Hotel in Reading, Pennsylvania on October 3rd; and, the West Region GCB Award ceremony will be at the Doubletree Inn in Spokane, Washington on October 10th. UOAA is pleased to be a sponsor of these Awards and is represented by Kristin Knipp on the Award Selection Committee.



It is still not too late to sign up for the inaugural Midwest GYGIG Ride that takes place this October 2nd through the 4th. The word is in that our senior statesman athlete, Charlie Grotevant, will be riding both as a member of UOAA and a member of GYGIG's Board of Directors. Charlie's wife Joyce will be driving their van as part of the support crew.

The ride will begin and end in northern Illinois with most of the 210 mile ride in Wisconsin. Camps are located near Pleasant Lake and Elkhorn, Wisconsin.

The GYGIG rides raise funds for organizations, like UOAA that promote awareness about IBD and the ostomy surgery that these diseases often necessitate. As UOAA's Ride representatives, I urge you to consider financially supporting Charlie and his wife, since he rides for all of us. Charlie's ride number is **Rider MW-17** and Joyce is **Crew MW-C11**. For more information regarding donations, please check out the GYGIG website www.ibdride.org.

MBOD MEETING DELIBERATIONS

From UOAA's MBoD meeting in New Orleans, three outcomes of importance are as follows:

- The Annual Affiliation Fee will remain unchanged at \$ 2.00 per member or \$ 25 if you group reports "No Members"
- Ballots for the Fall election will be mailed by the end of August to each ASG at the address on record. If you do not receive your ballot by mid-September, please report this to Joan McGorry at 800-826-0826
- Starting in 2011, UOAA will institute a new election procedure. There will be a workshop at the Reno Conference where ASG representatives will have an opportunity to hear the candidates speak and to ask them their opinions on certain issues. Representatives of those ASGs at the conference will be given ballots to cast. If they turn in their ballot before leaving the conference they will be given a coupon for a 50% reduction in a registration for the 2013 Conference. Details of exactly how this will work will be shared at a later date. It is hoped that this will stimulate interest in the election process and promote Conference attendance.

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 the first 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 below 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 asking to be added. Once determined eligible, you will receive confirmation.



It might seem like several steps, 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.

❑ COMING SOON!

In the not-too-distant future you will be receiving in the US mail from UOAA:

- A copy of the new Visitor Training DVD
- A copy of the new Public Relations DVD, "Living with an Ostomy"
- A manual containing Nursing Information Modules entitled "Living with an Ostomy" that can be used by members of your ASG to discuss with Home Health Care and other Nurses what the needs of an ostomate are.
- Ballots for the Fall election.

❑ 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.

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

On Tuesday, October 13th, 2009 and "Ostomy 104: Managing those Ostomy Nightmares" seminar will be sponsored by UOAA's Peoria Ostomy Support Group and the WOCNurses 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-Hopes 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

❑ OSTOMY SUPPORT GROUP of LAWTON – FT. SILL, OKLAHOMA OSTOMY CARE TRAINING SEMINAR

On September 30, 2009, between the hours 12:30 and 5:00 pm the Ostomy Support Group of Lawton – Ft. Sill, Oklahoma, in conjunction with the medical staff of the Comanche County Memorial Hospital, will hold an Ostomy Care Training Seminar. There is a serious shortage of WOCNurses in this Oklahoma area and it is hoped that this seminar will improve a general nurses care and treatment of ostomy patients thereby impacting their patient's quality of life. For additional information visit the support group's website at www.ostomyok.org/lawton or call Mel Springborn at 580-248-3535

❑ IN CONCLUSION

Linda and I will be traveling to Budapest, Hungary over Labor Day to speak at a Conference of Hungarian Colorectal Surgeons, with attendees also from the rest of Europe and the USA. I will be speaking on the general public's regard of a fecal or urinary stoma as a stigma and what UOAA is doing to combat this mindset. I will be showing our new "Living with an Ostomy" DVD to these medical professionals ... hopefully they will use it in their practice to alleviate the fears of potential ostomy patients. I'll fill you in about their acceptance of our DVD when I return.

Best wishes for now,

Ken Aukett